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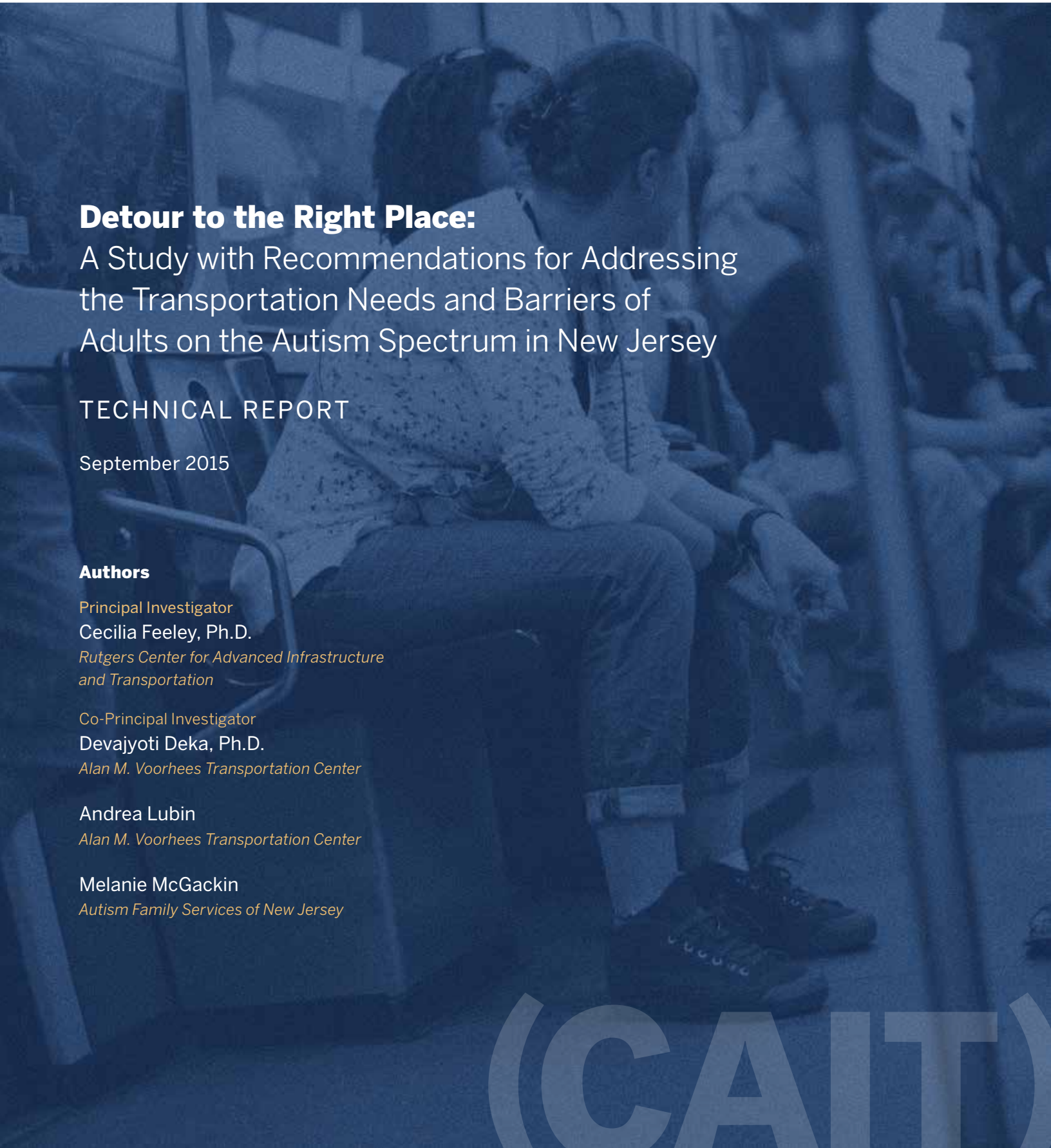

Detour to the Right Place:
A Study with Recommendations for Addressing the Transportation Needs and Barriers of Adults on the Autism Spectrum in New Jersey

TECHNICAL REPORT

September 2015

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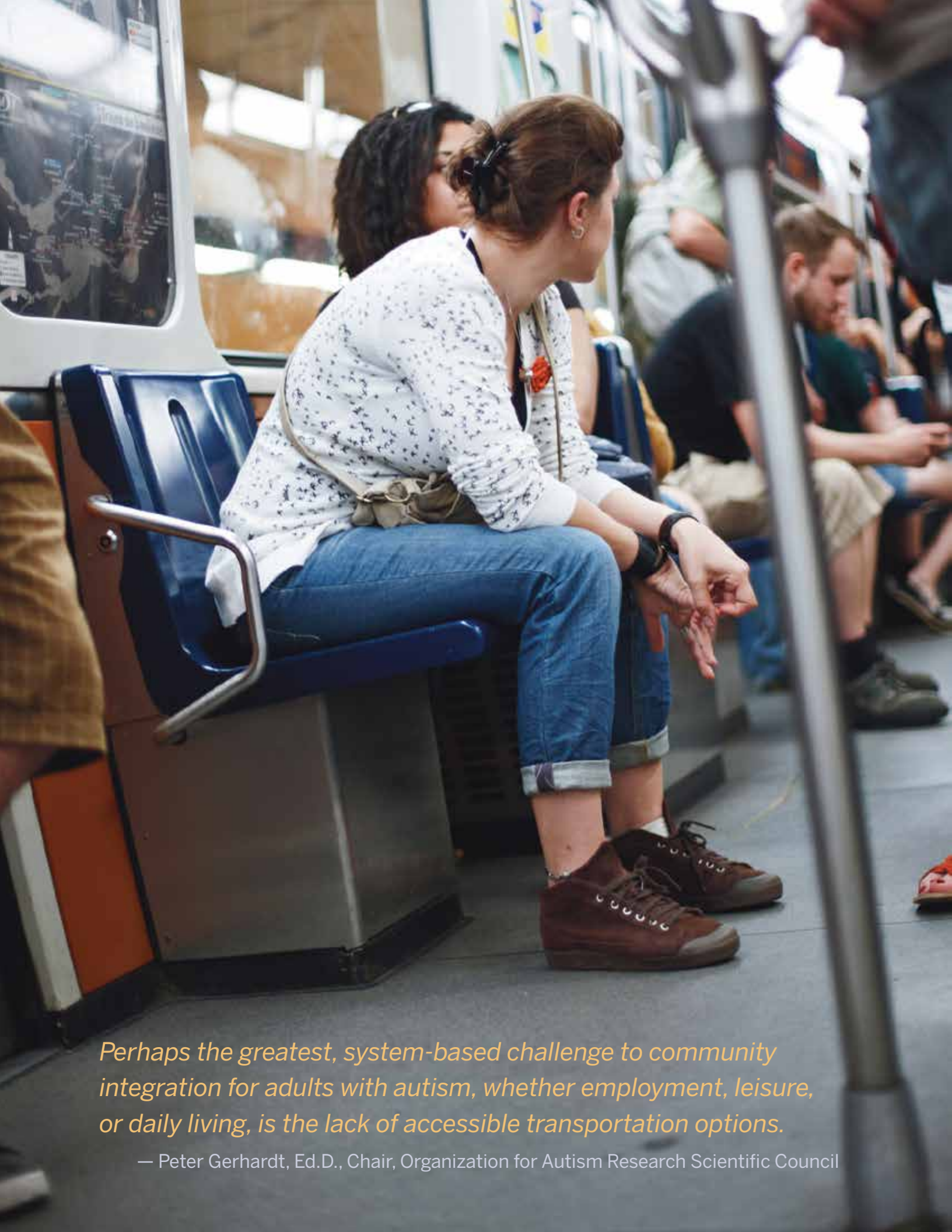

Perhaps the greatest, system-based challenge to community integration for adults with autism, whether employment, leisure, or daily living, is the lack of accessible transportation options.

— Peter Gerhardt, Ed.D., Chair, Organization for Autism Research Scientific Council

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EXECUTIVE SUMMARY

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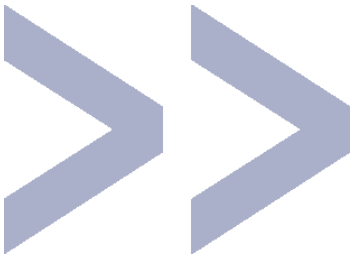
A Study with Recommendations for Addressing the Transportation Needs and Barriers of Adults on the Autism Spectrum in New Jersey

Although advances have been made in many fields related to quality of life improvements for persons with Autism Spectrum Disorder (ASD), efforts have been more limited in the realm of transportation planning and policy. Most organizations involved in transportation planning and policy collect travel data for broad population groups—such as persons with disabilities—instead of specific population groups like persons with ASD. As a result, very little is known about the travel patterns, needs, and barriers of persons with ASD. The primary focus of the research described herein was to gain insights about the transportation barriers experienced by the New Jersey adult ASD population.



Additionally, this research sought to identify the characteristics and traits commonly found in adults with ASD and their impact upon transportation choices, which in turn affect employment opportunities, community involvement, and overall quality of life.

This research study included four broad components: (a) a review of pertinent literature; (b) interviews with 25 key stakeholders; (c) a survey of 703 adults with ASD and/or their family members regarding transportation barriers; and (d) six focus groups – four with adults with ASD, and two with parents/guardians of this population.

Many studies in the context of access to employment have emphasized the importance of transportation, but they have not provided an in-depth understanding of the way adults with ASD travel, their need for travel, or the barriers they face when they travel. While a few studies have been published about the transportation needs of persons with developmental and cognitive disabilities, they are not specific to adults with ASD. This research bridges a gap in existing literature by providing insights from interviews with stakeholders from the ASD and transportation sectors, a survey of persons with ASD, and focus groups with adults with ASD and parents or guardians supporting this population in the context of New Jersey.

The stakeholder interviews provide insights about the struggles of adults with ASD regarding their travel needs and barriers. Some stakeholders were from agencies that work for the betterment of persons with ASD, whereas others were from agencies that provide transportation. On the whole, all interviewees were sympathetic to the diverse travel needs of adults with ASD and emphasized that transportation access was a critical component of their successful integration into society.

Availability of transportation options, as well as the ability of persons on the autism spectrum to use various options, directly affects their ability to live independently and to pursue opportunities including employment and continuing education.

From the stakeholder interviews, it became evident that the transportation barriers of adults with ASD are not limited to public transportation issues, but are also related to walking, driving, the locales where they reside, the schools and day programs they attend, the training they receive on various aspects of life, and also certain limitations that are imposed by their disabilities. Although efforts are sometimes made to train school-age students to walk safely and use public transit, such training is neither common, nor uniformly implemented, and usually disappears as they get older. As a result, families of adults with ASD often have to bear the burden of providing all transportation.

The stakeholders generally agreed on the following: that not all adults with ASD have or can obtain the skills required to drive; training for vehicle operators who transport adults with ASD should be improved; there are conflicting views on whether - adults with ASD should become more independent; safe travel skills and travel instruction should be taught in school and included in Individualized Education Plans (IEPs); and finally, there is a need to increase awareness among the general population about ASD. The interviewees also agreed that persons on the autism spectrum will likely experience more successful community integration with certain improvements in transportation systems and greater understanding among transportation professionals about the needs of persons with ASD.

The survey's primary objective was to collect and summarize information on the travel patterns, needs, and barriers of adults with ASD in New Jersey. Although the intent of the survey was to collect data from adults of all ages, most survey respondents were below the age of 30 and lived with their parents. The survey revealed that adults with ASD often have to forgo trips because of the unavailability of persons who can give them rides. Meanwhile, their parents and family members often forgo other activities, including work, in order to provide transportation to the person with ASD. In addition, adults with ASD experience many difficulties that prevent

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them from participating in activities that others take for granted, including employment. For example, while most adults among the general population make work trips almost daily, the proportion of work trips is small among persons with ASD.

The survey demonstrated that persons with ASD have many travel-related concerns and barriers that others do not face. Driving is an option for only a very small proportion of adults with ASD. Even among the small proportion of persons with ASD who have a driver's license, very few actually drive on a regular basis. Similarly, using public transit is difficult for many people with ASD. Although many more adults with ASD can walk than drive or take transit, even walking in their neighborhoods is a challenge for many, as they have difficulty crossing roads, judging distance, and comprehending direction. Even when they are able to walk, the propensity to walk is low among this population, since the activities they typically visit are not within walking distance. Because of their difficulties with driving, taking transit, and walking, the most common practice among the adults with ASD is to take rides from others, especially from parents, other family members, and friends.

The survey results raise a number of issues about meeting the travel needs of adults with ASD through planning and policy. To a great extent, adults with ASD are able to satisfy their travel needs because of parents and other family members who often provide rides. However, when parents are no longer able to provide rides due to aging, or when the persons with ASD begin to live independently, there may be a need for society to step in to address unmet travel needs. Because of their disability, some adults with ASD may never be able to use fixed-route transit such as buses and trains. Others may be able to use these modes, if they live close to transit stations or stops and they receive travel training. For some, ulti-

mately, travel may only be possible when they can secure rides from others, whether it is from Access Link, county paratransit, voluntary drivers, or agencies that cater to the needs of persons with disabilities.

Based on the survey results, very few of the adults with ASD can be expected to drive to their day-to-day travel destinations. Most others will need assistance from socially-provided transportation services. Finally, since walking is the most common practice among persons with ASD after taking rides from others, the location of needed and desired services should be considered when making housing location decisions. For example, if one's residence is located in close proximity to desired destinations, then a person with ASD who has received pedestrian training could likely satisfy some of her or his travel needs simply by walking. Furthermore, improvements of sidewalks and crosswalks, and traffic-calming measures, could also encourage people with ASD to walk more often.

Focus group participants with ASD and parent or guardian participants shared a number of concerns and challenges related to using various transport modes for persons on the autism spectrum. All emphasized the critical role that transportation plays in the lives of adults with ASD in providing linkage to both meaningful opportunities in their community and enabling fulfillment of daily living needs, including employment, continuing education, healthcare, and socially-focused pursuits. The adults with ASD expressed a strong desire for independence, which they felt they could achieve only with appropriate transportation options.

Adults with ASD and parents or guardians expressed the sentiment that finding feasible transport options was especially challenging in the post-school transition period, as transportation options are few and information on existing transportation options is difficult to find. This leaves parents to function as the primary transportation providers, and they experience various negative effects of the responsibility. Despite this, parents who indicated they most often drive their adult children with ASD seemed to accept this practice as part of their "everyday reality." As one parent said, "My life is my son." Participants with ASD who frequently take rides from parents expressed mixed feelings, with some indicating a preference for this mode of travel, and others citing dissatisfaction due to the burden they impose on their parents and their own lack of independence.

