



The Technical Assistance Center for Lifespan Respite Fact Sheet Number 60, November 2012

Transportation Access and Respite Care: Critical Information for Family Caregivers, Care Recipients, and Respite Providers

Introduction

When family caregivers are asked what kind of help they need, the most frequent response is “I need a break!” Respite care provides that break. Access to reliable, accessible transportation is a critical element in the process of providing respite care. This fact sheet provides strategies for identifying transportation options and eliminating transportation barriers related to the provision and receipt of respite care. In it, we address the importance of transportation and how to:

- identify community transportation resources,
- determine the best transportation options,
- include transportation in the respite planning process, and
- create transportation options that meet the needs of family caregivers, care recipients, and respite workers and volunteers.

Access to transportation promotes independence, community integration, and improved quality of life for children and adults with disabilities and older adults while providing a vital connection to needed services in the community. For family caregivers and organizations’ staff members who provide respite care, access to transportation services can not only make both in-home and out-of-home respite care possible, but can support an improved quality of life for all.

Understanding How Transportation Affects Access to Respite

Family caregivers and care recipients may need to address a variety of issues as they try to find and

access respite services. The type and frequency of issues related to transportation may vary depending on the age or condition of the care recipient. Respite workers or volunteers trying to get to a respite program or the home of a family caregiver may also face transportation challenges.

Geographic isolation and limited public transportation in rural areas can result in significant transportation barriers, but such transportation barriers can exist in urban and suburban areas as well. Additionally, the level of accessibility a care recipient requires, the employment status of the family caregiver, and the cost of transportation may present challenges to securing needed transportation. The intermittent nature of respite may compound the issue. Establishing regular transportation solutions to coincide with what might be irregular use of respite care could pose a problem.

A description of the range of issues that care recipients and caregivers may need to address follows.

- **Family caregivers** may not have their own means of transportation, be unaware of transportation options in their communities, and/or learn that their communities lack suitable alternative transportation options. Those who do have their own means of transportation, however, may find it difficult to transport their children who have health-care needs or aging family members with functional limitations. For example, although they may own personal vehicles, those vehicles may not be wheelchair accessible. They may also lack other special equipment (i.e., special car

seats/restraints, etc.) that is needed in order to provide safe transport.

- **Care recipients** may also lack their own means of transportation, be unaware of transportation options in their communities, face accessibility barriers, and/or learn that their communities lack suitable alternative transportation options. They may express concern that they are a burden to family caregivers or express frustration or anger that they cannot travel independently due to their disability or health issue. They may even identify reasons not to take the trip. Depending on age or disability, they could get extremely anxious or confused when being transported, making the ride to respite care a stressful experience for all involved. For some older individuals, use of public transportation has been shown to generate fear of the unknown or concerns related to debilitating health status (Robinson, K., et al, 2012). For children, few transportation options beyond their family caregivers may be available – making planning for respite care particularly challenging.
- **Veterans and their caregivers** can face both common and unique challenges when it comes to transportation and respite care. Transportation barriers identified in Easter Seals Project ACTION's 2012 Online Dialogue on Veterans' Transportation included: liability concerns associated with transporting veterans, transportation only being available for medical appointments, buses being prohibited from entering a military post/base, veterans' homelessness and consequent changing locations, and lack of transportation services in rural areas.
- **Caregivers and care recipients in rural and small urban communities** who do not have their own means of transportation may find few or no other suitable transportation options. For those who do have their own means of transportation, the distance they must travel to receive respite may be long, which is both costly and time-consuming. Although other transportation options may be available, they may not

be affordable. For example, in some rural communities that do not have more affordable options like public transit, costly medical transportation may be the only transportation option.

