

In Their Own Words:

**Recommendations on transportation
inspired by interviews with
persons with Developmental Disabilities
in New Jersey**



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A man with a mustache, wearing a dark blue flat cap, glasses, and a black zip-up jacket over a white shirt, stands in front of a colorful mural. The mural features a yellow sign with the text "SHARE WHAT YOU HAVE" in black capital letters. The background of the mural includes various colorful elements like fish, a sun, and flowers. The man is looking directly at the camera with a neutral expression.

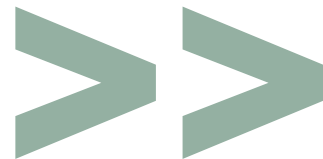
SHARE
WHAT
YOU
HAVE

*“If I had some transportation to get to where I need to go, that would be easier for me, having somebody to take me from point A to point B, get me where I need to go.”
(William)*

In Their Own Words:

Recommendations on transportation inspired by interviews with persons with Developmental Disabilities in New Jersey

Persons with developmental disabilities (DD) must access a diverse array of services during their lifetimes that may include supportive housing, employment/vocational training, recreational opportunities, healthcare, continuing education, and daily living trips such as shopping. Transportation provides access to these vital services and activities.



Transportation is the essential link for community inclusion for everyone, including people with disabilities. In an automobile focused state such as New Jersey, the challenges of meeting these needs without a driver's license or access to a car can be insurmountable.

As a result, reliable and accessible transport options that can help achieve healthy social living outcomes and physical independence are needed.

Background

The findings presented in this report reflect a collaborative research endeavor funded by The New Jersey Council on Developmental Disabilities and undertaken by The Arc of New Jersey and Rutgers, The State University of New Jersey.

The guiding principle of this research was to capture transportation experiences, both positive and challenging, directly from persons with developmental disabilities living in New Jersey. The researchers conducted interviews with individual volunteers. They audio-recorded their responses for analysis and dissemination to a wide audience of diverse stakeholders through means including The Arc-developed project website <https://www.arcnj.org/programs/njsap/intheirownwords.html>.

All participating researchers and team members were committed to the charge of amplifying the voices of persons with a developmental disability living in New Jersey. This was accomplished both literally through the interview audio recordings, as well as through this written report – regarding their transportation experiences, issues, and needs, with the core objective of achieving positive change and system improvements.

Finding Highlights

The interviews were conducted over the course of a one-year period with a total of 210 individuals, who volunteered to participate. Interviews were conducted statewide at 16 sites, with 27 interviews conducted via telephone. The overwhelming majority of interviews were conducted with

adults with DD (89.5%), with 10% conducted with parents/guardians, and one percent with persons who work with adults with DD. Interviewees live in one of 79 NJ municipalities from a total of 18 counties. Of the participants responding to the demographic questions posed during the interviews, slightly more than half were female. The majority (64%) identified as White not Hispanic, with most falling between the ages of 22 and 64 (87%).

The study team analyzed the audio recordings to identify both positive and challenging transportation experiences. Transportation barriers were mentioned by just under half of the interviewees. Most interviewees discussed general transportation barriers, followed by financial constraints, and safety concerns. General barriers included a lack of available services either where one resides or near desired destinations, uncertainty with how to determine available services, and difficulty in relying upon others for transport. Regarding how respondents learned to travel using the modes relied upon, the most common response was from family, followed by learning from support agency staff, and many noting they taught themselves to travel independently.

Participant experiences with eight specific transport modes were collected. The three modes most frequently commented on by interviewees included walking, followed by NJ TRANSIT fixed route services, and then by NJ ADA Complementary Paratransit (Access Link). Participants shared examples of both positive and challenging encounters with their travel mode(s). Many expressed their appreciation for the availability of the mode(s) utilized. They considered themselves satisfied users, even as they acknowledged one or more negative experiences in using a particular mode. Negative or challenging experiences discussed were typically mode specific, although themes such as safety were discussed in relation to several modes such as walking and driving. Detailed interviewee feedback related to specific modes is in the report appendix.