When focus group participants were asked to describe their version of an optimum transportation service for persons with ASD, many of the same features were sought by both parents and adults on the spectrum. Specifically, there is strong desire for a service that is reliable and consistent, crosses county borders, and picks up customers close to their homes. In addition, travel instruction was deemed necessary, to empower adults with ASD to safely and independently use the public transit service. Parents noted the need for drivers to be well-trained in transporting adults with ASD. Adults on the spectrum desired service frequency in both peak- and off-peak hours to enhance ability to pursue social events and outings. Both parents and adults with ASD lamented that travel instruction was not offered in schools, nor was transportation included in their IEPs. As one adult with ASD stated "I needed information in school on how to use public transportation, and not just information on the food pyramid."

GENERAL FINDINGS AND RECOMMENDATIONS

This research included four broad components: (a) a review of pertinent literature, (b) interviews with stakeholders, (c) a survey of adults with ASD, and (d) six focus groups with adults with ASD and parents/guardians of this population. In addition to providing valuable insights about the travel patterns, needs, and barriers of adults with ASD in New Jersey, this research helped to garner insights from various stakeholders supporting the needs of persons with ASD, as well as from the parents/guardians of adults with ASD. A number of critical observations can be made from this research.

- First, the literature review in Chapter 2 revealed that very little has been written specifically about the transportation issues encountered by adults with ASD. As a result, the findings of this research should be of interest not only to New Jersey's transportation providers and agencies and organizations working for the betterment of persons with ASD, but also to similarly-situated stakeholders nationwide.

- Second, rightly or wrongly, the role of availability of accessible public transportation is often viewed as crucial for persons with all types of disabilities. Adults with ASD and their families are scattered all over New Jersey. Some have access to public transportation while others do not. Limited public transportation options in suburban and rural areas create challenges, since individuals do not have these services and often never have the opportunity to learn how to use public transit. As a result of suburbanization over several decades, both the adults with ASD and the activities they need to visit are scattered all over space, creating an environment where public transit cannot operate efficiently. Although schools, healthcare facilities, day programs, job training facilities, etc., that are commonly visited by adults with ASD were established without much thought about transportation options, the stakeholder interviews revealed that there is a growing recognition that such facilities should be located in areas that can be easily accessed by multiple travel modes, including fixed-route transit and paratransit.

- Third, adults with ASD mostly travel as passengers of cars driven by their parents or other family members. This dependence creates inconvenience and generates stress for both adults with ASD and their parents. The survey revealed that approximately seventy-two percent of the parents and caregivers miss at least some of their own activities due to the responsibility of giving rides to their adult children with ASD, and seventy-two percent of the adults with ASD missed at least some of their desired activities due to the unavailability of persons to give them rides. The focus groups revealed that many parents of adults with ASD give up employment altogether or find low-paying jobs so that they can attend to the needs of their children. However, such sacrifices often cause emotional stress for the parents. Even the children are often dissatisfied by their dependence on rides from parents as they feel such arrangements make them lose independence and flexibility.

- Fourth, the most difficult time for adults with ASD and their parents is upon the former's transition from school, which usually occurs at age 21. Around this time, government support and school transportation disappear and the adults with ASD and their families have to find alternative modes of transportation to job-training or employment locations. Although many parents are willing to continue providing rides to their children, they also recognize that they cannot do so forever. A persistent complaint among parents of adults with ASD is that their children do not receive adequate training at school on safe pedestrian skills or how to travel by public transportation. As a result, many parents are unwilling to allow their children to use public transportation on their own. Travel education, orientation and training during school years are minimal to nonexistent and should be included in students' IEPs.

- Fifth, many adults with ASD lack basic safe walking skills such as crossing roads (54 percent) and judging distances to oncoming vehicles, many others reported in the survey that they walk in their neighborhoods (45 percent). The survey also revealed that walking trips to specific activities are seldom made by the adults with ASD. It can be construed from the focus group discussions that they do not make walking trips to activities because the activities they seek to access are not located close to home. In other cases these trips are not made due to lack of pedestrian skills and/or poor infrastructure conditions.

- Sixth, by combining information from the survey and the focus groups, one can conclude that some adults with ASD are interested in driving automobiles because they view driving as a symbol of independence, but in reality a very small proportion of them actually drive or obtain driver's licenses. Even those who do drive revealed that they encounter certain problems such as multi-tasking, while driving that can make driving difficult. Parents' concern about safety appears to be one of the primary reasons for a small proportion of adults with ASD driving. The focus groups revealed that skills vary widely among adults with ASD and only the high-functioning adults can use automobiles on a regular basis.

- Seventh, the stakeholder interviews, the survey, and the focus groups demonstrated that improved awareness among society at large regarding the characteristics and needs of adults with ASD is important for them to be able to live and travel more successfully and independently. One of the themes that emerged from the stakeholder interviews was that society has to be educated about persons ASD if they are to be fully integrated into society. The survey revealed that adults with ASD are concerned about how fellow passengers and vehicle operators would treat them if they are to use public transportation. The focus groups revealed that even high-functioning adults who can drive are concerned about how law enforcement officials would treat them. Lack of understanding and awareness about ASD among the public at large imposes negative impacts on persons with ASD among those who seek to fully participate in their respective community.

RECOMMENDATIONS MADE ON THE BASIS OF THIS RESEARCH STUDY

1 Establish a New Jersey Autism and Developmental Disabilities Transportation Research Center to investigate and implement strategies to address the transport needs of adults and adolescents on the autism spectrum and those with related developmental disabilities. Establishing a research center in New Jersey will allow for a dedicated interdisciplinary team of experts to explore and address these critical transportation and mobility barriers that limit successful community integration of this vulnerable population. The work undertaken at the center would encompass the review, analysis, and development of "best practice" recommendations of transportation-focused strategies for rural, suburban and urban locations. The Center would also function as a nationwide information clearinghouse for cutting-edge and other potentially viable transportation strategies identified.

A broad universe of transportation options, including community paratransit, must be considered for adults with ASD, and those options must not be limited to public transportation and driving. The feasibility of any specific travel mode for any given person with ASD depends, to some extent, on the type and severity of ASD characteristics expressed by that individual. Public transportation should not be seen as the only travel alternative for adults with ASD, as some individuals do not have the required skills and capabilities to travel by public transportation without assistance from others. Similarly, although adults with ASD may express interest in driving, it is not a feasible or safe option for many adults on the spectrum.

2 Develop a Statewide Steering Group to review and assist with the implementation of this report's

recommendations, and to consider emerging transportation barriers and obstacles for this population. The steering group would be comprised of adults with ASD, family members or guardians, and representatives from various government agencies, transportation service providers, the employment sector, residential facilities, day programs, caregivers, and other related stakeholders.

3 Develop and provide continuing support for transportation-focused training programs in the educational setting, as part of students' IEPs. Specific training should include pedestrian skills and intersection navigation, travel training for fixed route and paratransit services, and driver education. Training of children with ASD at schools about safe pedestrian skills and how to use public transportation is needed and should be pursued, as it would better prepare them to use these modes after they graduate from school and seek employment and/or further educational opportunities. The benefits of including these skills in IEPs must be considered and discussed with the New Jersey Department of Education, as such action could produce a statewide mandate that these skills be taught.

4 Educate families with children who have ASD and/or other developmental disabilities on transportation and mobility issues and options prior to aging out of school. Also, since this study's findings support that parents are often reluctant to permit their children with ASD to use public transportation out of fear, arrangements should be made for parents to be informed of and given the opportunity to participate in travel training and or travel orientation activities. Parental involvement in training will serve to decrease their reluctance in supporting their adult child's usage of public and/or community transportation and thus could contribute to the latter's independence. Research the relationship between employment and transportation for adults on the autism spectrum. As New Jersey is an Employment First state, the issue of transportation as it relates to employment must be investigated and addressed. Identifying and analyzing the specific transportation and mobility barriers and obstacles to a diverse range of employment opportunities in the State is the most appropriate avenue for the successful development of sound strategies to overcome these barriers.

5 Pursue locational efficiency strategies for entities that support adults on the spectrum—including job-training centers, sheltered work programs, residential facilities (e.g. group homes), day programs, employment sites, and healthcare sites. Specifically, these stakeholders should make a deliberate effort to locate in areas that are accessible by multiple travel modes—including fixed-route transit and paratransit—to improve access to these life-enhancing (and sometimes life-sustaining) destinations. The oft-pursued paradigm of placing these destinations in remote locales due to factors including lower-cost real estate is no longer a viable model, as it greatly hinders the ability of many persons on the spectrum to reach these sites and to achieve independence.

6 Conduct a holistic review of current infrastructure design practices, to determine recommendations that are better suited to the needs of individuals with ASD and/or other developmental disabilities. While previous research has been undertaken to achieve ADA compliance of the built environment and associated infrastructure components, actual design components that can be considered conducive as well as limiting or inhibitive to those on the autism spectrum has been limited. This recommendation seeks to address that issue and will focus on a review of current guidelines, principles, and recommendations to ensure that the most autism-friendly and autism-conducive design features are identified.

A focus on reviewing ADA infrastructure design guidelines, Universal Design principles, and Complete Streets recommendations will be pursued. In addition, New Jersey-based design requirements for infrastruc-

ture improvement projects will be evaluated. These design requirements will be analyzed in conjunction with the characteristics and traits of individuals with autism that can hinder their ability to travel independently by various modes. This work would focus on determining recommendations for autism-friendly infrastructure improvements to the built environment and will be especially beneficial as the study survey demonstrated that environmental barriers between residences of adults on the spectrum and transit stations or stops were a significant concern for respondents. Almost half the respondents were dissatisfied with the sidewalks, street crossings, and intersections near their home. These findings demonstrate the need and potential benefits of the proposed recommendation to review and consider infrastructure design standards that can better serve the population on the spectrum.

7 Integrate the transportation needs of adults with ASD with current research being conducted by Intelligent Transportation Systems (ITS) experts. Evaluate new technologies that can provide support for independent or semi-independent travel for this population and collaborate with engineers and technologists to develop innovative methods to improve transportation access for adults with ASD. Technologies considered can include smart phones, phone applications, Google glasses, Bluetooth supports, Google cars, vehicle-to-vehicle technology, pedestrian-to-vehicle technology, pedestrian-to-infrastructure technology, and vehicle-to-infrastructure technology, among others.

8 Develop and implement targeted vehicle operator training and training for front line staff that come in contact with adults with ASD for fixed route transportation services (NJ TRANSIT, SEPTA), paratransit (NJT Access Link, county and municipal services), private and volunteer services (NGOs), and emerging on-demand private services (Uber and Lyft). Transit operators who transport persons with disabilities should receive targeted training that will enable them to better understand and assist persons with ASD. The ASD stakeholder community can work collaboratively with the transit industry to develop one or more modules to fulfill this recommendation.

9 Establish protocols for New Jersey NGOs that support persons with autism, to permit them to work with transportation researchers, planners, and professionals to develop a sustainable transportation infrastructure that better addresses the needs of New Jersey's adults on the autism spectrum. This work would include the development of replicable pilot projects with NGOs to address the diverse needs of residents with autism and developmental disabilities throughout the state. The NGOs should also strive to ensure that needs of adults on the spectrum are integrated in the Coordinated Public Transit Human Services Transportation Plans that are developed, maintained, and updated by each of New Jersey's 21 counties by working with transportation planners, engineers, transit agencies, and paratransit service providers.

10 Conduct a nationwide and global studies inquiry to identify "best practice" methods and strategies that can work to ameliorate transportation barriers for this population. This effort will include identifying areas with best practices, studying methodologies for best practices, identifying and analyzing replicable qualities of best practices, conducting pilot tests on replication practices and, upon completion, conducting outreach of replicable best practices to improve access and mobility. One example of a best practice to be explored is the reportedly high level of public transit usage by adults with ASD in Chapel Hill, NC.

11 Consider creation of a statewide mobility manager who will be dedicated to assisting adults on the autism spectrum and their guardians, families, caregivers, and service providers in identifying and securing feasible transportation alternatives. Establishment of a specialized, statewide mobility manager would allow for uniformity in access to transportation service

information and planning guidance to all New Jersey residents, regardless of location. The mobility manger could provide a coordinated, seamless service to address trip planning and scheduling, to meet the needs of the individuals and/or their families.

12 The benefit of employing a dedicated mobility manager is that this individual will be knowledgeable of public transportation ADA legislation and practices, including Title II Part B of the ADA and private transportation, Title III. In addition, this dedicated statewide mobility manager will have integral knowledge of transportation-related resources within a community, and can address the particular needs of individuals across the state, including those residing in urban, suburban, and rural locales. The mobility manager can also serve to assist the state and counties with coordination strategies, to link various regions and connect existing transit services in an economically efficient manner.

13 Discuss with transportation providers, including NJ TRANSIT, the potential for service expansion. While public transportation should not be seen as the only travel mode alternative for persons on the spectrum, expansion of service to areas currently not served or underserved will benefit a proportion of adults with ASD. This research revealed adults with ASD are more likely to use paratransit than fixed-route transit; thus, expansion of paratransit would be especially beneficial for this population. In addition, families with children with ASD should actively support and advocate for improved high-quality pedestrian infrastructure and traffic calming measures in their area of residence to better facilitate safe walking of persons with ASD and safe access to existing transportation services.

14 Implement a multi-pronged study findings outreach initiative—through conferences, presentations, and educational seminars to various public and private stakeholder audiences—to discuss transportation options for adults with ASD. Provide analysis and briefings to legislators and elected officials regarding policies that may impose additional barriers (e.g. crossing county-line transit restrictions) as well as policies that reduce obstacles for independent travel. Conduct annual statewide conferences on current transportation options, open to various stakeholders.

15 Improve awareness among the general population about the characteristics of ASD. This effort is needed so adults on the spectrum can more readily achieve successful community integration. The broad and diverse New Jersey autism stakeholder community should work to guide this improved awareness effort.