- **Respite workers and respite care programs in rural communities** may find that their geographic isolation results in “fewer direct service agencies available to provide services; fewer direct service workers available for agencies to hire, and great size of service regions and distances between individuals in need of services and service agencies, resulting in direct service workers spending more of their time traveling to and from people in need of services and less time providing services,” according to a 2011 report by the National Direct Service Workforce Resource Center. In addition, the report goes on to say that “rural...areas also struggle with the low pay and benefits of direct service work combined with transportation costs as an obstacle to worker recruitment and retention.”
- **Caregivers, care recipients, respite workers and volunteers, and respite programs in urban areas** may have access to robust public transit service, but the care recipient may live beyond the fixed-route or paratransit service areas. In some cases, care recipients may be too young or otherwise unable to travel safely on their own on public or private transportation. For a family caregiver, traffic congestion in urban areas can make a geographically-short trip to a respite-care program time-consuming, costly, and stressful. The same may hold true for a respite worker or volunteer trying to get to the home of the family caregiver to provide respite. Finding accessible, affordable transportation options for both care recipients and respite providers can have its challenges – even in urban communities.

Transportation Options

Transportation services in most communities are provided through public or private operators. Transportation options may be available to all members of the general public or may be limited to

certain eligible individuals depending on the agency that funds and operates the service. For example, a bus transportation system operated on a fixed route by a city or county government will be open to the general public; whereas a van operated by a human services agency may only be available to individuals eligible to participate in that agency's programs.

In recent years, transportation operators who provide services funded with federal dollars have been required to coordinate transportation services at the community level. Coordination means that two or more agencies can use the same pool of vehicles for different services or two or more agencies may combine their funds to expand service options. In many communities, coordination means that more individuals, including riders of all ages, people with disabilities, and people of varying income levels and ethnicity are now involved in the planning process used to decide what types of transportation will be available in a given town, county or region.

Mobility managers, who are generally part-time or full-time staff members of a human service agency, transportation system, planning organization or an education or medical facility, assist with this coordination process. They often provide information on the transportation options available at the local or state level, coordinate transportation planning meetings, write policy or work with an individual to determine specific transportation needs. In this case, mobility managers may customize and facilitate access to transportation options for an individual based on the service available in the community. In this last example, mobility managers customize transportation options for an individual based on the service available in the community, and they also facilitate the individual's ability to access transportation.

Except for extremely rural areas, a family of transportation services is available in most communities. The following sections describe the range of transportation services and how mobility managers can assist in identifying transportation in greater detail.

The Family of Transportation Services

Family caregivers, respite providers and administrators, and Lifespan Respite programs would be well-served to familiarize themselves with transportation options. The variety of programs and transportation options that can provide mobility to older adults and people with disabilities across the lifespan is known as the *family of transportation services*. Some members of this *family* that may be available in the community include:

- **Public transit/fixed-route** – vehicles run on regular, scheduled routes with fixed stops or stations. Most prevalent in urban areas, but also available in a number of small urban and rural communities, public transit bus and train service is a particularly good fit for those individuals who are old enough or otherwise able to travel on their own or with an assistant, are able to travel to and from the nearest bus/train stop (with or without an assistant), are cognitively capable to navigate through the transit system (with or without assistance or training), and are seeking a highly-affordable and accessible transportation option.
- **Public transit/demand-responsive** – public “demand response” and “dial-a-ride” community transportation services using lift-equipped vans, small buses, or sedans. The service may operate as “curb-to-curb” or “door-to-door” service. Curb-to-curb service provides for passenger pick-up and drop-off at the curb or roadside near a residence or destination, while door-to-door service provides for passenger pick-up and assistance to the doors of homes and destinations. More common in rural and small urban areas than in urban areas, demand-responsive public transit service is a good fit for those individuals who are old enough or otherwise able to travel on their own or with an assistant, who are able to travel to and from the pick-up and drop-off locations (with or without an assistant), and are seeking a highly affordable and accessible transportation option.
- **Paratransit** – required by the Americans with Disabilities Act (ADA) for individuals whose

disabilities prevent independent use of the fixed-route transportation system. The ADA requires specific service characteristics related to service area, eligibility, reservations, response time, and operational performance. ADA complementary paratransit is only available in communities that have fixed-route public transit (i.e., bus or rail) service and only for those individuals who qualify. There is an application process for use of this service, which typically requires documentation from a medical professional and sometimes an in-person assessment. Under the ADA, public-transit providers are permitted to charge fares for this service of up to twice the amount of the fixed-route fare. ADA complementary paratransit can be a good option for care recipients who cannot access the fixed-route system due to their disabilities or cannot navigate the fixed-route system due to their disabilities, but still want an affordable and accessible transportation option.