Recommendations

Based upon suggestions shared by interviewees and the analysis conducted by the researchers, 15 recommendations in three core categories were developed to improve the current transportation environment for New Jerseyans with DD.

The three themes for the 15 recommendations include:

- 1) Increased Investment in Transportation
- 2) Mobility as a Service
- 3) Advocacy and Education

Potential implementation partners as well as implementation time frame parameters are included in the Recommendation Implementation Matrix. This matrix should serve as a living document for the NJCDD and other interested partners, as they seek to achieve positive transportation changes.

The recommendations are presented below, a summary of interviews and demographics data can be found at The Arc of New Jersey's [In Their Own Words](https://www.arcnj.org/programs/njsap/intheirownwords.html) website: <https://www.arcnj.org/programs/njsap/intheirownwords.html>.

Increased Investment in Transportation

1 Develop DDD Payment Program for NJ County Paratransit Services

Restructure the current provider system to encourage the use of the state's 21 community/county paratransit services. This recommendation would be especially beneficial because of the positive experiences with these services shared by many interviewees. Specifically, over 70% of interviewees who discussed this mode indicated they were satisfied users.

A pilot project should be established that would permit a portion of the DDD budget to be allocated to New Jersey's community/county transport providers willing to crossing county boundaries.

2 Reinstate NJ DHS Transportation Planning Coordinator Position

Re-establish the Transportation Planning Coordinator position within the Department of Human Services, Division of Developmental Disabilities. The person appointed to this position must have substantial knowledge and experience in transportation services for and needs of persons with DD. This individual should be charged with coordinating the current, emerging, and forecasted needs of the state's DD population with the state's various transportation providers and services. The person would serve a vital role in coordinating with NJ TRANSIT, the state's 21 county paratransit providers, and other public and private transport services. The Coordinator would develop a continued dialogue with these transportation providers so they are more aware of the transport needs and issues affecting the state's population with DD.

3 Create Voucher Program using DDD Funds to be Used for PASS Trained Ride-hailing or Taxi Services

Provide a system that allows a limited portion of an individual's DD budget to be used for state approved and PASS trained ride-hailing transportation and/or taxi services. This would facilitate needed spontaneous and emergency travel. A limited number of these trips could be allotted per month, as well as a limited amount of spending on the services determined. (Note - PASS, or Passenger Service and Safety training is the industry standard of training related to assistance that drivers should provide to passengers with special needs.)

4 Support and Expand Existing Successful Transport Services

The interviewees noted that several transportation modes were working well and could be expanded, including NJ County Paratransit Services and NJ TRANSIT fixed route services. These services should be supported and expanded to ensure their availability for both current and prospective users.

5 Invest in Intelligent Transportation Technologies that are Person-Centered

Various technologies exist that can improve quality of life, such as transportation-focused apps (e.g. Go Bus) and GIS-based navigation programs. Persons using public or community transportation must often rely upon transportation providers to utilize existing technologies that can contribute to a customer's improved quality of life.

These transportation providers should be encouraged to invest in person-centered Intelligent Transportation technologies that can better serve their customers. NJ TRANSIT's Access Link service offers one example of a NJ provider who has focused much recent effort on implementing more people-centered technologies (e.g. service reminder calls, email reservations) to better serve their customers.

6 Utilize University Research Expertise

Stakeholders supporting the DD community should use the state's transportation research expertise available at state universities. They should conduct best practice research and assess service needs among the DD community.

By working with state universities and developing appropriate research programs, the university centers can provide the needed expert, unbiased knowledge and research on state transportation issues, without advocating for any one system or service. They can assist with service and model pilot testing and forecasting of future transportation requirements for various modes. The university centers can also assist with educational training and programs for the school system.

Mobility as a Service

7 Institute a Statewide Mobility Manager Dedicated to the Needs of Persons with DD

NJ should establish a dedicated statewide mobility manager for persons with DD. A trained mobility manager would assist residents throughout the state seeking information on transportation. The



"[Traveling is] hard because sometimes people discriminate against people with disabilities." Myrta

position should function as a resource for persons with developmental disabilities, as well as for service providers.