IMPLEMENTATION MATRIX FOR RUTGERS TRANSPORTATION AUTISM PROJECT

Recommendations	Potential Primary & Supporting Partners								
	NJ DHS-DDD	NJ DOE	NJ DOH	NJ DOT	NJ Legislature	NJ Transit	Counties	NGOs	Other
1. Establish Transportation Autism and Developmental Disabilities Research Center	P	S	S	S	P			S	
2. Develop Statewide Steering Committee	P	P	P	P	P	P		P	
3. Develop and include in IEPs Transportation Educational Training Programs for Students	S	P		S					NJ DCF
4. Educate families and communities on transportation and mobility options for adults with ASDs	P	S	S	S	P	S	S	S	
5. Research the relationship between employment and transportation for adults on the autism spectrum	P	S	S		S				NJ DVRS NJ DOL
6. Pursue locational efficiency strategies of entities supporting adults with ASD	S		S	S	S	S		P	NJ DCA US HUD
7. Conduct review of infrastructure design practices			S	P	S	S	S		
8. Integrate the transportation needs of adults with ASD with Intelligent Transportation Systems (ITS)	S		S	P	S	S	S		
9. Develop and implement targeted vehicle operator and transportation provider front-line staff training on ASD				S	S	P	P	P	
10. Establish protocols for NGOs statewide that support persons with ASD to collaborate more effectively with the transportation community	S		S	S	S			P	
11. Conduct nationwide and global studies inquiry on "Best Practices" to ameliorate transportation barriers for persons with ASD	S		P		P				
12. Create a statewide mobility manager dedicated to serving the needs of adults with ASD				S	P	S	S		MPOs TMAs
13. Discuss possibilities for transportation service expansion				S	S	P	P	S	
14. Implement multi-pronged study findings outreach initiative	P	S	P	S	S	S	S	S	
15. Improve awareness among general population about ASD characteristics	P	S	P		S	S		P	

P = Primary Partner S = Supporting Partner

NJ DHS-DDD = NJ Department of Human Services Division of Developmental Disabilities

NJ DCA = NJ Department of Community Affairs

NJ DCF = NJ Department of Children and Family Services

NJ DOE = NJ Department of Education

NJ DOH = NJ Department of Health

NJ DOL = NJ Department of Labor

NJ DOT = NJ Department of Transportation

NJ DVRS = NJ Division of Vocation Rehabilitation Services

US HUD = US Department of Housing and Urban Development

NGOs = Non-Governmental Organizations

MPOs = Metropolitan Planning Organizations

TMAs = Transportation Management Associations

INTRODUCTION

Although researchers from many other disciplines have taken great strides to understand the needs and barriers of persons with Autism Spectrum Disorder (ASD), little has been done by researchers to understand such needs and barriers in the context of transportation. Many studies on access to employment have emphasized the importance of transportation, but they have not provided an in-depth understanding of the way adults with ASD travel, the needs they feel for travel, or the barriers they face when they need to travel. While a few studies have been published about the transportation needs of persons with developmental and cognitive disabilities, they are not specific to adults with ASD. This research seeks to bridge a gap in existing literature by providing insights from interviews with stakeholders from the ASD and transportation sectors, a survey of persons with ASD, and focus groups with adults with ASD and parents/guardians supporting this population in the context of New Jersey.

- The Literature Review section of this report provides a detailed review of pertinent literature. It covers diverse topics, including definition of ASD, prevalence of ASD, specific impairments associated with ASD, employment challenges of adults with ASD, and the role of transportation for persons with disabilities with special attention to adults with ASD. The literature review basically demonstrates how little is known about the travel aspects of adults with ASD.

- The Stakeholders Interviews section provides the insights from 25 interviews with key stakeholders from various agencies and organizations within New Jersey. Some of the agencies and organizations cater to the needs of persons with ASD, while others are providers of transportation for persons with disabilities. The chapter discusses eight themes that emerged from the interviews.

- The Survey of Adults with ASD section of the report describes the key findings from a survey of adults with ASD in New Jersey. Data was collected through the online survey from 703 adults with ASD or their parents/guardians. As expected, most of the surveys were completed by the parents/guardians. The survey provided detailed information on transportation modes used, trip purposes, travel needs for various purposes, availability of transportation options, and barriers encountered while walking, using public transportation, taking rides from others, and driving by adults with ASD.

- The Focus Groups with Adults with ASD and Parents section of the report describes the findings from six focus groups. Four of the focus groups were conducted for adults with ASD and the other two were conducted for parents and guardians of adults with ASD. Twenty-two adults with ASD participated in the first set of focus groups, while 19 parents and guardians participated in the second set. One of the four focus groups for adults with ASD was conducted exclusively for persons who could drive an automobile.

LITERATURE REVIEW

This literature review was prepared primarily to assist in developing the subsequent tasks of the research project, namely, the stakeholder interviews, the survey, and the focus groups. It includes a review on literature on the characteristics of persons with ASD; issues relating to their employment, postsecondary education, and living; and issues relating to their transportation needs and barriers. Although the literature review is meant to be focused on persons with ASD, a few studies that focused on cognitive and intellectual disabilities were also included in the review.

The first section provides a general understanding about the characteristics of persons with ASD. It describes scientific definitions and medical and behavioral characteristics of persons with ASD. The second section presents a discussion on the prevalence of ASD in the US and New Jersey. The third section specifically focuses on studies on adults with ASD and includes discussions on issues relating to employment, postsecondary education, and living conditions. National data on young adults with ASD are presented. The last section provides a review of studies that mentioned or addressed transportation issues of persons with ASD.

AUTISM SPECTRUM DISORDER AND CHARACTERISTICS

Autism Spectrum Disorder (ASD) is a group of developmental disabilities (CDC, 2012). The newest version of the Diagnostic and Statistical Manual of Mental Disorders, DSM-5, prepared by the American Psychiatric Society (2013), describes the characteristics of ASD. While in the past, autism was a type of "Pervasive Developmental Disorder," DSM-5 created a single diagnosis, Autism Spectrum Disorder, which includes Autistic Disorder, Asperger Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified, or PPDNOS (Ozonoff, 2012).

According to DSM-5, ASD is characterized by "persistent deficits in social communication and social interactions across multiple contexts," and manifested in (a) deficits in social-emotional reciprocity, (b) deficits in nonverbal communicative behaviors used in social interactions, and (c) deficits in developing, maintaining, and understanding relationships. According to the DSM-5, the three levels of severity of ASD, namely, requiring support (Level 1), requiring substantial support (Level 2), and requiring very substantial support (Level 3) are based on (a) social communication impairments and (b) restricted, repetitive patterns of behavior. Social communication impairments may be characterized by deficits in *verbal* and *nonverbal* social communication skills, limited initiation of social interaction, and minimal response to social overtures from others. Restricted, repetitive behavior may include (a) stereotyped or repetitive motor movements, use of objects, or speech, (b) insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior, (c) highly restricted or fixated interests with high intensity or focus, and (d) hyper- or hypo-reactivity to sensory input or unusual in sensory aspects of the environment. Behavioral difficulties of persons with ASD could include "tantrums, aggression, self-injury, property destruction, ritualistic destruction, and pica" (Hendricks, 2010, p. 127).

Diagnosis of ASD could be challenging. One of the challenges is comorbidity, i.e., many persons with ASD may suffer from other impairments (Leyfer et al., 2006). On the other hand, many persons without ASD may have impairments that are present in persons with ASD. DSM-5 mentions that intellectual disability, or intellectual developmental disability, frequently co-occur with autism. In addition to intellectual disability, DSM-5 mentions some of the commonalities between ASD and Rett syndrome, selective mutism, language disorders, social (pragmatic) communication disorders, stereotype motion disorder, attention-deficit/hyperactive disorder (ADHD), and schizophrenia. Leyfer et al. (2006) mention that cognitive problems of persons with ASD often make it difficult to describe their mental states and experi-

ences, thereby adding to the challenges of identifying comorbidity.

Another challenge in the diagnosis of ASD is the heterogeneity of characteristics of persons with ASD (Waterhouse et al., 1996). According to DSM-5, some of the characteristics used for diagnosis may change with age. For example, many adults with ASD without intellectual or language disabilities learn to suppress repetitive behavior. According to DSM-5, most individuals with ASD improve behaviorally during adolescence, whereas a small proportion deteriorates.

PREVALENCE OF ASD IN THE US AND NJ

ASD prevalence rate in the US has been controversial. According to Yeargin-Allsopp et al. (2003), ASD prevalence rate in the US in studies prior to 1985 was 4 to 5 children per 10,000 children, whereas the prevalence rate for narrowly focused classic autism was 2 per 10,000 children. In contrast, DSM-5, published in 2013, mentions that the ASD prevalence rate in the US and other countries is approximately 1% (or one in 100).

Another source of information for the prevalence of ASD is the Centers for Disease Control and Prevention (CDC). However, the CDC (2012) cautions that its ASD prevalence rate should not be used as representative of the US as a whole since the data are collected from selected sites. According to a report published by the CDC (2009), the ASD prevalence rate among 8-year old children at 11 sites combined was one in 110 (or 0.91%). According to a subsequent report by the CDC (2012), the prevalence rate in 2008 for children of the same age at 14 sites combined was found to be one in 88. According to the latest CDC report (2014), the prevalence rate for the 14 sites nationally is one in 68 (or 14.7 per 1,000 children). For the lone New Jersey site studied by the CDC, the prevalence rate was one in 45 children (or 21.9 per 1,000 children).

In 2006, when the ASD prevalence rate for the US was considered to be one in 110, the prevalence rate for New Jersey was slightly higher, one in 94 (Jackett, 2010). Since the CDC estimates ASD prevalence for 8-year old children, its prevalence rates do not necessarily reflect prevalence rates for people of all ages. However, DSM-5 mentions that the prevalence rates for adults and children were found to be similar in samples drawn in several countries. DSM-5 also mentions that ASD is diagnosed four times more often in males than females. In clinical samples, females are more likely than men to show accompanying intellectual disability. DSM-5 also mentions that African American children may be underdiagnosed or diagnosed later in life than children of other races. It is important to note however that recorded incidence of ASD exists among all socioeconomic, racial, and ethnic groups.

ADULTS WITH ASD

A vast majority of studies on ASD have addressed children instead of adults. One reason for the greater emphasis of the studies on children may be the increase in ASD prevalence among children. However, because of the increasingly larger number of children with ASD growing up to be adults, studies have often emphasized the need to focus on adults with ASD (Graetz, 2010; Gerhardt and Lainer, 2011).

Because of a very high rate of unemployment among adults with ASD, a large number of studies have addressed their employment issues (Hendricks and Wehman, 2009; Hendricks, 2010; Jackett, 2010; Lugas et al., 2010; McDonough and Revell, 2010; Taylor and Seltzer, 2011; Cimera et al., 2012; Gentry et al., 2012; Shattuck et al., 2012; Westbrook et al., 2012). However, obtaining an exact estimate of the number or proportion of adults with ASD who are gainfully employed is difficult since most national data sources, such as the decennial census or the American Community Survey, do not identify persons with ASD or autism as a separate category of persons with disability. Gentry (2012) and McDonough and Revell (2010) mentioned studies that found that only 15% of adults with ASD are employed. Based on other studies, Gentry (2012)

further mentioned that only 6% of the adults with ASD are competitively employed. In contrast, based on several studies, Hendricks (2010) estimated that 25% to 50% of adults with ASD could be employed. The nonprofit organization Autism Speaks (2015) recently found that nine of ten adults on the spectrum are unemployed or underemployed regardless of their IQ or education level. In sum, it is difficult to generalize about the specific number or proportion of adults with ASD that are employed; however existing data points to a significant underrepresentation in the labor market among adults with ASD.

The only reliable national data source for the performance of persons with ASD in the labor market is a report by the National Center for Special education Research of the Institute of Education Sciences, US Department of Education (Newman et al., 2011). This report, prepared from the National Longitudinal Transition Study-2 (NLTS2), provides information on the post-high school outcomes of young adults (age 21-25) with disabilities up to 8 years after high school. Although the report is primarily based on a telephone survey conducted in 2009 as part of the 5th and final wave of NLTS2 data collection, it provides some information based on all waves of the survey. According to the study, 37.2% of the persons with autism were employed at the time of the survey and 63.2% were employed at some point since leaving high school. The report also shows that workers with autism worked an average of 24 hours a week and their average hourly wage was $9.20. Among the survey respondents with autism, 43.9% had enrolled in postsecondary schools and only 17% lived independently. The study further showed that employment, wages, weekly hours of work, and the rate of postsecondary school attendance among the adults with autism is lower than persons with most other types of disabilities (see **Table 1**). In addition to the data presented in **Table 2.1**, it can be noted that 91.1% of the young adults with autism earn less than $25,000 annual income, a proportion that is higher than the rate for all types of disabilities except mental retardation and multiple disabilities.

Table 2.1. Employment and Postsecondary Education of High School Graduates with ASD Compared with Persons with Other Types of Disabilities

	Employed at time of interview	Employed since high school	Average hours worked per week	Average hours worked per week	Any post-secondary school	Independent Living
Autism	37.2	63.2	24.1	$9.20	43.9	17.0
Learning disability	67.3	94.9	37.7	$10.60	66.8	64.9
Speech/ language impairment	63.9	94.0	34.2	$10.80	66.9	51.2
Mental retardation	38.8	76.2	27.6	$7.90	28.7	36.3
Emotional disturbance	49.6	91.2	35.6	$11.00	53.0	63.1
Hearing impairment	57.2	91.5	31.3	$10.50	74.7	50.5
Visual impairment	43.8	78.0	31.5	$11.10	71.0	55.4
Orthopedic impairment	35.0	67.7	26.8	$9.10	62.0	30.5
Other health impairment	64.4	95.5	35.0	$10.70	65.7	58.2
Traumatic brain injury	51.6	81.4	35.5	$9.30	61.0	42.8
Multiple disabilities	39.2	62.5	24.8	$8.80	32.8	16.4
Deaf- blindness	30.1	70.4	24.7	$9.20	56.8	26.4

Although the data shown in Table 1 is useful for making comparisons between persons with different types of disabilities, it should be noted that the data pertain to only persons aged 21-25 who graduated from high school. When persons from other age groups and persons without completing high school are considered, the outcomes may be different. It is possible that, consistent with the data presented by Hendricks (2010), the unemployment rate among all adults with ASD could be as high as 75%. Hendricks (2010, 27) mentions that even among the high functioning adults with ASD, employment outcomes are "appalling." She mentions that in addition to being unemployed and underemployed, adults with ASD switch jobs frequently and experience difficulty in new job settings. It has also been noted that adults with autism are more likely to be denied vocational rehabilitation services compared to persons with other types of disabilities because their disabilities are considered to be more severe than that of others' (Lawer et al., 2009).

