2021 Trends Report



Photo: ButterFLi, Los Angeles, California



The National Aging and Disability Transportation Center (NADTC)

NADTC is a national program funded by the Federal Transit Administration and administered by Easterseals Inc. and USAging, with guidance from the U.S. Department of Health and Human Services, Administration for Community Living.

Our Mission:

To promote the availability and accessibility of transportation options that meet the needs of older adults, people with disabilities and caregivers.

The mission of NADTC is to:

- **Serve** professionals in the fields of transportation, aging, disability, human services and caregiving.
- **Provide** resources and training through an information and referral hotline, website, as well as both distance and online training.
- **Empower** communities across the country to implement or improve innovative transportation programs at the local level.
- **Support** older adults, people with disabilities of all ages, and their families to help them find the best mobility options in their communities to reach their destination of choice.

For more information about NADTC and the services we provide, please visit www.nadtc.org/

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Serving People with Autism on Transportation

Background

According to the Autism Society of America, "Autism, or Autism Spectrum Disorder (ASD), is a complex, lifelong developmental disability that typically appears during early childhood and can impact a person's social skills, communication, relationships, and self-regulation. Autism is defined by a certain set of behaviors and is a 'spectrum condition' that affects people differently and to varying degrees." According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), the characteristics of Autism can include differences in communication skills, interpersonal relationships, restricted and repetitive behaviors, activities, and interests. Persons with Autism may be verbal or non-verbal; have atypical speech patterns; have trouble understanding non-verbal communication such as body language; have difficulty maintaining typical conversation flow; repeat sounds, phrases, or movements; prefer routine; and/or have either increased or decreased sensitivity to sensory stimuli.

People with Autism are individualized and may experience many or few of the characteristics described above. This creates a situation where transit personnel may not be able to easily recognize that a person has Autism or determine what types of assistance people with Autism may need. This brief will provide you the basic requirements for transit personnel assistance for people with disabilities, additional Americans with Disabilities Act (ADA) requirements that may affect the services provided to people with Autism, transportation challenges, tips, and promising practices for serving people with Autism, and additional resources.

Requirements for Assisting Passengers with Disabilities

Transit agency personnel, including vehicle operators, rail conductors, and bus/rail station attendants are required to provide assistance to people with disabilities, including individuals with Autism, when accessing transit agency services. According to U.S. DOT regulations implementing the Americans with Disabilities Act (ADA), "Where necessary or upon request, the entity's personnel shall assist individuals with disabilities with the use of securement systems, ramps and lifts. If it is necessary for the personnel to leave their seats to provide this assistance, they shall do



so" (49 CFR § 37.165(f)). Personnel should assist with deploying lifts/ramps, securing passengers' wheelchairs, the proper use of seat belts and shoulder harnesses, and persons using wheelchairs when navigating on and off lift platforms or up/down ramps."

While transit personnel are not required to provide services typically provided by a personal care attendant (PCA), they are required to provide a "reasonable level of assistance to customers with and without disabilities as a part of their routine job of serving the public and in the interest of customer service." This general assistance includes, but is not limited to, assistance with fare handling. For example, assisting passengers that cannot reach or insert a fare into the fare box should be provided. However, transit personnel would not be required to reach into pockets, backpacks, or other personal items to retrieve fare payments. It could be the case that a person with Autism might have difficulty following instructions on how to pay the bus fare and may need the instructions provided in a different way, which could include simplified written directions, verbal directions, or to have directions repeated several times.

Transit agencies are not required to provide passengers with PCAs. Transit agencies should follow their stated policies on luggage and packages but are not required to provide services above and beyond those policies. Apart from an emergency situation, transit personnel are not required to lift a passenger into or out of a mobility device, otherwise called hand-carrying.

Additional ADA Requirements

Additional ADA requirements for people with disabilities riding public transportation include, but are not limited to accessible signage, adequate boarding time, and operator training.

- Accessible Signage: Transit signage in stations and on vehicles must comply with all ADA standards.
- Adequate Boarding Time: Transit operators must allow adequate time for people with disabilities to board and alight transit vehicles.
- Operator Training: Transit operators are required to be trained to proficiency in the use
 of all vehicle equipment, ADA requirements, passenger assistance techniques, and any
 other aspect of their job requirements.

Transportation Challenges

Many people with Autism are very individualized, transit personnel may experience a range of challenges in providing assistance. Some individuals may need no assistance at all. Others may need assistance, but the type of assistance may not be apparent. This presents a challenge for transit staff. There are challenges specific to the common characteristics that many people with autism experience.