- **Taxi, including accessible taxis** – individualized service between destinations, which can be arranged in advance or on demand through a dispatcher. Fares vary by provider, are distance and/or time-based, and, in some cases, are subsidized through a transportation voucher

program. Often more expensive than public transit, taxicabs can still be an affordable option when transportation vouchers are applied or when the trip distance is very short and the time brief. Taxi service can be a particularly good fit in areas that are not served by public transit or in situations when the care recipient is unable to travel in a vehicle with other passengers or for extended periods of time. Of course, the availability of taxi service and accessible taxi service (i.e., taxicabs with wheelchair lifts or ramps) in particular, varies by community.

- **Voucher programs** – typically administered through a social service agency, such programs enable qualified people to purchase vouchers for transportation services at a reduced rate from providers, such as public transit, volunteer programs, or taxis. Transportation voucher programs exist in some rural, small urban, and urban communities. In some communities that have public transit, voucher programs are used to fill service gaps (i.e., offering an affordable evening or Sunday transportation option when the public transit service is not running). They are also used in some rural and small urban communities that do not have any transit service as a means to provide an affordable

Transportation Voucher Program: American Council of the Blind of Nebraska

The American Council of the Blind of Nebraska (ACBN) has worked closely with the Abbott Foundation and with Lions Clubs throughout the state to develop private funding for a voucher transportation program. Funding from these sources has supported ongoing voucher programs in Lincoln, Omaha, and the Grand Islands/Hastings area. In 2005, the funding provided by these private organizations was combined with funding received from the Nebraska Commission for the Blind and Visually-Impaired to provide transportation for more than 760 individuals with vision disabilities throughout the state. ACBN also is working

with the Lions Clubs to identify club members willing to serve as volunteer drivers, an important part of the voucher program. As a member-based organization, all of the local voucher programs are also staffed and managed by volunteer members of ACBN and local Centers for Independent Living. ACBN reports that its fund-raising efforts have been successful partly because it can ensure that all monies provided are used in direct service provision (rather than administrative costs) (*Transportation Services for People with Disabilities in Rural and Small Urban Communities* Easter Seals Project ACTION, 2006).

transportation option to people with disabilities, older adults, or both. The number of accessible taxis can vary by community, which can, in turn, influence the number of accessible vehicles available to people with disabilities who qualify for the taxi voucher program.

- **Travel training programs** – hands-on, in-the-field instruction on how to travel safely and independently within public transit systems; most often provided by public transit agencies or organizations that serve people with disabilities or older adults free of charge or at a low cost. This is a particularly good strategy for individuals with disabilities or older adults who would physically and cognitively be able to access and navigate through the fixed-route bus or train system, but require instruction and practice to do so with greater ease and confidence.
- **Volunteer driver programs** – a network of volunteers that provides one-way, round-trip, and multi-stop rides. These programs are provided free of charge, on a donation basis, through membership dues, or at a minimal cost, and typically have an eligibility process and advance reservation requirements. Volunteer driver programs exist in some rural, small urban, and urban areas. Volunteer driver programs may or may not use accessible vehicles, which can be an important consideration for respite recipients who require a wheelchair accessible vehicle.
- **Carpools and Vanpools (rideshare programs)** – riders travel together in a carpool or vanpool, sharing expenses and responsibilities, such as driving. Such programs are often administered through commuter networks, transit agencies, or a partnership of employers. Rideshare programs are particularly prevalent in large urban/suburban areas where traffic congestion and travel restrictions on major roads make ridesharing attractive to commuters. If the care recipient requires a wheelchair accessible vehicle, you will want to inquire about this in advance.