A nationally representative survey conducted by Shattuck et al. (2012) of young adults with ASD and their parents found that only slightly more than half of the young adults with ASD had paid employment during their first six years post-high school. Also, survey respondents with ASD had the lowest employment participation rates and the highest rates of no participation compared with respondents in other disability categories.

Because of the high unemployment and low participation in secondary education among adults with ASD, many studies have focused on transition from high school to college or employment (Hendricks and Wehman, 2009; Geller and Greenberg, 2009; McDonough and Revell, 2010; Roberts, 2010; Gerhardt and Lainer, 2011; Shattuck et al., 2011). The federal Individuals with Disabilities Education Act (IDEA) provide entitlements and services to individuals with disabilities between the ages of 3 and 21, but the services provided under the law do not extend beyond age 21 (Jacket, 2010; McDonough and Revell, 2010). Since the post-secondary services for persons with disabilities are not entitlement-based, persons with ASD or their families have to work through a complex system to determine what types of programs may be available. Because of the diversity of skills and skill deficits of the adults with ASD, identifying suitable programs may often be difficult (McClannahan et al., 2002).

Although vocational rehabilitation for the adults with ASD is an option, Lawer et al. (2009) mentioned that rehabilitation of adults with ASD can be more expensive than the rehabilitation of persons with other types of disabilities. However, rehabilitated persons with ASD are also more likely to be competitively employed. On-the-job support appears to be crucial for the employment success of persons with ASD.

TRANSPORTATION IN THE CONTEXT OF ADULTS WITH ASD

A large number of studies have mentioned transportation for adults with ASD, sometimes to describe it as a need and sometimes to describe it as a barrier. Some studies that mentioned transportation for adults with ASD but did not seriously discuss transportation issues include Unger et al. (1998), Capo (2001), McClannahan et al. (2002), Gantz (2007), Eaves and Ho (2008), Verdonschot et al. (2009), Farley et al. (2009), Geller and Greenberg, (2009), Hart et al. (2010), and Roberts (2010). In many of these studies, transportation is mentioned in the context of access to jobs or societal activities.

In contrast to the abovementioned studies, other studies placed greater emphasis on transportation for persons with ASD. Sheppard et al. (2010), Huang et al. (2012), Classen et al. (2013), and Reimer et al. (2013) are examples of studies that focused on driving skills of persons with ASD. By using video clips in an experimental study, Sheppard et al. (2010) found that person with ASD identified fewer driving hazards

and were slower to respond to hazards compared to persons without ASD. In a study involving 15-18 year old teens, Huang et al. (2012) found that the teens with ASD who drove were more likely to attend full-time regular education, more likely to plan to attend college, and more likely to hold a paid job than the non-driving teens of identical age groups. The findings indicate that high functioning persons with ASD are more likely to drive than others with ASD. Similar to Sheppard et al. (2010), Classen et al. (2013) compared the driving skills of teenage persons with ASD with a control group in a simulated environment. The study concluded that persons with ASD (and ADHD) performed at a lower level on visual function, motor function, and cognition while driving than the control group. In yet another experimental study in simulated condition, Reimer at al. (2013) compared high functioning young male adults with ASD (age 18-24) with a control group and concluded that their driving pattern deviated from the optimal. Together, these studies indicate that many adults with ASD may not have the required skills for driving, especially in hazardous conditions with high traffic volumes. Furthermore, even some high functioning adults with ASD may be slow to recognize driving hazards or could be slow to respond to hazards.

Several studies dealt with public transportation in the context of persons with cognitive and intellectual disabilities, but did not specifically address persons with ASD. Examples include Carmien et al. (2005), Sohlberg et al. (2005), and Sohlberg et al. (2009), and Precin et al. (2012). All of these studies focused on some aspects of community transportation for persons with disabilities. Some other studies, such as Davies et al. (2010) and Mechling and O'Brien (2010), studied the application of technologies to aid transit passengers with intellectual or cognitive disabilities. Stock et al. (2011) mentioned the difficulties faced by persons with cognitive and intellectual disabilities in using different travel modes. The study found that persons with such disabilities often do not possess the required driving skills, cannot afford to pay for regular use of taxis, and cannot take public transportation because of certain limitations.

Wasfi and Levinson (2007) prepared a comprehensive study on transportation needs for persons with developmental disabilities in Hennepin County, Minnesota, but the number of persons with ASD in the sample was small. Through a survey, Feeley (2010) collected data from 548 adults with ASD in New Jersey and found that more than 80% of the respondents were reliant on friends and family for their transportation. Close to 22% of the respondents reported using fixed-route and paratransit service. More than 50% considered lack of transportation to be a barrier to work. Dudley et al. (2012) prepared a report for Autism Calgary by specifically focusing on the transportation needs of persons with ASD. The report included a literature review and some discussions, but did not include any empirical analysis. It theoretically described the transportation needs of persons with ASD belonging to different age groups.

LITERATURE REVIEW CONCLUSIONS

This literature review was conducted to gather background information on persons with ASD and the various issues they encounter in life so that their transportation needs and barriers studied through this research could be fully contextualized. This review showed that a large number of studies on persons with ASD pertain to children instead of adults. However, there is an increasing emphasis to study issues pertaining to adults because of the growing number of children growing into adulthood.

The review showed that the prevalence of ASD among children has increased significantly over time. It also showed some of the characteristics of persons with ASD that impede their search for basic needs like jobs and transportation. The review showed that adults with ASD perform at a lower level in the labor market than persons with many other types of disabilities.

One of the challenges for persons with ASD is the transition into adulthood around age 21, when the government's support programs disappear, putting pressure on the persons with ASD and their families. Perhaps for that reason, a substantial amount of literature on persons with ASD has focused on job training and employment for adults with ASD.

Many studies on job training and employment of adults with ASD have emphasized the importance of transportation for their success. However, these studies were mainly concerned about training and employment issues instead of specific transportation issues. Although a few studies were conducted with the primary focus on transportation, they were mostly concerned about driving skills instead of being concerned about the skills required to use other modes of transportation. Since the studies that focused on driving showed that only high-functioning adults with ASD have the skills required to drive, it is important for research to concentrate on skills that are useful for traveling by other modes, including public transportation and walking. Overall, this literature review provided a context to study the transportation needs and barriers of adults with ASD. It showed that comprehensive transportation studies on adults with ASD have been rare in the past, and as a result, little is known about the way this population travels, the purposes they travel for, the transportation systems that serve them, and the barriers they encounter while traveling to various activities.

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STAKEHOLDER INTERVIEWS

This research included semi-structured interviews with 25 stakeholders from various ASD-focused and transportation-focused agencies that are pertinent for this research. Interviews can be used to understand unique and contextual issues for distinct groups of stakeholders in regards to social issues as well as transportation. The qualitative semi-structured interviews conducted for this study allowed a better understanding of the barriers to transportation and mobility for adults with ASD.

At the outset of this task, an interview script and an interview protocol were prepared. The Rutgers University Institutional Review Board subsequently reviewed and approved the script and the protocol. Stakeholders were then selected from the fields of transportation, autism, and disabilities in general. The stakeholders included individuals on the spectrum, family members, and officials from various governmental and non-governmental agencies that provide services or support to adults with ASD. The stakeholders were selected to ensure that diverse interests and backgrounds were represented.

All interviews were conducted in-person or by telephone between December 2013 and July 2014. The interviews were conducted in a semi-structured format, meaning that the interviewees responded to a common set of questions as well as a set of questions specifically designed for that specific agency or organization. Since various types of stakeholders were involved, the structure of the questionnaires was flexible so that different types of information could be obtained from the various stakeholders.

The interviews were transcribed, summarized and reviewed for accuracy. A system of coding and analysis was implemented with the content of the interviews to identify common and emergent themes. The interview summaries were also analyzed by specific field for four distinct groups – (a) agencies/organizations that provided any form of transportation services (including day programs that provide transportation), (b) agencies/organizations that provided any type of direct services, (c) transportation-based agencies and organizations, and (d) organizations that provided any type of transportation and/or mobility training.

ANALYSIS OF THE INTERVIEWS

Eight common themes emerged from the 25 documented interviews. They are summarized below.

1 *A significant gap exists in public transit use between those residing in areas with multiple transit services and those who live in areas with limited or no transit services nearby*

The most critical barrier for individuals to learn mobility skills for public transit use is residence in areas that have limited or no transit. Individuals that are outside the areas served by fixed-route transit are also outside of the areas served by ADA-complementary Access Link paratransit service, which greatly limits access to public transit. This was cited as a barrier by an overwhelming majority of the interviewees. For individuals and organizations located outside of the ADA paratransit service area, getting to a transit station or stop itself was difficult. In some adult programs and schools, the use of transit would be the goal of a field trip or community based instruction, but not the actual means to get to a destination. Trying to build the mobility skills in schools and adult programs is difficult in such places due to the lack of proximity to transit.

One interviewee mentioned that schools and day programs are often located without much thought about public transportation. In the words of the interviewee:

> "Often locations are determined solely by price but the lack of transportation is often not considered a primary factor in that choice. Transportation should be a major component that needs to be included in the decision making process. "How do we get to the [human service] programs?" needs to be considered. Planning for transportation needs to be included in all aspects of adult life."

For many of the transportation providers interviewed, it is frustrating that programs, residential settings, and employment facilities are often located far from transit routes. There is a myth that "if you build it, transit will come." It appeared from the interviews that some of the state agencies have become more conscious about locating facilities near transit routes. Some of the autism organization programs have also become very mindful about choosing locations that are accessible by transit as well as by car.

Overall, there are numerous transit options in New Jersey's densely populated urban areas, including appropriate infrastructure sidewalks, signalized and signed intersections, and crosswalks. In most suburban and rural communities there are no transit options available. Even when transit is available, there is a lack of sidewalks and other infrastructure that is needed for safe pedestrian travel.

For adult programs and schools that are located in pedestrian- and transit-friendly communities, there are numerous options to integrate various instruction methods for safe travel and mobility. However, such options do not exist in rural and suburban areas. Since the automobile is the only travel mode that can be used in such areas, and since most adults with ASD cannot drive because of their disability, taking rides from others is their only feasible travel option.

2 *Little opportunity with limited resources in adult services to work on teaching and/or improving mobility skills and inform adults of transportation options available in their respective communities*

More than two-thirds of the stakeholders interviewed cited the lack of resources for training in adult services as a barrier to travel training/instruction. Many adult service programs cannot afford to provide the same level of training as schools. The higher ratio of consumers to staff members in adult services provides less opportunity for one-on-one training for adults as compared to students at schools.

Some of the adults do have the opportunity to learn travel and mobility skills in the proximity of their day programs, but they do not learn how to safely travel within their residential communities. The lack of training in an individual's own community is an issue for adults as well as transition age school students.

An interviewee who is an internationally renowned expert on adults with ASD commented:

> "Adult services do not have the time or the resources to effectively teach safety skills needed for independent travel."

Another interviewee commented:

> "Transportation options for adults that have aged out of school are very limited. Often choices about placement are determined by transportation."

3 *A part of the barrier in using public transit is explained by a lack of skills as well as characteristics associated with ASD*

While access to public transit is important for those who can use it, lack of skills in how to use public transit is an impediment to independent travel by many adults with ASD. A large proportion of the stakeholders noted the lack of specific skills among adults with ASD as barriers to using any type of public transit, including ADA-complementary paratransit service. In addition to the skills needed to use transit services, lack of safety perceptions and behavioral issues associated with ASD were also mentioned as barriers for independent travel. Interviewees discussed certain issues specific to fixed-route and ADA paratransit. Regarding paratransit, one interviewee stated:

> "Since [ADA complementary paratransit services] have so many variables – the large pick-up window with varying routes and riders – this lack of consistency can be frustrating for individuals with autism and their families."

One interviewee from one of the autism organizations commented:

"Many of the transit services are not designed for individuals on the Autism Spectrum. The services can be unpredictable which can cause anxiety for this population. In addition many services do not offer the flexibility that is required by this population."

4 *Families and caregivers often view individuals on the autism spectrum as vulnerable and consequently feel over-protective in regards to adults with ASD pursuing independent travel*

Family and caregivers were identified by a large proportion of the stakeholders as an impediment to independent travel by adults with ASD. Families are often afraid for their adult children regarding independent travel. However, five interviewees referenced "the dignity of risk" philosophy in regards to independent travel, explaining that each individual has a right to self-determination and to make choices and decisions that will support autonomy, such as learning independent travel skills. Numerous suggestions were shared about the benefits of parents encouraging adults with ASD to use transportation independently, but interviewees also acknowledged that it is often difficult for parents to feel safe about their children when they are on their own.

An interviewee from an autism advocacy organization stated:

"The fear involves letting go of members of a vulnerable population. Some of these fears can be addressed through teaching safety skills that specifically address the parents' concerns. The parental fears can also be alleviated by introducing them to the transportation systems and services that their children (family members) will be utilizing. There are also concerns regarding the lack of awareness of the general public regarding how to work with people with disabilities. Parents' fears can also be alleviated through adequate travel training procedures. It is essential that a good travel training program include "what if" scenarios as part of the training. Also parents must let go of the perception that public transit is limited to urban areas of the state. Many people in the suburbs would benefit by using their local public transit services."

Another interviewee discussed the importance of including the parents in travel training to ensure successful outcomes. The interviewee noted that when the parents' questions and concerns are addressed by travel trainers, the former are more likely to support and allow their adult children to travel independently. When parents are unfamiliar with or afraid of public transportation, failure is likely.

Five of the 25 stakeholders disclosed that they were also family members of individuals on the autism spectrum or other developmental disabilities and they confirmed that families and caregivers often discourage adults with ASD from pursing independent travel.

5 *Although the school transition period is a critical time for learning transportation and mobility skills, all too often these skills are not taught*

The education transition period for individuals with ASD (from age 16 to 21) was often referred to as the most critical period to teach transportation and mobility skills. More than half of the interviewees expressed that these young adults did not receive the required training to travel independently. When schools do train transitioning adults, transportation and mobility skills, the latter are often successful in navigating transit systems and learning pedestrian skills. In New Jersey, the transition period can provide individuals up to 7 years of continuously reinforced travel and mobility training.

An interviewee from an educational services establishment remarked:

"For former students, the outcomes have been better for those who have some travel training. The lack of travel training means a

lack of options that are available once school is complete. The ability to travel independently is directly related to the employment options that are available."

Transportation and travel training are not explicitly stated or required by federal laws. These skills are only to be instructed if appropriate. Many interviewees recommended that travel instruction be included in a student's Individualized Education Program (IEP). The majority of interviewees lamented that currently few young adults on the spectrum receive any travel instruction during their transition years; however, this current state could change dramatically if travel instruction was mandated by legislation for inclusion in IEPs.