The mobility manager would be accessible via phone and would serve as a one-stop resource for transportation information for persons with DD and those who support this population. It is important to note that the mobility manager would not provide transportation.

The manager should serve as a critical missing link in helping to match available transportation services in the state for individuals with DD needing those services and seeking assistance from the mobility manager.

8 Provide Accurate Ride Times

The most frequent specific suggestion to improve transportation and mobility in NJ was to provide accurate ride time estimates. Interviewees requested both an accurate pick-up time window, as well as accuracy in estimating the transit time for reservation transportation services like Access Link, and for general public transit services. It

should be noted that Access Link and many of the county services are currently working to improve their performance on these issues, as technologies exist in the marketplace that would allow for more accurate ride time estimates.

9 Expand Service Routes and Hours

Expanding service hours and routes, both for fixed route services as well as paratransit services, should be pursued. In order to expand route service and hours, it is necessary to engage in a continuing dialogue with transportation providers, especially NJ TRANSIT, to investigate opportunities for service expansion and possible funding mechanisms to support the expansion.

While public transportation is not the only travel mode suitable for persons with developmental disabilities, expansion of these services to areas currently not served or under-served could benefit many adults with DD, their families, as well their caretakers and service providers.

10 Implement Enhanced Transportation Staff Training

Staff training for all transportation modes should

be improved. It is recommended that a specific training program be developed and implemented targeted to vehicle operators and front-line staff who have direct contact with adults with developmental disabilities. This training is needed for those operating all types of fixed-route transportation services (NJ TRANSIT, SEPTA), paratransit (NJ Transit Access Link, county and municipal services), private and volunteer services (NGOs), and ride-hailing and taxi services (Uber, Lyft, Taxis). It is vital that all levels of staff at transit agencies who interact with riders with developmental disabilities receive targeted training that will enable them to better understand and assist their customers.

11 Ensure Multimodal Accessible Vehicles and Stations

Ensuring vehicle and station accessibility is vital. A first step in addressing grievances related to a lack of accessible services is for individuals to be aware of their rights in this regard and the procedure(s) for submitting complaints to agencies such as NJ TRANSIT when their accessible service features do not work properly (e.g. wheelchair lift, bus kneeling feature) or when vehicle operators do not stop to pick up a customer in a wheelchair.



NJ TRANSIT should also be encouraged to reconvene a once active voluntary body called the NJT ADA Task Force. This group discussed, reviewed, and recommended strategies to address issues concerning accessible vehicles and stations, as well as other barriers to transportation. The ADA Task Force can once again serve to help identify and address barriers and obstacles to persons with disabilities using accessible public transportation services. Finally, The Council and DDD should develop a dialogue with ride-hailing providers in NJ,

“I like to go to the mall and stuff, I sometimes will take an Uber... I have been working on studying for my permit test.” Carly



such as Uber and Lyft, to discuss the pressing need for accessible ride-hailing vehicle options to better serve persons with DD in the State.

Advocacy & Education

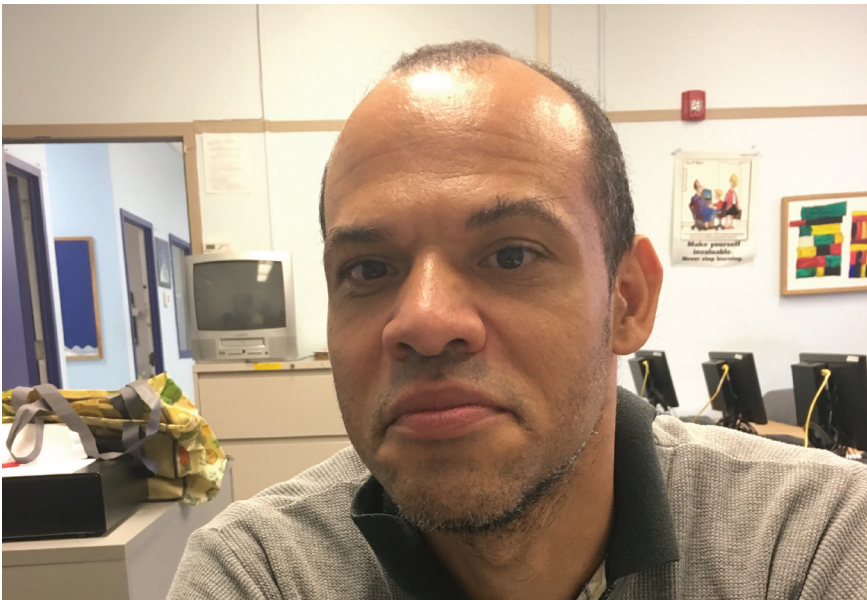
12 Develop a Guide of Rights, Rules and Responsibilities for All Modes