Identifying Services in the Community

If you are a family caregiver exploring transportation options for respite care, first ask the respite care provider if they offer transportation services. If they do not, ask if they can refer you to transportation services or a mobility manager in the community. If they do not provide transportation services and/or are unable to refer you to transportation services or a mobility manager in the community, take one or more of the following actions:

- Search “transportation” in the yellow pages or phone directory
- Contact the local One-Call/One-Click Resource Center. Dial 211 or 311 service (or other three-digit number, depending on the area). Follow instructions for transportation options
- Use the Internet to search the following key words: transit, transportation, transportation assistance, transportation mobility management, and volunteer drivers
- Contact the local Center for Independent Living <http://www.ilru.org/html/publications/directory/index.html>
- For older adults, contact the state or local Area Agency on Aging http://www.aoa.gov/AoA_programs/OAA/How_To_Find/Agencies/find_agencies.aspx or use the Eldercare Locator <http://www.eldercare.gov>
- For children, contact the state Parent Training and Information Center /Community Parent Resource Center <http://www.parentcenternetwork.org/parentcenterlisting.html>

Consultation with a transportation provider or the program administrator of a particular option for the potential eligibility requirements of that transportation option is suggested.

Selecting the Best Transportation Option(s)

Once transportation options in the community are identified, several considerations should be explored to determine the best transportation option for the individual served.

Accessibility Considerations: General

The following accessibility considerations apply to all transportation options:

- Does the individual seeking transport use a wheelchair, mobility device, or cane?
- If he/she uses a wheelchair, can the wheelchair be folded so that he/she can transfer to a seat in a car while the wheelchair is stowed in the vehicle? Or does he/she require an accessible vehicle with a ramp or lift?
- Does he/she have the ability to climb stairs?
- Does he/she have the ability to get in and out of a car by him/herself?
- If he/she cannot get in and out of a car by him/herself, can he/she do so with assistance? Can the driver or someone else provide that assistance?
- If he/she is an adult, can he/she drive safely?
- Does he/she feel comfortable asking family or friends to “help out”?
- If a relative or caregiver provides transportation, can the individual get into their vehicle? How high is the vehicle from the ground (e.g., a truck, van, or SUV is often high off the ground)? If so, is a step stool needed? Is there a grab handle?
- For longer trips, is access to a bathroom necessary? If so, is it possible to make a rest stop along the way?

Accessibility Considerations: Public Transit

In addition to the above general accessibility considerations, the following accessibility considerations apply specifically to public transit.

- Is the individual able to ride with others? For example, does he/she have severe allergic reactions to things that are commonly present in public or shared spaces (e.g., cleaning product fumes, perfumes)?
- Is he/she able to ride for up to an hour?
- Will he/she need a seat at all times (i.e., while waiting to be picked up and while riding on public transit)?
- Is he/she able to travel alone?

- If the individual is unable to travel alone, is there a personal care attendant, friend, or family member who can travel with him/her? If so, the personal care attendant, family member, or friend would be permitted to travel with him/her on public transit in order to provide assistance before, during, or after the trip.
- Is he/she a young child? If so, each public transit agency has a policy addressing the minimum age children are permitted to travel without being accompanied by an adult. (**Note:** See also “Special Considerations for Transporting Children” on page 7.)
- Will he/she be able to use stairs, ramps, elevators or escalators in stations and at stops?

Special Considerations for Older Adults and Their Drivers

Drivers of older adult passengers should consider the following:

- Some destinations are more enjoyable than others. The thought of some destinations may cause stress to the passenger.
- Traffic, weather, and parking don’t only affect the driver; they also affect the passenger and can be a source of additional stress.
- The passenger’s physical condition in general as well as specifically on the day of the trip can affect transport. Are they well-rested; having a good day in terms of aches, pain, and balance; and feeling strong enough to transfer in and out of the vehicle?
- The passenger’s mental fitness just prior to the trip can affect transport.
- The driver’s tight time constraints might not fit the passenger’s need for extra time to walk, take a bathroom break, or get in and out of the vehicle.

Based on the above considerations, drivers can:

- Adjust their interactions with the passenger during the trip (e.g., pace, communication) given the passenger’s current physical status.
- Consider how the passenger feels based on the passenger’s current mental status. Think “how

I would feel if..." and adjust your interactions accordingly.