Some educators commented that the success in independent travel often leads to successful professional outcomes in adulthood. Another concern that was expressed is that transition programming is conducted on an individualized basis as determined by the home school districts and therefore consistency was lacking across school districts.

Since travel training is not a required service by law and school districts are not required to provide travel training instruction, even if appropriate, there may be lost opportunities to teach travel instruction to young adults with ASD. In many cases, individuals are not given the opportunity to learn travel training through their educational programming.

6 *More specific training modules on the diverse characteristics of autism should be made available and be required for transit vehicle operators and front line staff working with this population to enable safe travel*

Many stakeholders expressed that additional training should be required for transit vehicle operators and front line staff about the characteristics of persons with ASD. All of the transit-related agencies interviewed provided some level of training to the vehicle operators. Some of the interviewees from transit- related agencies acknowledged that additional training would be helpful, although most of the drivers receive some training. Although Community Transportation Association of America's Passenger Service and Safety (hereafter PASS) training is the most common for vehicle operators, PASS does have a designated module on Autism.

A PASS-certified trainer who was interviewed acknowledged the limitations of vehicle operators in assisting passengers while operating a vehicle. It was noted that while an individual on the spectrum had a right to use paratransit services, they cannot infringe on other passengers using the service. The trainer stated:

"While drivers do receive training, they are not specialists in coping with symptoms and/or behaviors related to any particular disability. In addition, drivers must be focused on maintaining the safety of all passengers and thus, any accommodation made for a given passenger must be reasonable and not negatively impact other passengers."

All of the transit agencies noted that the vehicle operators must focus on transporting people safely. Vehicle operators cannot drive the vehicle when they are at risk or other passengers are at risk.

Issues involving the right to privacy and having one's disability disclosed was also discussed. Transit vehicle operators are only aware of a passenger's specific disability when the individual or his/her family discloses the information. In most instances, vehicle operators do not know about the disabilities of the passengers. Some interviewees noted that the federal Health Insurance Portability and Accountability Act (HIPAA) is the reason for disability information not being shared with the vehicle operators.

7 *While driving is the primary transportation mode for the general population of New Jersey, persons on the spectrum seem to be taught mostly about transit and pedestrian skills in schools, day programs and public funded agencies, while other means of travel are not taught at all*

For adults on the spectrum interested in driving, there are not a lot of avenues to learn driving skills. About half of the stakeholders noted that driving was important for living in the region. Although some individuals do not have the ability to learn the skills needed to drive a vehicle on a regular basis, many adults on the spectrum are high functioning and they could learn to drive if opportunities existed. However, at present it is entirely up to the parents and family members to teach their children how to drive.

One certified driver rehabilitation specialist mentioned that there was little encouragement for adults on the autism spectrum to learn to drive or get a driver's license. One interviewee who encouraged adults on the autism spectrum to drive noted:

> "There is evidence as well as theory that driving may be dangerous for folks with autism, but, in reality, driving is dangerous for everyone. There are challenges and adversity on the road but through assessment and training, the opportunity to drive can be provided … Aside from the ability to drive - people need the time, money and opportunity – so they can learn to drive."

An internationally recognized advocate noted that having a license is important, but the adults on the spectrum will need their own cars. Specifically, the person mentioned:

> "Having one's own car is just as important as being able to drive – there is also anxiety with sharing a car since the vehicle may not be available when a person needs it."

The majority of the interviewees did little to encourage individuals to drive. One interviewee advised that adults on the spectrum who are interested in driving should obtain a permit by themselves. Another interviewee encouraged adults on the spectrum to gather information themselves to show their interest in driving. Aside from the cognitive issues related to driving, the responsibilities and costs involved in car ownership were also discussed.

8 *Educating the public about adults on the spectrum is necessary to achieve full community integration, including using any mode of transportation*

About half of the interviewees emphasized the importance of educating the public about adults on the autism spectrum. Awareness campaigns regarding adults with autism including characteristics, deficits and abilities have not been conducted. Full community integration cannot be achieved by adults on the spectrum until they are not treated any differently by the general public.

The lack of familiarization of the general public with adults on the spectrum and their characteristics was seen as a significant barrier to independent travel. Many stakeholders noted that the public perception is limited to seeing children on the spectrum, but people know little about adults.

An interviewee from a family support planning organization commented:

> "A PR campaign training the general public about adults on the spectrum would help by de-sensitizing the public to the unusual aspects of developmental disabilities and autism spectrum disorder. However this would require a large paradigm shift but [I] believe it could be done and would be beneficial for adults with developmental disabilities in participating in their communities, including using public transit services. Public transit agencies would also have to embrace this new paradigm.

Another interviewee commented:

> "It is very important that we educate the community at large regarding the needs of adults on the autism spectrum. This would involve making the awareness of the impacts of autism extend beyond children, into adults, including their needs and supports… this would have to be done in a method that respects the diversity and dignity of adults on the autism spectrum."

Finally, in addition to the eight common themes discussed above, several interviewees emphasized costs associated with transportation service. The cost for day programs to provide transportation services was described as significant, if not burdensome. The budget for transporting individuals is very expensive due to the nature of their needs and level of the services required. One of the interviewees noted:

> "Providing all individuals on the spectrum with a full time personal driver could solve one set of problems but is unrealistic and not cost effective for most people. Only those with the means can have a private service provider."

Another interviewee stated:

> "For-hire services are cost-prohibitive to both the individual's budget and the agencies budget. … Transportation is also a difficult fundraising issue because many donors think the costs are already being covered and don't understand the expenses in transporting individuals to the program."

STAKEHOLDER INTERVIEW CONCLUSIONS

The stakeholder interviews provided insights about the struggles encountered by adults with ASD regarding their travel needs and barriers. Since some of the interviewees were from agencies that work for the betterment of persons with ASD, whereas others were from agencies that provide transportation, a mix of perspectives could be observed through the interviews. On the whole, all interviewees were sympathetic to the overall travel needs of adults with ASD and emphasized that transportation access was a critical component to the successful integration of adults with ASD in their respective communities. Availability of transport options and ability of persons on the spectrum to use various options directly impacts their ability to live independently and to pursue opportunities including employment and continuing education.

From the eight themes that emerged from the interviews, one can clearly see that the transportation barriers of the adults with ASD are not only about public transportation, but are also related to walking, driving, the places they live in, the schools and day programs they attend, the training they receive on various aspects of life, and also certain limitations that are imposed by their disabilities.

As many New Jersey adults with autism live in areas where transit service is rare or non-existent, there is little scope for them to use transit or to get training to use transit. Although some efforts are made to train school students to walk safely and use public transit, such training disappears as they get older. As a result, families often have to bear the burden of all transportation. However, in places where transit is available, some adults with ASD can and do use public transit.

Unfortunately, not all adults with ASD have the skills required to drive. However, because of the locations where many live, having the ability to drive would greatly add to their life experiences and opportunities. In certain cases, parental fears/concerns impede the desire to drive among adults with ASD. In addition, there are not many opportunities for adults on the spectrum to learn to drive because schools and day programs mainly focus on training of public transit use only.

The interviews clearly indicated that training for vehicle operators who transport adults with ASD could be improved. Although many are trained to deal with passengers with disabilities, they do not have adequate knowledge about autism. Laws and regulations also impose some restrictions in that all operators are not aware of the specific disabilities of their passengers. Vehicle operators' tasks are challenging because on the one hand they have to be helpful to all passengers, including passengers with ASD, but at the same time they also have to protect other passengers if a passenger acts unsafely because of a disability.

It also became clear from the interviews that there

is a conflict of perceptions as to the benefits of the adult with ASD becoming more independent. Some expressed that by trying to be independent; one could learn how to navigate through a complex web of transportation options. On the other hand, others felt that trying to be independent can also result in unwanted or unsafe outcomes.

Finally, the interviews demonstrated that there is a need for society to learn more about adults with ASD. In general, most people think about ASD only in the context of children without recognizing that many adults also have the same impairments. Many interviewees felt that society in general must be exposed to more persons on the spectrum so that they can have the opportunity to learn about adults with ASD. Many interviewees explained that if this occurs, persons on the spectrum will likely experience more successful community integration outcomes.

SURVEY OF ADULTS WITH ASD

One of the critical components of this research was a survey of adults with ASD in New Jersey. While the stakeholder interviews were conducted to learn about the perspectives of organizations and agencies serving persons with ASD, the survey was conducted to learn directly from the adults with ASD about their travel patterns and transportation needs and barriers.

Due to the extreme difficulty in contacting adults with ASD through random sampling, the research team took recourse to a convenience sampling design and used 27 different avenues to distribute the survey among potential respondents, including the use of websites and contact lists maintained by various organizations and agencies. In addition, members of the research team attended a number of events involving persons with ASD to publicize the survey.

The survey was conducted online, but prospective respondents were also given the opportunity to request paper copies of the survey for mailing back. The online survey was set up using Qualtrics®. The survey instrument was approved by the Rutgers University Institutional Review Board and pre-tested on approximately 20 adults with ASD or their guardians. The survey effort resulted in the collection of data from a total of 717 respondents, of which 14 were eliminated because they reported belonging to a state other than New Jersey. Thus the total number of targeted respondents who completed the survey was 703. Most of the respondents completed the full survey, although some did not respond to specific questions. Of the total, only six surveys were received by mail from respondents who requested paper copies and the rest were completed online. The survey was completed between the middle of 2014 and early 2015. Different parts of the state were represented well as the respondents belonged to 240 of the state's 565 municipalities, with the highest of 12 respondents belonging to one municipality. Figure 1 shows the distribution of survey respondents throughout New Jersey at the municipal level.

Based on prior experience of the research team, it was anticipated that many respondents would require assistance from others to complete the survey. The respondents were therefore given the opportunity to have the survey completed by others, including parents, guardians, et cetera. **Table 4.1** shows the distribution of survey takers. It is evident from the table that only a very small proportion of adults with ASD completed the survey on their own, whereas a very large proportion of the surveys were completed by the parents of the adults with ASD. A reason for such a large proportion of the surveys being completed by parents is that most of the respondents are of a young age. As **Table 4.2** shows, 86.1% of the adults with ASD surveyed were between the ages of 18 and 29, and only 13.9% were 30 or older. Another reason for the large proportion of the surveys being completed by parents is that 86.3% of the surveyed adults with ASD lived with their parents (see **Table 4.3**). In contrast, only 2.5% of the adults with ASD lived alone.

Some other characteristics of the survey participants are also important to note so that their responses to questions on transportation can be fully contextualized. Although the DSM-5 mentions that men are four times more likely to be diagnosed with ASD than women, the male to female ratio was 3.16 among the survey respondents. Of the respondents, 27.6% had less than a high school diploma, 41.5% had a high school diploma, and only 3% had a bachelor's degree or higher level of education. Partly because of their young age, 29.5% of the surveyed persons with ASD were students and another 20.2% were taking vocational training, whereas only 0.9% were employed fulltime, 15.9% were employed part time, 8.8% were employed as volunteers, and another 6.9% were employed at sheltered workshops.

The travel patterns and barriers for adults with ASD cannot be fully comprehended without understanding their impairments related to the disability. **Table 4.4** shows the responses as well as the proportion of re-

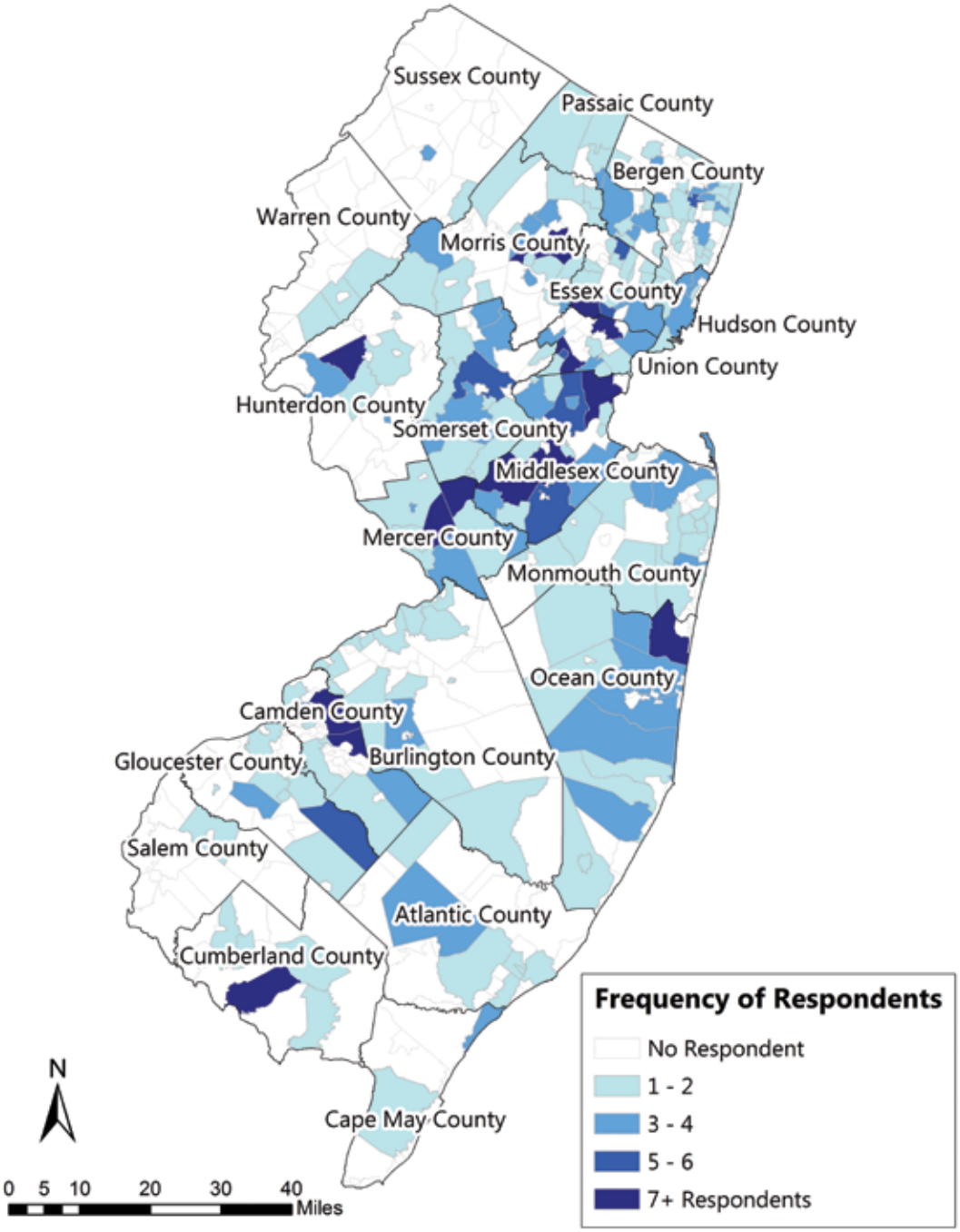

Figure 4.1. Distribution of Survey Respondents at the Municipal Level throughout New Jersey

sponses and the proportion of respondents to a multiple-choice question in the survey about impairments. The proportion of responses is shown because the respondents were allowed to select multiple impairments. One can observe from the table that almost two-third of the respondents have difficulty with social interaction and almost half have difficulty with executive functioning and organizational skills. Other highly common impairments include focused area of interest and perseveration, sensory issues, cognitive and intellectual impairments, and mental health issues. These and other impairments listed in **Table 4.4** are likely to have a significant effect on the way the individuals travel. For example, social interaction issues can affect a person's ability to take mass transportation since it requires the person to be in close proximity of others, executive and organizational difficulties can make it strenuous to plan trips, and cognitive and intellectual

