

Transportation: The Missing Link in Family Caregiver Support



Background

Family caregivers play a vital role in supporting individuals with disabilities, health issues, or aging-related challenges across the U.S. Among their many responsibilities, transportation is a key task they manage. According to the [Caregiving in the U.S. 2020 Report](#), 80% of caregivers provide transportation assistance, making it the most common Independent Activity of Daily Living they support. However, only 25% of these caregivers reported using transportation services. Despite the availability of transportation programs and services in communities nationwide, many caregivers are not utilizing these resources.

Caregiver support encompasses a broad range of services and resources tailored to meet the unique needs of family caregivers. While caregivers are often encouraged to seek help with daily living activities, meals, medical tasks, and supervision, transportation support is frequently overlooked.

Access to transportation can profoundly impact the quality of life of older adults and individuals with disabilities. Trips to medical appointments, shopping and social activities allow a person to remain active in the community, reduces isolation and loneliness and improves physical health. When these trips cannot be done independently, the family caregiver often shoulders the responsibility putting undue burden on the caregiver and likely limits the places their loved one can go. Building community transportation into a caregivers' support plan can reduce the load for the caregiver and increase independence for their loved one.

This resource provides information for caregiver support professionals about typical community transportation options and associated support services that could be used to support family caregivers. There are also recommendations on forming partnerships with transportation providers to improve transportation options that are accessible and accommodating to the unique needs of family caregivers.

Understanding Community Transportation Options

Becoming familiar with available transportation services is the first step to accessing alternative transportation. While transportation options and services vary widely from one area to another, most communities offer a range of common services and supports. Below is an overview of typical services available in most communities.

Public Transit

Public transit organizations receive federal funding to provide transportation within a region or community. Typically referred to as **fixed route**, these services are provided by bus, train or trolleys along established routes with set schedules and no reservations required. Passengers are picked up and dropped off at designated stops along the route. Most prevalent in urban areas, fixed route transit is best suited for individuals who can travel on their own or with minimal assistance. Additionally, most fixed route systems offer accommodations such as priority seating near the front of the vehicle as well as ramps and lifts to make using the system easier. The cost of the service is minimal and discounts for older adults, people with disabilities and Medicare recipients are common. Individuals who cannot ride the fixed route without assistance due to a disability or condition may qualify for ADA Complementary Paratransit.

ADA Complementary Paratransit

Guided by requirements of the Americans with Disabilities Act (ADA), public transit agencies must offer comparable transportation to individuals who are unable to independently utilize the fixed route service due to a disability. To use paratransit services, individuals must submit an application and complete an in-person assessment in order to determine eligibility. Eligibility is not based on the type of disability but by the demonstrated inability to use the fixed route independently. Once deemed eligible, rides are scheduled in advance, usually with a designated paratransit provider in an accessible vehicle. The passenger is picked up from their location and transported to their destination which must be during regular hours of operation and within $\frac{3}{4}$ mile of the fixed route service. Paratransit drivers are trained to assist passengers with disabilities to get in and out of the vehicle, secure mobility devices and other needs related to the trip. If the individual needs additional assistance during the trip, a person acting in the capacity of a personal care attendant (i.e., helping with communication, mobility or personal care) is allowed to accompany the individual at no extra charge. The regular cost of a paratransit ride can be no more than double the cost of a fixed route fare.

Demand Response

In addition to public transit, demand response transportation is frequently available from agencies that provide services to older adults and people with disabilities such as human

service agencies, area agencies on aging and independent living centers. Rides can be scheduled from different pick up and drop off locations at times requested by passengers. Typically, rides need to be scheduled 24-48 hours in advance by phone, through a website or mobile app. Demand response services usually operate as a shared ride service, meaning multiple passengers may be riding together in the same vehicle. Accessible vehicles are often available, and riders are picked up and dropped off at the curb which is referred to as curb-to-curb service. Drivers will aid in entering and exiting the vehicle. If assistance is needed to get from the vehicle to the door, this service must be requested ahead of time. Demand response is a good alternative for those who are unable or unlikely to use the fixed route or do not qualify for ADA complementary paratransit.