- Do their best to think realistically about the amount of time needed.
- Add additional time to "play it safe" and create the most relaxed environment.
- Plan for the trip with the passenger.
- Consider giving the passenger something he/she can hold related to the trip (e.g., a card with the name and address of the destination, paperwork needed for the trip, directions to the destination).
- Prepare them to answer the same question repeatedly in a positive manner and tone.
- Choose the best route from several options. Are surface streets preferable to the expressway, for example? Is a more scenic or familiar route more enjoyable for the passenger?
- If time is flexible, drivers and passengers can consider traveling during non-peak hours to avoid heavy traffic.

For additional tips for drivers of older adult passengers, see *Tips for Drivers and Older Adult Passengers*, a publication by the National Center on Senior Transportation. https://secure2.convio.net/es/site/Ecommerce?VIEW_PRODUCT=true&product_id=7521&store_id=6563&autologin=true

Special Considerations for Transporting Children

The American Academy of Pediatrics provides specific guidance on transporting children with special health-care needs. Important general considerations include:

- The rear seat is the safest seat for all children.
- For a child with special health care needs who requires frequent observation during travel and for whom no adult is able to accompany the child in the back seat, an airbag on/off switch should be considered for the vehicle.
- Instructions provided by the vehicle manufacturer and the car seat manufacturer must be followed.
- Selecting the most appropriate restraint and receiving proper training on the proper use of that restraint is essential.
- Older children with hyperactivity, autism or emotional problems may require a safety restraint that is less likely to be unlocked by the child.
- Ancillary pieces of medical equipment should be secured on the vehicle floor, underneath a vehicle seat or wheelchair, or on the bus seat, bus floor, or bus wall below the window line so that they do not become projectiles during a crash.
- Electrical equipment for use during transit should have portable, self-contained power for at least twice the expected duration of the trip.

For more detailed guidance, see the American Academy of Pediatrics' article titled *Transporting Children with Special Health Care Needs*. <http://pediatrics.aappublications.org/content/104/4/988.full>

Many organizations and agencies require that parents and caregivers transport children themselves, as opposed to offering transportation services. And each public transit agency has a policy addressing the minimum age children are permitted to travel without being accompanied by an adult.

For children who are enrolled in Head Start programs, school, or early intervention programs, there are requirements to address transportation needs in the child's Individualized Education Plan (IEP) for school or Individualized Family Service Plan (IFSP) used by early intervention programs. At a minimum, the following considerations should be addressed:

- Special pick-up and drop-off locations to ensure adult supervision at all times
- Special seating requirements
- Special equipment needs
- Additional assistance
- Specialized training for drivers

For more information on transportation services for children with disabilities in the community or on including transportation in the IEP or IFSP, you may want to contact the state Parent Training and Information Center/Community Parent Resource Center <http://www.parentcenternetwork.org/parentcenterlisting.html>.

Personal Care Attendants and “Door-Through-Door” Service

Sometimes individuals need extra help that goes beyond what can reasonably be expected of the transportation provider when traveling on public transit or in a taxicab. For example, they might need help getting organized and out the door at home and then getting through the door and situated when they arrive at their final destination. If the family caregiver or parent cannot accompany the care recipient, providing either a paid or volunteer personal care attendant to assist them can make

more affordable transportation options like public transit or taxicabs work. Sometimes human service providers offer this *door-through-door* service as an option. But, if it is not an option offered by a provider in the area, it can also be arranged for privately. For example, contact the local Center for Independent Living for a list of personal care attendants in the area who provide this door-through-door assistance <http://www.ilru.org/html/publications/directory/index.html>. In Connecticut, New Jersey, Massachusetts, Rhode Island, and Vermont, personal care attendants can be found through the online directory, Rewarding Work at <http://www.rewardingwork.org>.