Table 4.1. Distribution of Survey Takers

Survey Taker	Frequency	Percent
Individual on the Autism Spectrum	45	6.7
Parent	547	81.9
Legal Guardian, Non-Parent	16	2.4
Sibling/Other Family Member	13	1.9
School/Educator	10	1.5
Counselor/Day Program	24	3.6
Others	13	1.9
Total	668	100
Non Response	35	5.0

Table 4.2. Age Distribution of the Surveyed Adults with ASD

Age	Frequency	Percent
18 to 21 years old	261	45.9
22 to 29 years old	229	40.2
30 to 39 years old	50	8.8
40 to 49 years old	17	3.0
50 to 64 years old	12	2.1
Total	569	100.0
Non Response	134	19.1

Table 4.3. Living Arrangement of the Surveyed Adults with ASD

Living Arrangement	Frequency	Percent
With parents	512	86.3
Assisted living center or group home	46	7.8
Lives alone	15	2.5
With relatives	3	0.5
With spouse or partner	2	0.3
With dependent children	8	1.3
With adult children	4	0.7
College dorm	2	0.3
Lives with friend	1	0.2
Total	593	100.0
Non Response	110	15.6

Table 4.4. Difficulties Related to ASD Experienced by the Survey Respondents

Impairments	Responses	Percent of Responses	Percent of Respondents
Severe cognitive or intellectual impairment	170	5.8	24.2
Mild cognitive or intellectual impairment	253	8.6	36.0
Some difficulty with speech	198	6.7	28.2
No speech	73	2.5	10.4
Other communication difficulties	208	7.0	29.6
Executive functioning or organizational skills difficulties	348	11.8	49.5
Social interaction and social literacy difficulties	460	15.6	65.4
Focused area of interest/perseveration	301	10.2	42.8
Sensory issues (hyper- or hypo-sensitivities)	291	9.8	41.4
Self-care difficulties	112	3.8	15.9
Physical coordination issues	112	3.8	15.9
Co-existing mental health issues (Depression, Anxiety, etc.)	236	8.0	33.6
Co-existing medical issues	138	4.7	19.6
Other, Please Specify	56	1.9	8.0
Total	2956	100.0	NA

difficulties can make an individual require assistance from others while making trips.

TRAVEL PATTERNS OF ADULTS WITH ASD

Travel Modes Used

Since persons with disabilities travel far less than the general population, instead of inquiring about the travel modes they used on the day of the survey, they were asked which travel modes they used during the past three months. The respondents were provided a list of travel modes to select from with instruction to select all modes they used during the stipulated period. The responses to the question are summarized in **Table 4.5**, where it is evident that the most common practice for the respondents is to take rides as passengers of vehicles driven by others. Most of these rides are taken from parents, but rides provided by friends, volunteer drivers, and local government or non-profit agencies also constitute large shares. Only a very small proportion drives, but a much larger proportion walks outside of their homes. The use of fixed-route transit, consisting of commuter train, light rail, and buses, is not very common, but Access Link, the ADA-complementary paratransit service provided by NJ TRANSIT, seems to be used by many. Among the fixed-route transit modes, buses are used most commonly. The reason could be that buses typically pick up and drop off riders closer to homes than trains.

In addition to the question on travel modes used during the past three months, the respondents were asked about the frequency of using specific modes. The question on walking revealed that 55.2% of the respondents never walked in their neighborhoods, whereas 25.9% sometimes walked, 14.2% often walked, and only 4.7% always walked. Similarly, the question on public transit use revealed that 61.4% of the respondents never used any form of transit, whereas 31.5% sometimes used, 5.7% often used, and 1.4% always used transit. When those who never used transit were asked if they considered using transit,

Table 4.5. Travel Modes Used by Adults with ASD During Past Three Months

Travel Mode Used in Past Three Months	Responses	Percent of Responses	Percent of Respondents
Drives himself/herself in a private car	22	1.6	3.1
Passenger in a private car with parents or family	480	35.8	68.3
Passenger in a private car with friends	98	7.3	13.9
Bus/van operated by a county, municipality or non-profit	110	8.2	15.6
Taxi or other for hire vehicle	52	3.9	7.4
Walk	201	15.0	28.6
Bicycle	41	3.1	5.8
Passenger in a private car with volunteer driver	84	6.3	11.9
NJ Transit train	38	2.8	5.4
NJ Transit light rail/subway	12	0.9	1.7
NJ Transit bus	45	3.4	6.4
Access Link from NJ Transit	88	6.6	12.5
SEPTA/PATCO public transportation services	3	0.2	0.4
Day Program	6	0.4	0.9
Group home	6	0.4	0.9
School/Educational Institution	11	0.8	1.6
Other, Please Specify	44	3.3	6.3
Total	1341	100.0	NA

68.4% mentioned never considering it, indicating that approximately 42% of all respondents never considered using any form of public transit.

Because of their low likelihood of driving, instead of directly inquiring about driving frequency, the respondents were first asked whether they had a driver's license and then those having a license were asked how frequently they drove. As expected, only 9.3% of the respondents mentioned having a driver's license. Of them, 23.9% drove every day, another 30.4% drove one or more times a week but did not drive every day, 19.4% drove less than once a week, and 26.1% never drove. The respondents were not asked how frequently they took rides from others, but the response to a question revealed that 97.6% of all respondents took rides from others for school, work, recreational, social, or other activities. In sum, the questions on travel mode use revealed that driving and taking fixed-route transit are not very common among the survey respondents. Although walking is more common, more than half the respondents never walked outside their homes. The most common mode of transportation for the persons with ASD is taking rides, and in most cases the rides are provided by someone in their own household.

Trip Purpose by Travel Mode

The survey respondents who mentioned walking, driving, or taking any form of transit were asked three separate questions about the purposes of their trips by these modes. Since people make trips using the same mode for multiple purposes, the respondents were allowed to select as many trip purposes as relevant from a given list. The responses to the questions are sum-

marized in **Table 4.6**, where the bottom row shows the total number of responses for each mode. The lists of purposes for driving and public transit trips were the same, but additional purposes were listed as potential responses to walking trips.

It is evident from **Table 4.6** that work/employment is not one of the most common trip purposes for any of the travel modes. The reason is that only a few of the respondents are gainfully employed. In contrast, a fairly large proportion of respondents for each of the three modes mentioned making trips for social and recreational purposes and for shopping and daily errands. For driving and public transit, the proportions of trips for education and vocational training and visiting families/friends are also substantial, but not many walking trips are made for those purposes. The most common purpose for walking trips is exercise, but walking to transit stations is also not too uncommon. However, the responses clearly reveal that walking is not very common when it comes to trips to work, education, and medical/health appointments. Although it appears from **Table 4.5** that more adults with ASD are capable of walking than driving or taking any transit mode, their low propensity to make walking trips for transportation purposes could potentially be the result of their destinations being too far from their homes or other factors including lack of adequate pedestrian infrastructure and/or parental opposition to independent walking.

Travel Needs and Availability of Transportation

All respondents were asked through a series of questions about the purposes for which they needed transportation. They were required to select yes or no to indicate whether they needed or did not need transportation for specific purposes. The questions were not meant to learn about the gap between availability and need for transportation, but instead to learn about the importance of traveling for different purposes. The responses to the questions are summarized in **Table 4.7**.

It can be observed from **Table 4.7** that the need for transportation is felt the most for trips to social and recreational activities, followed respectively by trips for medical/healthcare appointments and education/

Table 4.6. Trip Purposes by Travel Mode

Trip Purpose	Walking (%)	Driving (%)	Public Transit (%)
Work/employment	4.5	11.9	12.4
Education, vocational or job training	6.2	10.1	21.5
Social or recreational activities	14.5	16.5	31.5
Medical and health-care appointments	1.5	11.9	7.1
Religious activities	3.0	5.5	1.2
Visiting families and friends	8.5	16.5	12.4
Shopping/daily errands	17.7	18.3	9.7
Exercise	33.6	NA	NA
To get to bus stop or train station	8.1	NA	NA
Walking dog	1.7	NA	NA
Other purposes	0.9	9.2	4.4
Total	100.0	100.0	100.0
Total responses (N)	470	109	340

TABLE 4.7. Transportation Needed for Different Purposes

Trip Purpose	Respondents			Percent			Percent of Total Respondents Selecting Yes*
	Yes	No	Total	Yes	No	Total	
Work/employment	333	114	447	74.5	25.5	100.0	47.4
Education, vocational or job training	408	63	471	86.6	13.4	100.0	58.0
Shopping/daily errands	408	70	478	85.4	14.6	100.0	58.0
Social or recreational activities	445	40	485	91.8	8.2	100.0	63.3
Support group	255	111	366	69.7	30.3	100.0	36.3
Religious services	245	126	371	66.0	34.0	100.0	34.9
Medical and healthcare appointments	433	48	481	90.0	10.0	100.0	61.6
Visiting family and friends	405	66	471	86.0	14.0	100.0	57.6

* Estimated out of 703 total respondents

training. Transportation is also highly important for visiting family and friends and shopping and errands, but not so important for trips to religious activities, attending support group events, or employment. When the responses summarized in **Table 4.7** are compared with the purposes of actual travel shown in **Table 4.6**, it becomes evident that there is a consistency between trips made and transportation needed for most purposes. One exception is trips for medical and healthcare purposes, for which transportation need is felt very highly, but such trips are not made very frequently.

Another question in the survey inquired about the availability of transportation, both private and public, for trips with different purposes. The responses revealed that transportation is available to a greater extent for trips that have a higher need. For example, fewer respondents mentioned that transportation was unavailable for trips to education and training activities, medical and healthcare appointments, and shopping and errands than trips to religious and support groups activities. The results indicate that persons with ASD and their families make adjustments of time and resources to ensure that transportation is available for trips that are of utmost importance, but do not necessarily make such adjustments for trips with lower priorities.

TRANSPORTATION BARRIERS

The most important objective of the survey was to identify the transportation barriers encountered by adults with ASD. Pertinent to this objective, a number of questions were included in the survey, each set addressing issues related to the use of a specific mode, including walking, driving, taking rides from others, and taking public transit. The responses from the survey are summarized below for each mode.

Barriers to Walking

The survey respondents were given a list of potential barriers that could prevent them from walking in their neighborhoods. The list included absence of or poor quality of sidewalks, absence of streetlights, poor quality of intersections or street crossings, traffic speed and volume, crime, and the absence of destinations nearby. In addition, the respondents were allowed to select a separate category called "Other" and specify barriers that were not in the list. The barriers selected by most respondents from the list were absence of

destinations (25.0% respondents), traffic speed and volume (24.9%), and absence or poor quality of sidewalks (17.4%). The barriers selected least commonly were crime (5.3% respondents), absence of streetlights (8.7%) and poor quality of intersections and crossings (11.9%). It is important to note that 28.2% of the respondents selected the "Other" category and invariably specified their impairments related to the disability as barriers to walking. Thus, while the responses showed that some of the environmental barriers to walking encountered by the general population are also encountered by persons with ASD, they encounter additional barriers because of their impairments.

Although individuals without ASD might not think about walking in their neighborhoods as a difficult task, walking requires certain skills and abilities that many persons with ASD do not have. To examine whether the respondents had the critical skills to safely walk in their neighborhoods, they were asked whether they had any difficulty with various aspects of walking. Once again, they were given a list and instructed to indicate whether they had difficulty with one or more aspects. Their responses are summarized in **Table 4.8**. It is evident from the responses that basic skills such as crossing roads, judging vehicle distance, and determining direction, which the general population take for granted, are difficult for a large proportion of persons with ASD. In addition, a substantial proportion of them also have to deal with distractions while walking because of their disability. Due to these difficulties, 53.5% of the respondents indicated in response to another question that they did not know how to safely cross a road without assistance from others.

Barriers to Driving

Unavailability of vehicles in their households is not a barrier to driving for most surveyed adults with ASD. The survey revealed that only 3.6% of the respondents did not have any vehicle in their households, while 26.4% had one vehicle, 46.9% had two vehicles, and 23.1% had three or more vehicles. However, only 9.3% of the adults with ASD had a driver's license, many using it only as a form of an identity card instead of an actual license to drive. Of the 47 individuals who had a driver's license, 61.4% mentioned that they had some form of difficulty when driving. In response to a question inquiring about specific difficulties, 55.3% of the persons with a driver's license mentioned difficulty dealing with traffic, 34.0% mentioned difficulty due to distractions near roads, 27.7% mentioned difficulty judging distance, and another 27.7% mentioned difficulty with parking. Due to these difficulties, 26.1% of those with driver's licenses did not drive at all, 19.6%

Table 4.8. Difficulty with Different Aspects of Walking

Difficult Aspects of Walking	Responses	Percent of Responses	Percent of Respondents
Crossing a street	290	16.7	41.3
Judging the distance and/or speed of cars	318	18.3	45.2
Walking in areas without sidewalks (on grass or in streets)	193	11.1	27.5
Dealing with distractions while walking	282	16.2	40.1
Too many people on the sidewalk	64	3.7	9.1
Too many cars or too much traffic	257	14.8	36.6
Difficulty determining directions/route	247	14.2	35.1
Other, please specify:	86	5.0	12.2
Total	1737	100.0	NA

drove less than once a week, 30.4% drove once or more a week, and only 23.9% drove daily.