Family Grateful for Community Transportation

When Ruth started relying on a walker for mobility and was unable to lift the walker in and out of the car, she feared she would miss her weekly hair appointment. Because her family lived out of state and could not provide the rides, they contacted Freeman (SD) Community Transit who provides demand-response transportation. An accessible van and trained driver were scheduled to take Ruth to and from the beauty shop each week. While not as critical as medical appointments, trips such as these are also important in maintaining a meaningful life and the service provided relief to her family.

Microtransit

Microtransit, also referred to as on-demand, is a newer service model that is growing in popularity but may not be available in all areas. Rides are requested, scheduled and paid for through an app, website or call center when the ride is needed, without advance reservations. Shared-ride vehicles pick up and drop off individuals within a defined perimeter or area of town. Curb-to-curb service is provided with some assistance from the driver to enter and exit the vehicle. Accessible vehicles may or may not be available. The cost of demand response and Microtransit varies by community or provider; however, vouchers or other assistance programs are sometimes available to help with the cost of the fare.

Shared Ride Services

Companies such as Uber and Lyft or local taxi companies provide flexible transportation options in many communities. Passengers connect with drivers via mobile app or call center to schedule and pay for their ride at the time and location needed. This curb-to-curb service can be very convenient but may not meet the needs of people with disabilities nor exist in all communities. If a wheelchair accessible vehicle or assistance

with boarding and disembarking is needed, the passenger must make those requests when scheduling since accessible vehicles and driver assistance to get in and out of the vehicle may not be available. Cost of this service can be high, and it is less likely that there are voucher programs to cover these rides.

Volunteer Driver Programs

Frequently offered by local nonprofit organizations, volunteer driver programs coordinate volunteers to provide pre-arranged rides for passengers to medical appointments or other destinations. Volunteers often use their own vehicles, but some programs might provide an agency vehicle which may or may not be accessible. Rides need to be scheduled one to several days in advance. Volunteers may provide help getting from the home to the vehicle and from the vehicle to the destination which is known as a door-to-door service. Costs vary but volunteers usually are only reimbursed for mileage.

Volunteer Driver Program Provides Access to Dialysis for Working Families

The Aging & Disability Resource Center (ADRC) of Portage County plays a crucial role in supporting a family whose son requires dialysis three times a week. Since the family members have full-time jobs, they are unable to provide rides for their son during the week. The ADRC arranged for a volunteer driver to transport their son to and from the dialysis clinic each week, enabling his caregivers to continue working without interruption.

Non-Emergency Medical Transportation (NEMT)

NEMT is a service that provides transportation for individuals who need to get to planned medical appointments and do not have access to reliable transportation. This service is often covered by Medicaid, Medicare Advantage Plans and some private health insurance plans. Eligibility requirements must be met, and these vary from state to state. Rides need to be scheduled in advance through a transportation broker or designated NEMT provider. Caregivers can accompany the person at no additional cost.

Family, Friends and Neighbors

Besides community transportation programs, neighbors, friends or relatives might be willing to offer to provide rides. Many people are eager to help but aren't sure how to do so. Asking for assistance with transportation could provide them with the perfect opportunity to help, especially if they were already planning to make the trip for their own purpose.

Special Considerations for Travel

When assessing community transportation options, it is important to consider any specific needs the rider may have to ensure a safe and successful journey. The following questions can help identify areas of concern for the rider when using alternative transportation.

- Does the rider need assistance getting in and out of the vehicle safely?
- Does the rider need assistance getting from their door to the vehicle?
- Does the rider need accommodation for a wheelchair or mobility device?
- If there are stairs, ramps, elevators and/or escalators involved at the pick-up or drop-off location, can they manage on their own?
- How long can the person ride in a vehicle?
- If there is a wait to board, will they need a place to sit?
- Does the rider have a cognitive impairment that could affect their ability to safely travel on their own?
- Can they carry the belongings needed for the trip, including items purchased or acquired during their outing?
- What funding source can help pay for the cost of the ride? Medicaid? Medicare Advantage? Other? (note: traditional Medicare only cover ambulance transportation)

Travel Training Program Provides Respite for Mother of Disabled Adult

Stephen is a 35-year-old with autism, lives with his parents and works five days a week at DRTC, a vocational program in Oklahoma City. DRTC partners with EMBARK, the local transportation system, to provide travel training for workers and their families. After Stephen and his mother completed the training, he learned to ride the bus independently to and from work each day. Stephen's mother is delighted with the extra time she now has, not being the sole transportation provider. Meanwhile, Stephen takes pride in his newfound independence and has started using the bus to travel to other destinations as well.