Budgetary Considerations

The cost of available transportation options may affect which ones are chosen. Knowledge of available payments methods and resources

Examples of Volunteer Driver Programs

- **TimeBanks USA** was founded in 1995 and its central office is located in Washington D.C. The mission of TimeBanks is to “nurture and expand a movement that promotes equality and builds caring community economies through inclusive exchange of time and talent.” For each hour of service a member volunteer provides, such as transportation or respite, they earn “time dollars” that can be exchanged for services provided by other volunteers. To find a local TimeBank, visit <http://community.timebanks.org>.
- **National Volunteer Caregiving Network (formerly Faith in Action)**: More than 600 local programs utilizing volunteers from faith communities provide volunteer caregiving services, which may include transportation, for their neighbors in need. For more information about the National Volunteer Caregiving Network, call 304-907-0428 or email info@nvcnetwork.org. To find local NVCN initiatives, visit <http://www.nvcnetwork.org/index.php/find-a-program>.
- **VA’s Volunteer Transportation Network (VTN)** was established by the U.S. Department of Veteran’s Affairs (VA) to provide needed transportation for veterans seeking services from a VA facility and/or authorized facility. VTN guidelines permit volunteer participation in providing transportation to veterans using a volunteer’s privately-owned conveyance or a government-owned vehicle, including donated vehicles, county vehicles, Disabled American Veterans Department (State) or Chapter (local) vehicles, public transportation and contracted transportation. For more information regarding the Volunteer Transportation Network, contact the local VA Voluntary Service Office at the nearest VA Medical Center or visit <http://www.dav.org/volunteers/Ride.aspx>.

can be especially useful for family caregivers, respite providers and administrators, and Lifespan Respite programs when considering the inclusion of transportation in any respite services hired, developed or provided.

For Family Caregivers

- **Fees.** Many transportation providers charge a fee. What is the individual's or caregiver's budget for transportation? You will want to discuss this early on to determine which transportation options best fit your budget, if applicable. For example, public transit fares are often lower than private taxicab fares. When available, however, transportation voucher programs can make taxicab service more affordable for those individuals who qualify for them.
- **Transportation voucher or volunteer driver programs.** Are transportation voucher programs available that will either reimburse drivers or a taxi provider? Are there volunteer driver programs in the community that could help? As mentioned earlier, you can dial the local 211 or 311 service, contact the local Center for Independent Living (for people with disabilities), contact the local Area Agency on Aging (for older adults), contact the local Veterans' Service Organization (for veterans), or look up "transportation" on the internet or, specifically, on the Eldercare Locator to determine if there are any transportation voucher or volunteer driver programs in the community. For contact information for each of these suggestions, see the **Resources** section on page 14 or the highlighted programs on the bottom of page 8.
- **Medicaid eligibility.** If the individual is a Medicaid recipient and the purpose of the trip is medical, will Medicaid cover the cost of the transportation? Note: What is covered can vary by state and by individual plan. You will need to call the Medicaid transportation provider for your Medicaid plan first to determine what transportation services are covered. For example, is transportation to and from a day program for the individual covered?

Medicaid Transportation Funding: Lane Transit District, Oregon

The Lane Transit District (LTD) in Eugene, Ore., works with the Oregon Department of Human Services (DHS) to leverage federal Medicaid funding to maximize support trips for Medicaid-eligible riders traveling to and from Medicaid-supported programs – particularly programs for people with developmental disabilities. Through coordination with local Developmental Disabilities Services agencies, DHS reimburses Lane Transit District for 60 percent of the total fully-allocated cost of these trips and LTD provides local funding for the remaining 40 percent. DHS passes through 50-60 percent of the trip cost from Medicaid funding (*Transportation Services for People with Disabilities in Rural and Small Urban Communities*, Easter Seals Project ACTION, 2006).

Medicaid waivers can also be applied to transportation costs associated with respite care. Again, coverage varies by state. Some states reimburse directly for transportation associated with respite care whereas others include the cost of transportation in the respite rate. To view a state-by-state table of Medicaid waiver coverage as it relates to respite care and to determine if transportation costs are incorporated into the respite rate, see the ARCH guide titled *Home and Community-Based 1915(c) Medicaid Waivers for Respite Support: State-by-State Tables of Medicaid Waiver Information*. http://archrespite.org/images/docs/Home_CommunityBased_Waivers_Respite_3_16_2011_Web.pdf

For Respite Workers, Volunteers, and Programs

If respite workers or volunteers are expected to travel long distances to reach their destination or

if affordable public transit is not readily available, the cost of transportation for the respite provider may be prohibitive. If funding is available, respite programs or family caregivers may want to consider reimbursing respite providers or volunteers for total or partial transportation costs incurred in getting to the respite program or to the family caregiver's home. Medicaid waiver funding may include the cost of transportation in the respite payment. National volunteer programs, such as RSVP and Senior Companions may also include funds for reimbursing volunteer respite providers.