Barriers to Taking Rides from Others

As noted previously, the most common travel practice among the surveyed adults with ASD is taking rides from household members and others. Yet, even taking rides from others involves difficulties for some persons with ASD. Among the survey respondents, 11.7% reported having difficulties when taking rides from others. Among those who experienced difficulties, 16.1% experienced anxiety, 14.3% displayed aggression, 12.5% displayed agitation, and another 12.5% demonstrated compulsive behavior. Fear, attempts to injure oneself, and unsafe behavior such as trying to open car doors and unbuckle seatbelts were also mentioned by some.

Unavailability of persons who could give rides is also a serious travel barrier for adults with ASD. Although they most commonly travel by taking rides, 72.8% of the respondents reported missing activities at least sometimes because of the unavailability of persons who could give rides when needed. Like the persons with ASD themselves, the persons who provide those rides – mostly parents and other family members – also forgo time and resources to provide the rides. When asked about such sacrifices, 73.2% of the respondents reported that the ride givers at least sometimes missed their own activities, including work, to give the rides. Thus, despite being the most common form of travel for persons with ASD, getting rides from others is not always possible and it can be challenging for their family members to give rides when needed.

Barriers to Taking Public Transit

As mentioned previously, 61.4% of the respondents never used any form of public transit, and among them, 68.4% never considered using it. To examine how the transit users and non-users perceived the barriers to using transit, two separate questions were included in the survey, one for the transit users and the other for the non-users. The same list of potential barriers was provided and the respondents were instructed to select all that they considered to be barriers to using transit. The results are summarized in **Table 4.9**, where the three columns on the left hand side show the responses of the transit users and the three columns to the right show the responses of the non-users.

It is evident from **Table 4.9 t**hat even among those who have used transit in the past, more than half have difficulty planning public transit trips by themselves, more than 40% have difficulty getting to transit stations or stops without help, and similar proportions are concerned about treatment by transit drivers and other passengers. While little can perhaps be done by transit agencies to address some of these barriers, the survey also revealed that almost 50% feel public transit is not available to take them where they need to go and 39% feel that they cannot get transit when they need to use it.

Since the proportion of transit non-users who answered the question on barriers to using public transit was far smaller than the proportion of transit users who answered the question, the amounts in the sixth column are smaller than the amounts in the third column, where the proportions for transit users are shown. Yet the barriers of the two groups are similar in that not knowing how to plan transit trips, difficulty going to transit stations and stops without help, not having transit service to destinations, and concerns about treatment by drivers and fellow passengers are also the most common perceived barriers for transit non-users.

Since individuals' awareness can influence their perception of barriers to using transit, all survey respondents were asked if they were aware of NJ TRANSIT's reduced fare program, its ADA-complementary Access Link service, and county paratransit for persons with disabilities. Among the respondents, 53.1% mentioned being aware of the reduced fare program, 66.2%

Table 4.9. Barriers to Using Public Transit

Barriers	Transit Users (N=195)			Transit Non-Users (N=310)		
	Responses	Percent of Responses	Percent of Respondents	Responses	Percent of Responses	Percent of Respondents
Difficulty getting to the bus stop/train station without help	79	9.3	40.5	46	10.4	14.8
Difficulty getting on/off trains or buses	32	3.8	16.4	29	6.5	9.4
Public transportation service is not available when needed	76	9.0	39.0	37	8.4	11.9
Public transportation service is not available to destinations	94	11.1	48.2	52	11.7	16.8
Too many trip transfers needed	51	6.0	26.2	23	5.2	7.4
Public transportation fare is too high	26	3.1	13.3	8	1.8	2.6
Parents/guardians do not want the individual to use public transportation	33	3.9	16.9	19	4.3	6.1
Difficulty with planning a public transportation trip	99	11.7	50.8	45	10.2	14.5
Public transportation service is not reliable	53	6.2	27.2	25	5.6	8.1
Worried about crime on public transportation	58	6.8	29.7	31	7.0	10.0
Worried about finding a seat on a bus/train	42	4.9	21.5	19	4.3	6.1
Worried about public transportation driver friendliness/helpfulness	83	9.8	42.6	43	9.7	13.9
Worried about how other public transportation passengers will treat the individual	85	10.0	43.6	42	9.5	13.5
Other barriers	38	4.5	19.5	24	5.4	7.7
Total	849	100.0	NA	443	100.0	NA

mentioned being aware of the Access Link service, and 39.9% reported being aware of county paratransit services. However, among the respondents who were aware of the reduced fare program, only 43.8% took advantage of it. Similarly, among those who were aware of the Access Link service, 49.2% never applied for eligibility, but among those who applied and were eligible, 78.4% reported using the service. In contrast, only 23.8% of the respondents who were aware of county paratransit services had ever used such services. In sum, despite being aware of transit programs and services to assist persons with disabilities, many adults with ASD cannot or do not take advantage of the programs and services.

The survey respondents were also asked if they had received any form of travel training. Only 31.7% reported receiving such training. The most common practice appears to be receiving travel training from school instructors and parents. In response to a multiple-choice question, 77.9% reported receiving travel training from school instructors, 33.1% reported receiving training from parents, 18.8% reported receiving training from professional travel trainers, and 6.5% reported receiving training from therapists.

SURVEY CONCLUSIONS

The primary objective of this survey of adults in New Jersey with ASD was to provide information on their travel patterns, needs, and barriers. Although the intent of the survey was to collect data from adults of all ages, most survey respondents were below the age of 30 and lived with their parents.

The survey showed that the adults with ASD experience many difficulties that prevent them from participating in activities that others take for granted, including employment. While most adults among the general population make work trips almost every day, the proportion of work trips is small among persons with ASD. However, many regularly travel for education and training. The survey showed that education and training, healthcare, shopping and errands, and visiting friends and family members are their predominant trip purposes.

The survey also showed that persons with ASD have many travel-related concerns and barriers that others do not have. Although the primary mode of transportation for the general population in this country is to drive to various destinations, driving is an option for only a very small proportion of adults with ASD. Even among the small proportion of persons with ASD who have a driver's license, very few actually drive on a regular basis because of their impairments. Similarly, taking mass transit is a challenge for a large proportion of the persons with ASD because they often cannot travel to transit stations or stops on their own, cannot prepare travel plans involving transit, and are apprehensive of the treatment by other passengers and transit operators with whom they would have to ride. Although many more adults with ASD can walk than drive or take transit, even walking in their neighborhoods is a challenge for many as they have difficulty crossing roads, judging distance, and comprehending direction. Despite having the ability to walk, the propensity to walk is low among the survey respondents since the activities they typically visit are not within walking distance.

Because of their difficulties with driving, taking transit, and walking, the most common practice among the adults with ASD is to take rides from others, especially from parents, other family members, and friends. However, the survey revealed that they often have to forgo trips because of the unavailability of persons who can give rides. Even parents and family members often forgo other activities, including work, in order to provide the rides to the persons with ASD.

The survey results raise a number of issues about meeting the travel needs of adults with ASD through planning and policy. The survey showed that traveling for education and training, healthcare, shopping and errands, and social and recreational purposes is more common and also more important for persons with ASD than traveling for employment. However, when many surveyed adults with ASD complete education and training, they will also have to make work trips. While students and trainees often travel by school buses or get rides from parents and family members, many may not have those opportunities when they join the work force. In those circumstances, ADA-complementary services like Access Link or other socially sponsored transportation services may have to step in to meet their travel needs.

To a great extent, the survey respondents have been able to satisfy their travel needs because of parents and other family members, who often provide rides by giving up their own activities. However, when the parents are no longer able to provide the rides they are providing now because of aging, or when the persons with ASD begin to live independently, once again, there will be a need for society to step in if the travel needs of the persons with ASD have to be met. Because of their disability, some adults with ASD will perhaps never be able to use fixed-route transit such as buses and trains, but some may be able to use those modes if they live close to transit stations or

stops and they get travel training. For others, traveling may be possible only when they get rides from others, whether it is from Access Link, county paratransit, voluntary drivers, or agencies that cater to the needs of persons with disabilities. Based on the survey results, only a very small proportion of the adults with ASD can be expected to drive to their day-to-day travel destinations. Most others will need assistance from socially provided transportation services. Finally, since walking is the most common practice among persons with ASD after taking rides from others, if the persons with ASD could live in areas where activities and needed and desired destinations are within walking distance, they could satisfy some of their travel needs simply by walking. Improvements of sidewalks and crosswalks as well as traffic calming measures could also encourage the persons with ASD to walk more often.

FOCUS GROUPS WITH ADULTS WITH ASD AND PARENTS

Focus groups have often been used in transportation because they can generate information that cannot be obtained by other methods such as stakeholder interviews or surveys. Although the stakeholder interviews provided insights from individuals representing various agencies and organizations that work for the betterment of persons with disabilities and the survey generated responses from a large number of adults with ASD, the focus groups were necessary to obtain an in-depth understanding of the transportation issues faced by adults with ASD. An advantage of focus groups over surveys is that the former allows investigators to query further and further into issues that emerge during a focus group, whereas surveys only include pre-determined questions.

A total of six focus groups were convened. Four were for adults with ASD and the other two were for parents and guardians of adults with ASD. A total 41 persons participated in the six focus groups; 22 in the four focus groups for adults with ASD and 19 in the focus groups for parents and guardians. Most of the parent participants were not related to the adults with ASD who participated in the focus groups.

All participants were recruited from the respondents who completed the statewide survey described in Chapter 4 and volunteered to participate in other data collection efforts of this research. One of the selection criteria for recruiting the participants was geographic diversity to ensure that they were from different parts of the state. Diversity of age and functional skills was also sought and achieved. Each participant was paid a cash incentive for their participation. Participants signed a consent form and agreed to have the sessions audio-recorded. In addition to the session moderators, a psychologist or a licensed clinical social worker was present at each session to provide emotional support if needed.

Table 5.1 summarizes demographic characteristics of the focus group participants. The data presented under the parent/guardian column in the table denotes characteristics of the adult child with ASD the parent/guardian was representing at the focus group. A majority of the participants who participated on their own or were represented by parents/guardians were male, white, resided in households with an annual income of less than $25,000, and lived with parents. The adults with ASD who participated were slightly more likely to live and travel independently than those who were represented by parents/guardians. In addition, the adults with ASD had more diversity in diagnosis types and educational levels than were represented by the parents/guardians. In addition, the adults with ASD who participated had a higher representation of females.

KEY FINDINGS

The focus group discussion guide developed by the research team was approved by the Rutgers University Institutional Review Board. The same guide was used to moderate five of the focus groups, but the guide used for the remaining focus group, where only adults with ASD who could drive participated, included additional questions related to driving. The guide was primarily informed by findings from the stakeholder interviews conducted earlier in the study and the survey of adults with ASD. Key focus group questions and prompts as shown in **Table 5.2** helped to facilitate the discussions at the sessions and aimed primarily to acquire the participants' feedback on the role of transportation in their lives; transportation modes used; specific thoughts on public transportation; challenges associated with transportation; and travel skills related to walking, using public transportation, paratransit, and/or driving. The text of the parent/guardian guide was slightly altered from that shown in Table 5.2 to ensure that the participants responded on behalf of the adult child with ASD they represented.

Role of Transportation

All participants strongly emphasized the important role transportation plays in the lives of both adults with ASD and parents of adults with ASD. Discussions

Table 5.1. Focus Group Participants

Category	Parents/Guardians		Adults with ASD	
	n = 19	Prevalence (%)	n = 22	Prevalence (%)
Diagnosis of Adult with ASD				
Autism	15	79%	11	50%
Asperger's	1	5%	9	41%
PDD-NOS	3	16%	2	9%
Gender of Adult with ASD				
Female	3	16%	9	41%
Male	16	84%	13	59%
Age of Adult with ASD				
18-21	8	42%	7	32%
22-29	6	32%	9	41%
30-39	2	11%	3	14%
40-49	3	16%	0	0%
50-64	0	0%	3	14%
65 and older	0	0%	0	0%
Race of Adult with ASD				
Caucasian	15	79%	16	73%
African-American	2	11%	3	14%
Hispanic	0	0%	1	5%
Asian	2	11%	0	0%
Native American	0	0%	0	0%
Other	0	0%	0	0%
No Answer	0	0%	2	9%
Education of Adult with ASD				
High School - non diploma*	8	42%	60	27%
High School Graduate	10	53%	6	27%
Some College	1	5%	2	9%
College Graduate	0	0%	3	14%
Graduate Degree	0	0%	2	9%
No Answer	0	0%	3	14%
Household Income of Adult with ASD				
Less than $25,000	13	68%	11	50%
$25,000-$49,999	0	0%	2	9%
$50,000-$74,999	0	0%	2	9%
$75,000-$99,999	1	5%	0	0%
$100,000-$249,999	1	5%	0	0%
$250,000 and over	2	11%	0	0%
NA	2	11%	7	32%

(continued next page)

Table 5.1. Focus Group Participants (continued)

Category	Parents/Guardians		Adults with ASD	
	n = 19	Prevalence (%)	n = 22	Prevalence (%)
Housing Type of Adult with ASD				
By themselves	0	0%	3	14%
With Parents	16	84%	16	73%
Group Home	3	16%	0	0%
No Answer	0	0%	3	14%
Relationship to Adult with ASD				
Parent	17	89%	na	na
Sibling	2	11%	na	na
Other	0	0%	na	na

* Majority of those without a high school diploma were still actively enrolled in high school

Note: na= not applicable

centered around the difficulties in navigating post-school transition, which necessitates securing viable transportation for the adults on the spectrum. Parents lamented about the loss of school transportation after age 21 for their children with ASD and described the hardships associated with providing them other forms of transportation to participate in day programs, employment, continuing education, and to meet daily living needs, including shopping, healthcare, and social activities. The predominant sentiment among parent participants was expressed by one parent thus: "Our children fall off the cliff at age 21." Others acknowledged that any prospective opportunity or program for their children on the spectrum is possible only when transportation is available.

Several adults with ASD expressed feeling "isolated," experiencing periods of "depression," and reduced confidence due to transportation issues. One adult on the spectrum who facilitates a social group noted that transportation problems are frequently discussed by her peers. Desired destinations of the adults with ASD varied greatly and included employment, healthcare, education, and social activities such as trips to the beach, shopping malls, movies, and restaurants. Many noted that the transportation options they currently use do not allow them to make some of these trips; nor do they grant the opportunity to "stay out late" so they could socialize like other adults not on the spectrum.