Many interviewees had a limited understanding of an individual's rights and responsibilities in using transportation services, as well as the rules/regulations related to those service. This can create unrealistic expectations for the availability and quality of services, and the rights a customer has to the services. Development of a user-friendly Guide of Rights, Rules and Responsibilities for all modes in NJ should be created.

13 Expand Transportation Advocacy

Transportation advocacy with a focus on planning, pedestrian infrastructure, public transit service, Intelligent Transportation Systems, and autonomous and connected vehicles should be emphasized. Individuals with developmental disabilities must be involved in all transportation planning, design, operations, and research, and have a seat at the table for all decisions that will have an impact upon their lives. It is essential that persons with developmental disabilities and their caregivers actively support and advocate for improved high-quality pedestrian infrastructure and traffic calming measures in their community so persons with developmental disabilities can walk safely and have safe access to existing transportation services.

NJCDD and DDD should actively support efforts to integrate the transportation needs of persons with developmental disabilities with current research being conducted by Intelligent Transportation Systems (ITS) experts. Nationwide, new technologies that can provide support for independent or semi-independent travel for this population are under development, which can improve transportation access for adults with DD. Supporting these efforts can yield positive benefits for NJ's population with DD.



*“What that I don’t like, it is usually with the bigger buses – sometimes they don’t want to pick you up because you are in a wheel chair. Or they are complaining that the ramp doesn’t work.”
Omar*

Finally, to address interviewee’s limited awareness and/or understanding regarding various transportation services, an integrated transportation service information campaign should be developed and implemented. This work can be done, at least in part, through an ambassador campaign, whereby service providers and current users are teamed together to conduct outreach showing how supportive the various services offered throughout the state can be for persons with developmental disabilities. This ambassador approach could be a stand-alone program, or one component of the work undertaken under the auspices of the recommended State mobility manager.

14 Develop Educational Curricula

Educational curricula focused on transportation should be developed and provided while young persons with DD are covered under the educational entitlement. Families and caregivers should also be provided with information on mobility options. This training will continue to benefit the individual with DD and their family during adult life; facilitating access to employment, continuing education, day programs, medical-related trips, recreational destinations, and daily living travel needs.

Programs must be developed to provide continuing support for transportation-focused training programs in the educational setting, as part of

students’ Individualized Education Program (IEP). The benefits of including transportation skills in IEPs must be considered and discussed with the New Jersey Department of Education, since such action could produce a statewide mandate that these skills be taught. Since many persons with DD will not be able to access public transportation on their own, families should have the opportunity to participate in travel orientation/education activities for all modes of service.

15 Create Person-Centered Plans with Transportation Component

The final recommendation relates to the Person-Centered Planning Tool (PCPT). Person-centered planning is an approach, embraced by the NJDDD, designed to assist an individual with DD plan for life services and supports. The PCPT is a mandatory discovery tool used to guide the person-centered planning process and to assist in the development of an individual Service Plan. The PCPT on the New Jersey Department of Human Services Division of Developmental Disabilities website does not include questions about transportation and mobility in the community. This PCPT must be revised to include substantive and meaningful questions related to transportation, to enable the user of the tool to consider the vital role transportation has in meeting plan goals, as well as positive quality of life outcomes.