Funding for Transportation

Federal

Research and Demonstration Program to Improve Coordinated Transportation Systems for People with Disabilities and Older Adults

In collaboration with the Federal Transit Administration (FTA), the Administration for Community Living (ACL) solicited proposals in June 2012 for a research and demonstration project to identify and test approaches that involve people with disabilities, including people with intellectual and developmental disabilities and/or physical disabilities, and older adults in the design and implementation of coordinated transportation systems in ways that successfully make those systems responsive to their needs.

Section 1915(c) Home and Community-Based Medicaid Services Waivers (HCBS)

Under a Medicaid waiver, states can provide services not usually covered by the Medicaid state plan program, as long as these services are required to keep a person from being institutionalized. Services covered under waiver programs can include respite care. Generally, every state offers some respite assistance through various home and community-based Medicaid Waivers. States generally cover transportation costs for respite by incorporating these costs into the respite reimbursement rate. Each state's eligibility criteria and funding for waivers is different; check with

your state's Medicaid office or visit Medicaid waiver information by state on the National Respite Locator Service (<http://archrespice.org/respitelocator>) (Perrin, C., 2011)

Moving Ahead for Progress in the 21st Century (MAP-21)

A new two-year federal transportation program, Moving Ahead for Progress in the 21st Century (MAP-21), was enacted in July 2012. MAP-21 is the authorizing legislation that provides funding for public transit and transportation services for people with disabilities and older adults that go beyond the Americans with Disabilities Act. These funding opportunities could be of interest to respite providers, state respite coalitions, and lifespan respite care program grantees. While details regarding MAP-21 are still evolving at the time of the writing of this document, updates will be posted on the Federal Transit Administration website at www.fta.dot.gov/map21.

Similar to past transportation authorization legislation, MAP-21 emphasizes the importance of public transit and human services transportation coordination. Therefore, respite providers, state respite coalitions, and lifespan respite care program grantees that want to influence important transportation funding decisions at the local or state level and/or want their private nonprofit organizations to be considered for transportation funding, should learn more about and get involved in the coordinated public-transit human services transportation planning process.

To learn more about coordination efforts in a local area, contact the local Metropolitan Planning Organization (for urban areas with a population of 50,000 or more) <http://www.planning.dot.gov/mpo.asp> or the local public transit provider. For more information on specific state efforts, contact the State Transportation Association <http://web1.ctaa.org/webmodules/webarticles/anmviewer.asp?a=256>

Title III Older Americans Act (OAA)

Title III of OAA funds a range of community-based services through the Aging Services Network. These

services include home-delivered and congregate meals, case management, and homemaker and caregiver support. As part of the funding provided to states, transportation services are offered to people age 60 and older for a voluntary contribution. Typically, these services are arranged for or provided by AAAs or Aging and Disability Resource Centers (ADRCs) to older adults who are frail, disadvantaged, or “mobility impaired” (i.e., have no car; do not drive or do not live within ¾ mile of fixed route stop). For more information on use of these funds for transportation through the Aging Services Network, see *Use of Transportation Services among OAA Title III Program Participants, September 2012*. http://www.aoa.gov/AoARoot/Program_Results/docs/2012/AoA_6th_xation_Brief_Oct_2012.pdf

Social Services Block Grant

Social Services Block Grant (SSBG) funds are to enable each state to furnish social services best suited to meet the needs of the individuals residing within the state. Such services may be, but are not limited to: daycare for children or adults, protective services for children or adults, special services to persons with disabilities, adoption, case management, health-related services, transportation, foster care for children or adults, substance abuse, housing, home-delivered meals, independent/transitional living, employment services or any other social services found necessary by the state for its population. Respite care and transportation related to respite care may be covered.