Transportation Support Services

Many transportation providers offer additional support services for riders who need extra help and can be a determining factor in the success of the trip. Here are some examples of services that may be available.

Travel Training is a program designed to teach individuals how to use public or other transportation programs. It provides practical instruction and support to

individuals or groups of riders and may include reading bus schedules, transferring to other routes, paying the fare, scheduling rides and using an app.

Bus Buddies pairs an experienced transit user with a new rider to offer individual assistance and support when riding the bus, train or other transportation service until they are comfortable riding on their own.

Volunteer Chaperone Programs involve trained volunteers to assist and accompany a rider on a trip, frequently to medical appointments. The volunteer meets the person at their home, rides with them to the destination, waits at the clinic until the appointment is over and helps get them settled back at their home as needed. The volunteers do not participate in the actual appointment or relay medical information to the provider.

Dementia Friendly Programs aim to create an environment and service that is accepting and safe for people who have dementia. Drivers and other transportation staff are trained on topics including recognizing signs of dementia and effective communication. They also learn how to create a dementia-friendly environment such as clear signage and easy-to-read instructions that can help people with dementia feel welcome and supported when using the transportation service. Individualized support may be provided where needed to facilitate a successful trip.

Mobility Management is a service designed to assist riders and their caregivers in finding transportation options that best meet their needs. A transportation service coordinator provides information about available services and helps develop a transportation plan that addresses individual barriers, concerns and needs.

In addition to these programs, the ADA requires that transportation providers offer reasonable accommodation for riders' specific needs provided the requests do not harm other passengers or fundamentally alter the service. For example, a rule prohibiting eating on the bus could be waived for someone with an insulin condition.

Volunteer Chaperone Program Supports Family Caregiver

The AAA of South-Central Connecticut runs a Volunteer Chaperone program. After her father's sudden death, a woman became the primary caregiver for her mother, who had health issues requiring ongoing medical appointments. As the sole provider of rides, the daughter found her full-time job compromised, prompting her to call the agency. They paired her mother with a volunteer chaperone, providing safe transportation and companionship for the appointments. This support enabled the daughter to maintain her job while ensuring her mother's needs were met.

Where to Look for Transportation Options

Every community has a unique system for providing transportation. A variety of private, governmental and non-profit agencies offer transportation, so there is seldom one simple number to call. However, the following agencies typically have transportation or can suggest where else to look.

The **Public Transportation Authority** will have comprehensive information about bus routes, train schedules, fares and other services such as fixed route or ADA complementary paratransit. To learn more about available transportation options, the American Public Transportation Association (APTA) maintains a [database of US local and state transit links](#) to assist in finding information in your area.

Community organizations who provide services for older adults and people with disabilities such as **Area Agencies on Aging (AAA)**, **Centers for Independent Living (CIL)**, and **Aging and Disability Resource Centers (ADRC)** can connect you with local transportation options, including services that cater to individuals who may need additional support. They may also provide further caregiver support services to assist.

- [Eldercare Locator](#) is a comprehensive national information and referral center that helps connect people to resources in their local community, including AAAs, ADRCs, transportation providers and others. Learn more by visiting the website or by calling 800-677-1116.
- [Independent Living Centers Directory](#) is a list of Centers for Independent Living found across the country. This directory provides the contact information and counties served for each Center.

Community centers, libraries, governmental offices, Tribal Nations and faith-based communities may have information about the available transportation programs and services in the community.

Searching the internet using keywords such as transit, transportation, mobility management and volunteer drivers is another viable way to find what's available. The following online directories have contact information for agencies that can assist in finding transportation options in local communities.

- [National Congress of American Indians Tribal Directory](#) lists the names and locations of Tribal Nations across the country.
- [Community Transportation Provider Database](#) can help you find local community transportation providers by entering an address or location anywhere in the US.
- [2-1-1 Directory](#) is a community information and referral service that connects people to local resources. Call 2-1-1 or enter your zip code on the website to access local transportation information.