A reason for transportation being a significant issue for adults with ASD is that an overwhelming majority of them have to rely on their parents for rides for some, if not all, trips. This dependence is concerning to both adults with ASD and their parents. The two reasons most commonly cited by parents for the children's dependence on rides from family members were limited availability of transportation options and the special needs of their children.

The responsibility of regularly transporting their children imposes hardships on the parents and other family members. For example, due to limited transportation services, one parent reported driving her daughter on the spectrum 100 miles a day for her day program. Parental employment-related hardships were

Table 5.2. Focus Group Discussion Guide – Key Questions & Prompts

Question Type	Purpose	Question
Introduction	To Begin Discussion	How do you usually travel to work, school, social activities, recreation, shopping and to your doctor's and dentist offices?
	Prompt for Discussion	Do you usually travel alone or with someone else?
Key		What do you like/not like about the travel modes you usually use?
	Prompt for Discussion	Have you ever missed any activities, school or work due to transportation?
		If you could choose to travel using any mode, what mode would it be? Why?
		For those of you NOT using public transit currently, please tell us the reason(s) why not? (prompt if needed: cost, availability; accessibility issues; unfamiliarity)
	Mode Exploration: Pedestrian	Community walking skills including street-crossing a) Have each of you been taught community walking skills? b) Who taught you? c) About how old were you when you learned these skills? d) Did you have any difficulties learning these skills?
	Mode Exploration: Driving	Driving skills a) How many of you have a driver's license? b) Who taught you to drive? (for example, CDRS, parent, other?) c) About how old were you when you learned these skills? d) Did you have any difficulties learning these skills?
	Mode Exploration: Public Transit	Use of public transit (for example, NJ Transit bus, train) a) Have each of you been taught how to use public transit? b) Who taught you? i) Did anyone ever receive travel training? c) About how old were you when you learned how to use these services? d) Did you have any difficulty learning how to use public transit services?
	Mode Exploration: Paratransit	Use of paratransit services (for example, county services, Access Link) a) Have each of you been taught how to use paratransit? b) Who taught you? c) About how old were you when you learned how to use these services? d) Did you have any difficulty learning how to use paratransit services?
Key	Bring closure to discussion	Thinking back on everything we talked about today, how has being able to travel independently/or not independently affected your life?
Ending		Do you have any closing thoughts you want to share with us on how you think transportation can be improved in NJ for persons on the autism spectrum?

discussed most frequently. Parents serving as the primary transportation provider for their children on the spectrum mentioned they are often late for work as a consequence of meeting their child's transportation needs. Other parents mentioned that they have been unable to secure employment because of their primary role in providing transportation for their child. Several parents reported making the decision to alter their career path and accepting lower paying positions to serve their children's transportation and other needs. Other parents indicated they had not been able to sustain employment because of the competing demand to care for their children.

In addition to emphasizing the negative consequences related to employment, many parent participants at the focus groups also expressed severe emotional stress associated with their role as the primary transportation provider. This emotional toll was particularly evident when parents expressed deep concerns about their adult children not being able to meet their transportation and other needs when the parents are no longer able to do so due to age-related illnesses or their eventual passing.

The majority of adult participants with ASD also reported their most common practice was to travel as a passenger in cars driven by parents and other family members. Some expressed satisfaction with having their parents drive them, but others felt remorse for being a "burden" to their parents. Some participants with ASD also conveyed annoyance with having to rely on their parents for trips and having to schedule their trips ahead of time for the convenience of their parents. Some felt reliance on their parents for transportation limited their freedom. Others felt being an adult who needed to rely on parents for transportation was a stigma.

General Transportation Barriers

The adults with ASD and parent participants openly shared a variety of relevant transportation-related issues not necessarily involving any particular travel mode. The following are some of the issues most commonly mentioned by the parent participants:

- Safety concerns regarding their children with ASD not being able to successfully utilize transportation modes other than being a car or school bus passenger due to their disability;
- Lack of reasonably priced transportation options;
- Lack of available transportation options overall for persons on the spectrum and a sentiment that many transportation options are reserved for older adults (age 55+) only;
- Lack of travel instruction during their children's transition period at school; and
- Exclusion of transportation from their children's Individualized Education Program (IEP).

Safety in using various transport modes was expressed by most, if not all parent participants. They explained that certain characteristics associated with ASD could inhibit the use of different modes, particularly public transportation and automobiles. The most commonly cited ASD characteristics included lack of generalizing skills and problem solving skills, limited attention span, and lack of awareness of "stranger danger" issues.

The high cost of transportation options was also discussed by most parent participants as a barrier. They explained that if their adult children could not use public transportation due to its unavailability or the inability of the individuals with ASD to safely use the mode, the cost of other transportation services, such as livery, was prohibitive. One parent reported spending in excess of $85,000 over a ten-year period to cover transportation costs for her son, while another parent mentioned having to pay $700 monthly for her daughter's transportation. While some parents indicated they could afford to cover these costs, most indicated they could not do so and raised obvious equity concerns. Adding to the dilemma of a limited universe of transportation providers, parents relying on funding support to help pay these costs from the state's Di-

vision of Developmental Disabilities also expressed concerns that the transportation budget allocations were not adequate to meet their children's needs.

General transportation-related concerns shared by the participants with ASD similarly focused on lack of available transportation options to access desired destinations, lack of instructions about the use of various modes, and the high cost of transportation. Regarding cost, one participant with ASD reported, "I spend most of my budget on transportation."

Regarding safety, adults with ASD did not discuss as many concerns as the parent participants did. However, one safety issue the former group did cite was the need to learn how to address anxiety issues when using various transport modes. For example, several adults with ASD emphasized their discomfort in sitting next to a stranger on a vehicle or not having the same seat on a vehicle every time they use it.

Benefits and Obstacles Related to Transportation Modes

Although a majority of participants with ASD and parent participants reported that the most common practice for adults with ASD was to travel as a passenger in a car, usage of other travel modes was also discussed. Specifically, participants reported walking, using NJ TRANSIT bus and rail services, county paratransit services, taxis, and NJ TRANSIT's demand-responsive paratransit service called Access Link.

Almost all participants with ASD reported learning skills for crossing streets and using other travel modes from their parents. Parent participants provided similar feedback. Only a select few of the participants with ASD had formalized travel training. They said they mostly "learned by doing" with support from parents. Both parents and participants with ASD felt that it would have been helpful if transportation instruction was offered in school.

Most participants in all focus groups expressed that knowing how to safely walk in one's community is important to improve access to services and experience independence. However being able to safely walk depends on whether the community has appropriate pedestrian infrastructure (e.g., sidewalks, street-crossing signals) and whether streets connect to desired destinations. Participants residing in many suburban and rural communities indicated that destinations within walking distance were limited. Many of the parent participants and some of the participating adults on the spectrum indicated safety concerns about walking on roads without parent supervision. Parents explained that teaching the street-crossing skills to their children was difficult, expressing particular concerns about their inability to appropriately assess oncoming vehicle speed.

Like walking, the skills to use public transportation are also mostly learned by the adults with ASD from their parents. The participants mentioned several benefits of fixed-route public transit, including service reliability and consistency, absence of a pick-up time window required by paratransit, and the ability to relax and/or nap while onboard. However, the transit-using adults with ASD expressed concerns about the lack of adequate transit shelters, absence of real-time vehicle arrival information, exact fare requirements, overcrowding, "rowdy" passengers, and limited service frequency and geographic coverage.

Interestingly, many participants with ASD who do not currently use public transportation expressed interest and willingness to consider doing so in the future. This group of participants seemed to be inspired by their peers who reported successfully using public transportation and troubleshooting whatever obstacles arose when doing so. Several participants using public transportation explained that to successfully navigate the transit system, they use smart phone transportation applications, plan trips in advance, perform a "dry run" of a desired trip, use directions handwritten by self or parents, organize transit fare ahead of time in bags or enve-

lopes, and learn the travel route visually by memorizing landmarks.

Parent participants voiced concerns and doubts about the feasibility of fixed-route public transportation as a safe mode for their children. All parents at one session indicated that their children would need a companion to supervise public transit trips in order for them to complete the trip successfully. Many emphasized that fixed-route public transportation was not a feasible option for their children due to their difficulty with problem solving, lack of generalizing skills, and difficulty with handling unexpected events that might be encountered during a trip. As one parent expressed, "There is no fail safe with public transit." In contrast, however, some parents were open to the possibility of their children using fixed-route transit provided that they received travel training. Others mentioned that improved training for transit operators to support persons on the spectrum would be important to make public transportation a truly viable option for persons with ASD.

Many of the participants with ASD had at least some experience using paratransit services operated by counties, municipalities, day programs, and/or Access Link. The perceived benefits from paratransit varied somewhat across the services, but commonly shared responses included ability to access needed and new destinations, curb-to-curb or door-to-door service, service reliability, less crowding compared to fixed-route transit, reasonable fares, and the presence of friendly vehicle operators. Some parents and adults with ASD mentioned that an unanticipated benefit from using paratransit has been the opportunity to socialize with others. In general, parent participants seemed more comfortable with their children using paratransit as compared to fixed-route transit as they felt paratransit was more "personalized" due to its curb-to-curb service.

The most commonly cited disadvantages of paratransit at the focus groups were long waits due to a window around pick-up time, the requirement to reserve rides ahead of time, limited geographic coverage, and restrictions on trip purposes imposed by some paratransit providers. While parent participants were mostly concerned about limited geographic coverage and trip purpose restrictions, adult participants on the spectrum were more concerned about the pick-up window and the advanced reservation requirement. They felt the advanced reservation requirement hindered their ability to make spontaneous trips and thus limited their independence.

Focus group discussions included issues related to driving also. The most common theme that emerged from the parent participants was their children's safety. Many parents felt that even with instruction, their children on the spectrum would have difficulty handling many aspects of driving. In contrast, the majority of adult participants with ASD expressed keen interest in securing a driver's license at some point, if not in the immediate future. They shared feelings that having a driver's license and access to a motor vehicle would afford them ultimate freedom and ability to make spontaneous trips. While the desire to attain a driver's license was strong, less than one-third of the participants with ASD reported having a valid driver's license.

Adult participants with ASD provided a variety of reasons for not opting to acquire a driver's license or not driving despite having a license. Some noted their parents' concern as the primary reason, while others mentioned their inability to afford a car and vehicle insurance as the determining factor. Many mentioned a general fear or anxiety about handling negative events that might occur while driving, such as getting lost, having a motor vehicle accident, or having to deal with law enforcement. The most commonly cited driving difficulty by the participants with ASD included:

- Judging speed of traffic and/or distance of other traveling cars

- Determining how to adjust appropriately to speed limit changes
- Maintaining attention
- Following directions and/or reading maps
- Anticipating the actions of other drivers
- Reacting quickly to roadway situations
- Understanding various roadway signage and driving environments

Participants on the spectrum who reported they had a driver's license but did not drive shared many of the same concerns as their participating peers without a driver's license. They mentioned that navigating certain infrastructure features, such as jug handles and left-turn lanes, could be difficult. All of the driving participants with ASD reported that behind-the-wheel practice was extremely helpful in improving their ability and comfort level as drivers. Other drivers shared specific strategies that helped to improve their driving, including frequent use of rear view mirrors and GPS for navigation. The driving participants also emphasized the importance of self-regulating the emotional or other triggers that may negatively influence driving capability. One such participant mentioned that she knows she should not drive when she is emotionally upset. She added, "Time, maturity, and experience taught me this."

Another concern for the drivers with ASD was their feeling of uncertainty about the appropriate protocols to handle situations involving law enforcement officials, as one may encounter after a traffic accident or for a traffic violation. One participant shared an experience when he showed the attending law enforcement officer an ASD identification card when stopped for a violation. He believed that helped to facilitate a positive interaction between the two. However, the group's overall discomfort in handling situations with law enforcement was clearly evident in the focus groups.

FOCUS GROUP CONCLUSIONS

Focus group participants with ASD and parent/guardian participants shared a number of concerns and challenges related to using various transport modes for persons on the spectrum. All emphasized the critical role that transportation plays in the lives of adults with ASD in providing linkage to both meaningful opportunities in their community and enabling fulfillment of daily living needs, including employment, continuing education, healthcare, and socially-focused pursuits.

Parents/guardians and adults with ASD expressed the sentiment that determining feasible transport options was especially difficult in the post-school transition period, as transportation options are few and information on exiting transportation options is difficult to find. The result, as reported by the majority of participants, is that parents must often function as the primary transportation provider, which often yields negative impacts on the parent, adult child with ASD, and/or other family members. Despite this finding, however, parents who indicated they most often drive their adult children with ASD seemed to accept this practice as part of their "everyday reality." As one parent said, "My life is my son." Participants with ASD who frequently take rides from parents expressed mixed feelings, with some indicating a preference for this mode of travel, but others citing dissatisfaction due to the burden they impose on their parents and their own lack of independence.

A major theme that emerged from the focus groups involving adults with ASD was their strong desire for independence, which they felt they could achieve only with appropriate transportation options. While most of the participants with ASD reported not using fixed-route public transportation modes, many expressed willingness to use these modes provided they received training on how to do so. Due to their safety concerns, parent participants were generally hesitant to support public transportation usage by their children with ASD.

Interestingly, when all participants were asked to describe their version of an optimum transportation service for persons with ASD, many of the same features were sought by both parents and adults on the spectrum. Specifically, there is strong desire for a service that is reliable and consistent, crosses county borders, and picks up customers close to their homes. Parents added the need for drivers to be well-trained in transporting adults with ASD, while adults on the spectrum desired service frequency in both peak and off-peak hours to enhance ability to pursue social events/outings.

The focus group sessions provided evidence that one of the most beneficial strategies that should be pursued to better meet the transportation needs of adults with ASD is to provide travel instruction to this population so they can learn to safely utilize public transportation. Both parents and adults with ASD lamented that travel instruction was not offered in schools, nor was transportation included in their IEPs. As one adult with ASD stated "I needed information in school on how to use public transportation and not just information on the food pyramid."

It was evident from the focus groups that it was not only the adults with ASD who lacked familiarity with the available transportation options and opportunities for travel training. Their parents also often lacked awareness and comprehension of the region's transportation options. This lack of information and awareness seemingly contributed to the intense safety concerns of the participating parents, especially regarding the use of public transportation.

Both groups of participants acknowledged that driving is not a viable option for all adults on the spectrum. Although only a few participants with ASD reported having a driver's license, the majority of adults on the spectrum expressed interest in pursuing their license at some point. Discussions demonstrated that interest in driving was mainly due to participants' association of independence with the act of driving. Participants who drove explained that behind-the-wheel driving instruction and extensive practice contributed to their driving success.

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