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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

EXECUTIVE SUMMARY

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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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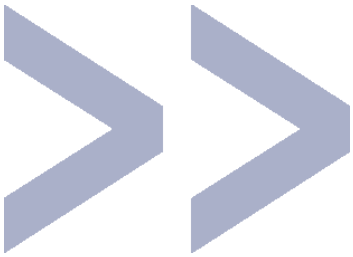
Although advances have been made in many fields related to quality of life improvements for persons with Autism Spectrum Disorder (ASD), efforts have been more limited in the realm of transportation planning and policy. Most organizations involved in transportation planning and policy collect travel 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 on 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 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, ultimately, 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."

CRITICAL OBSERVATIONS

There are several critical observations we can make based on this research:

- Very little has been written about the transportation issues encountered by adults with ASD. 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.

- Availability of accessible public transportation is 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 transportation.

- Adults with ASD mostly travel as passengers of cars driven by their parents or other family members. This dependence creates inconvenience and stress for adults with ASD and their parents. Seventy-two percent of the parents and caregivers miss some of their own activities in order to give rides to their adult children with ASD, and 72 percent of the adults with ASD miss some activities due to the unavailability of persons to give them rides.

- 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. A persistent complaint among parents is that their children do not receive adequate training at school on safe pedestrian skills or how to travel by public transportation. Travel education, orientation and training during school years are minimal to nonexistent and should be included in students' IEPs.

- Many adults with ASD lack basic safe walking skills such as crossing roads (54 percent) and judging distances to oncoming vehicles (45 percent). Walking trips to specific activities are seldom made by the adults with ASD, 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.

- 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.

- 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. 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

The following recommendations are based on 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.

5 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.

6 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.

7 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 infrastructure 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.

8 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.

9 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.

10 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 also should 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.

11 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.

12 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.

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

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