Creating a Transportation Plan

Once you understand the types of transportation and support services available in the community, it becomes clearer how a family caregiver can use these options as a means of support for their loved one. The next step is working with the caregiver to explore the various travel possibilities available to them and create a transportation plan. Use NADTC's [My Transportation Plan Tool](#) and follow the steps below to get started.

Learn about transportation options available in the community

Write down the provider's name, location and phone number; type of service; when and where they operate; how to schedule the ride; cost and the type of assistance they offer such as wheelchair accommodation or other special considerations. Include family, friends or neighbors who have offered to help.

Identify transportation needs

List the activities the care recipient is involved in such as social activities, shopping trips, hair appointments, church and medical appointments. Include recurring activities as well as unique trips.

Consider alternate rides for each activity

For each activity, identify a potential alternative ride. Not every activity may be suitable for someone else to provide transportation, such as medical appointments where a caregiver's presence may be necessary. Pick one or two trips for someone else to provide to put the plan into action.

Assess the plan regularly

Evaluate each trip and take notes on what worked and what did not. Perhaps the bus didn't work for grocery shopping because it was difficult to carry the bags afterwards, but it could work to get to a social event.

Note that even if the caregiver has access to a vehicle and wants to accompany their loved one, using a ride service could provide a less stressful journey. Navigating city traffic, driving at night or finding unfamiliar locations can be anxiety-inducing. Additionally, taking a loved one with mobility challenges to appointments or events where parking is far from the entrance may raise concerns, especially if the caregiver needs to leave them unattended while parking. Using a ride service allows the caregiver to focus entirely on their loved ones' needs while someone else handles the driving.

Caregiving in Rural Areas

Caregivers in rural areas face unique transportation challenges such as fewer transportation options and longer travel distances. While public transit is less robust, human service agencies and organizations who serve older adults and people with disabilities often provide transportation services, such as volunteer driver programs. These programs are sometimes limited to medical appointments or other trips that are considered essential. Consequently, people in rural areas may need to rely more heavily

on family and friends for transportation assistance.

Rural Demand Response Program Provides Access to Community

The South Central Transit Network provides on-demand transportation services across eight counties in rural North Dakota and is managed by Adult Services and senior centers throughout the region. They connected with an older woman living miles from town, who hadn't left her home in six years except for ambulance rides. They arranged weekly rides that accommodated her wheelchair, to bring her into the community, providing socialization and opportunities to address other needs.

Transportation and Caregiver Support Partnerships

In addition to helping individual caregivers find transportation options, caregiver support professionals can take steps on a larger scale to make transportation a more recognized and viable support for caregivers. Start by getting to know the transportation providers in the community and learning about their services. Then, inform them about your program and educate them about the needs of family caregivers. Work together to brainstorm ways to make transportation more accessible and useful for family caregivers. Support each other by collaborating on community engagement efforts. Participate in each other's committees, coalitions or boards to share insights on challenges and to develop solutions to better support family caregivers with transportation. Building these partnerships can lead to improved service delivery for both agencies and increased opportunities for family caregivers to find respite from their responsibilities.

Resources

American Public Transportation Association (APTA): [US Local and State Transit Links](#)

ARCH National Respite Network: [Resources for Caregivers](#)

Eldercare Locator: [Transportation Resources](#) and [Caregiver Corner](#)

Independent Living Research Utilization (ILRU) Program: [Directory of Centers for Independent Living \(CILs\)](#)

National Alliance for Caregiving: [Caregiving in the U.S. 2020 Report](#)

National Congress of American Indians: [Tribal Directory](#)

National Center for Mobility Management: [Community Transportation Provider Directory](#)

2-1-1: [Resource Directory](#)

NADTC: [My Transportation Plan tool](#)

This resource was created through a joint effort of ARCH National Respite Network and the National Aging & Disability Transportation Center to provide guidance and insight to support family caregivers in utilizing and coordinating with transportation programs.



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ARCH National Respite Network and Resource Center promotes the development of quality respite and crisis care programs, and serves as a strong voice for respite in all forums.