Recommendation Implementation Matrix for In Their Own Words

The matrix on the facing page presents the 15 recommendations in the three core themes developed from suggestions shared by interviewees and through the experience of the study team.

Transportation modes relevant to each recommendation are specified as are potential recommendation implementation partners.

Recommendation Matrix Transportation Modes Impacted

NJ ADA Complementary Paratransit (Access Link)

NJ TRANSIT Bus, Rail, and Light Rail

NJ County Paratransit Services

Agency Provided Transportation

Ride-Hailing Transportation and Taxi Service

Driven by Family and/or Friends

Driving Self

Walking

Recommendation Matrix Partner Acronyms

NJCDD = NJ Council on Developmental Disabilities

NJCOST = NJ Council of Special Transportation

NJDCF = NJ Department of Children and Family Services

NJDHS = NJ Department of Human Services including but limited to Division of Developmental Disabilities

NJDOT = NJ Department of Transportation

NJDOE = NJ Department of Education

NJT = NJ TRANSIT

CILs = Centers for Independent Living

MPOs = Metropolitan Planning Organizations

NGOs = Non-Governmental Organizations

TMA = Transportation Management Associations

Recommendation Matrix Implementation Time Frame

Short Range (immediate to 3 years)

Intermediate (3+ years)

“I just think that it is a wonderful way to go independent. And that is traveling independently. I think it’s an amazing way to explore adulthood in that aspect. I just think it is incredible to be able to have the ability to go certain areas on your own ... But I would say there are definitely pros and cons to transportation.” Se Quince

Recommendation Implementation Matrix for In Their Own Words

	Recommendations	Modes Impacted	Partners	Implementation Time Frame
Invest in Transportation	1. Develop DDD Payment Program for NJ County Paratransit Services	County Paratransit Agency Transportation Family & Friends	NJDHS NJCOST NJCDD * NJT	Intermediate
	2. Reinstate NJ DHS Transportation Planning Coordinator Position	All	NJDHS	Short Range
	3. Create Voucher Program using DDD Funds to be Spent on PASS Trained Ride-hailing or Taxi Services	Ride-hailing and Taxi Family & Friends	NJDHS NJCOST Uber/Lyft	Short Range
	4. Support and Expand Existing Successful Transport Services	All	NJDOT * NJT NJCOST * NJDHS MPOs	Short Range and Ongoing
	5. Invest in Person-Centered Intelligent Transportation Technology	All	NJDOT * NJT NJDHS NJCOST	Intermediate
	6. Utilize University Research Expertise	All	Universities NJDHS NJDOT * NJT NJDOE	Short Range and Ongoing
Mobility as a Service	7. Institute a Dedicated Statewide Mobility Manager for Persons with DD	NJ TRANSIT * Access Link County Paratransit Ride-Hailing & Taxi	NJDOT * NJT MPOs TMAs	Intermediate
	8. Provide Accurate Ride Times for All Modes	NJ TRANSIT Access Link County Paratransit	NJDOT * NJT NJCOST NJDHS	Intermediate
	9. Expand Service Routes and Hours	All	NJDOT * NJT NJCOST * NJDHS	Intermediate
	10. Implement Enhanced Transportation Staff Training	NJ TRANSIT * Access Link County Paratransit Ride-Hailing & Taxi Agency	NJDOT * NJT NJCOST NJDHS Uber & Lyft	Short Range
	11. Ensure Multimodal Accessible Vehicles and Stations	NJ TRANSIT Ride-Hailing & Taxi	NJDOT NJDHS NGOs Uber/Lyft	Intermediate
Advocacy & Education	12. Develop Guide on Users Rights, Rules, and Responsibilities	All	NJCDD NJDHS NJDOT * NJT NJCOST CILs * MPOs TMAs Universities	Short Range
	13. Expand Transportation Advocacy	All	NJCDD * CILs TMAs NJCOST	Short Range
	14. Develop Educational Curricula	All	NJDOE NJCDD NJDCF	Intermediate
	15. Create Person-Centered Plans with Transportation Component	All	NJDHS	Short Range



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