Common challenges include, but are not limited to:

- **Social Phobia**: Social phobias affect a person's ability to interact in standard ways with others. As public transportation is a shared ride service, issues with interacting with transit personnel and the public could cause challenges and may create situations where communication is very difficult or even impossible.
- Excessive Worry/Anxiety: Excessive anxiety, which can be experienced even in ordinary circumstances, can cause an increased heart rate, breathing rapidly, sweating, and trouble concentrating. A passenger exhibiting these symptoms may seem in need of immediate, emergency attention.
- Obsessive Compulsive Behaviors: Recurring, unwanted thoughts or sensations cause
 people to conduct repetitive behaviors such as checking whether tasks have been
 completed such as scanning a fare card multiple times, counting items or people, and
 repeating actions or phrases. On public transportation, this may cause the passenger to
 be distracted by exhibiting such behaviors instead of focusing on what is needed for a
 successful trip.
- Avoidance Behaviors: These behaviors occur when a person is trying to escape from
 difficult thoughts and feelings. If a person with Autism traveling on public transit
 becomes overly anxious, they may feel the need to avoid other people which could
 cause issues as the vehicles are confined spaces. This may further escalate their feelings
 of anxiety.
- Rigid Routines: Keeping rigid routines is often essential in the daily life of people with Autism. Anxiety will often increase when routines are not able to be kept. If a route, driver, person, or other action that is a part of the routine changes, the person with Autism's anxiety could be increased.
- **Self-injurious Behavior**: This behavior involves the occurrence of physical injury to one's own body. Common forms include head-hitting/banging and hand biting, and these behaviors may be exhibited by a person with Autism. This could be very unsettling for other passengers and may present an emergency situation on the vehicle.
- Stimming: This is a self-stimulating behavior that involves repetitive or unusual body
 movement or noises and can include hand-flapping, rocking back and forth, chewing on
 objects, listening to sounds over and over, and more. This behavior may concern other
 passengers but would generally not rise to the level of having transit personnel
 intervention.

- Oppositional Defiance: People with Autism may display angry and irritable symptoms, argumentative and defiant behavior, and vindictiveness as a part of oppositional defiance. These behaviors may present a problem if transit personnel requested something of the person that they did not want to give or do, or if it would change the individual's routine, and may present a considerable challenge on a transit vehicle in an emergency situation.
- Meltdowns: Autistic meltdowns are generally bigger, more emotional, last longer, and are more difficult to manage than a typical temper tantrum. They are not limited to children but can also occur in adults. They are often preceded by signs of distress.
 Depending on the behaviors exhibited during a meltdown, transit personnel may need to intervene.
- **Shut Down**: When a person with Autism shuts down, they are not able to respond and react in ways they typically would. They may not seem themselves, as their focus generally shifts to only basic functions. This may affect their ability to communicate and react. This would generally not be a situation requiring transit personnel intervention depending on when it occurred. If, however, it occurs during an emergency situation, the passenger may require additional assistance.
- **Difficulty in Transitions**: Many people with Autism, have difficulty in transitioning from one activity to another. This difficulty could present itself in the form of distraction, avoidance, or even meltdown. A person may exhibit these behaviors when boarding the bus if they did not want to transition from an activity they were involved in prior to boarding, or as they are preparing to deboard if they do not want the trip to end.

Tips and Promising Practices

There are many ways in which passengers with Autism can better prepare themselves for taking public transportation. Should you encounter a passenger that seems to be having difficulty in one or more of the areas mentioned above, and if you believe the tip would be useful to the passenger, suggest one of the actions below to either the passenger or their caregiver, if present.

- Block out noise by wearing headphones or another noise reduction product
- Travel at quieter, less busy times if possible
- Select a seat in an empty row, if available, and sit by the window (This will allow the person the ability to look out the window while traveling and may reduce stress.)
- Carry a familiar item with you (A favorite book, piece of clothing, or other item may reduce stress.)



The following are tips and promising practices for transit personnel when dealing with difficult situations with people with Autism.

- Ask what, if any, assistance is needed and provide it if reasonable and possible.
- If the passenger is a regular rider, take the time to learn how they communicate best.

 Always carry a pen and paper with you in case it is needed for effective communication.
- If a visual set of rules is not displaced in the station or on the transit vehicle, have copies to share if needed. If it is displayed, it may be necessary to briefly review the rules with the passenger.
- Briefly describe the steps of the transit trip to the passenger. Letting them know the
 next step, approximately how many stops before you reach their destination, or
 approximately how much time will elapse, could alleviate anxiety.
- Assure the passenger that you are there to help them and to keep them safe.
- Always stay calm.
- If you're aware of a change in what the passenger would consider a routine, let them know in advance, if possible.
- Have sensory items (squishy buses or other transit marketing items) available on the bus to provide to passengers if needed and appropriate.
- If a passenger is using a communication device, take the time to participate fully in the conversation even if it takes longer than usual.

Summary

Autism is a lifelong developmental disability that presents differently in each person; therefore, providing safe and reliable transportation to people with Autism can be a challenge. Taking the time to learn more about Autism, the ADA requirements, and your passengers will increase your compliance, improve customer service, and increase the quality of life of persons with Autism using your public transportation system.

Resources

<u>Safety for all: Autism Training for Transportation Staff</u> (designed for school transportation personnel but has a lot of useful information for public transportation)

The Arc's Autism Now Center

TCRP Synthesis 37: Communicating with Persons with Disabilities in a Multimodal Transit Environment

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) (Technical Report)