Social Services Block Grant (SSBG) funds are awarded directly to States, not to individuals. States are fully responsible, within the limitations of the law, for determining the use of their funds. Each State has the flexibility to determine what services will be provided, who is eligible to receive services, and how funds are distributed among various services within the State. States and local agencies may provide services directly or purchase them from qualified providers.

Veterans Transportation and Community Living Initiative

The Federal Transit Administration (FTA) awards competitive grants to help veterans, military families, and others connect to jobs and services in their communities by improving access to local transportation options. To learn more, visit the Veterans Transportation and Community Living Initiative web page at http://www.fta.dot.gov/grants/13094_13528.html

Department of Veterans Affairs, Family Caregiver Program

The VA Family Caregiver Program provides respite and support to eligible post-9/11 veterans who elect to receive their care in a home setting from a primary family caregiver. The Caregiver Support Program has partnered with the Fisher Foundation to provide airline travel to family caregivers participating in the post- 9/11 caregiver stipend program. Approved Veterans or their caregivers can fly somewhere to stay with friends or family to assist with respite, or family members or friends can be flown to the Veteran’s home to provide respite. For more information about the VA Caregiver Support Program, visit the Department of Veterans Affairs website at <http://www.caregiver.va.gov>.

Local, Regional, and Corporate Foundation Funding

In addition to state and federal funding for transportation, respite providers, state respite coalitions, and lifespan respite care grantees should also explore local, regional, and corporate foundation funding opportunities. Federal and state transportation funding often requires local match funding, which can sometimes be secured through private foundations. Whether or not you are pursuing federal/state transportation funding, foundations should not be overlooked.

Considerations for Respite Care Providers and Administrators

Including Transportation in the Respite Planning and Program Development Processes

To ensure that no transportation barriers to respite care exist, it is important to discuss transportation at the beginning of the respite care planning and program development process. Initial considerations include:

- How will the individual, worker or volunteer travel to and from respite care?
- Is this a reliable means of transportation?
- What other means of travel can be used as a back-up plan?
- How familiar is the individual, caregiver, worker or volunteer with transportation options in the community?
- Would he/she like some more information on who to contact for transportation information?

If the need for additional information on transportation options is indicated, take the following steps:

- 1 Compile information on the transportation options available.
- 2 Review the information with the individual.
- 3 Identify considerations that may impact mobility.
- 4 Select the best transportation option(s).
- 5 Determine if training is needed (i.e., travel training).
- 6 Obtain training, if needed.
- 7 Create a back-up plan.

Keeping Transportation in Mind During Program Implementation

Once a respite care provider compiles information on transportation options for one individual, they should save, add to, and update this list to refer to again when other individuals inquire about transportation options. The local public transit

provider might also have a list of transportation service providers in your area.

Respite care providers can take additional proactive measures to ensure that the transportation needs of respite care recipients, caregivers, workers, volunteers, and providers are met. They can:

- Provide transportation referral services to individuals and their caregivers
- Provide transportation referral services to their workers/volunteers
- Provide transportation benefits to their workers/volunteers (e.g., bus passes/tokens, mileage reimbursement)
- Consider offering transportation as a related service by contracting with a transportation provider
- Consider partnering with a transportation provider to provide *door-through-door* services
- Build working relationships with transportation providers in the community
- Join local/regional public transit and human service transportation coordination efforts. To learn more about coordination efforts in your area, contact your Metropolitan Planning Organization (for urban areas with a population of 50,000 or more) <http://www.planning.dot.gov/mpo.asp> or your local public transit provider
- Coordinate with other human service organizations that have vehicles for transporting clients (i.e., consider sharing vehicles, drivers, maintenance expenses. to save money while serving more people)
- Get involved in local/regional transportation planning efforts. To find out more about opportunities in your community, contact your Metropolitan Planning Organization (for urban areas with a population of 50,000 or more) <http://www.planning.dot.gov/mpo.asp> or your local public transit provider

For information on liability issues and risk management of volunteer driver programs, you may want to contact ITN America www.itnamerica.org

or the Beverly Foundation www.beverlyfoundation.org. The Beverly Foundation has a publication titled *Risk Management in Volunteer Driver Programs*. For risk management strategies for human service organizations providing transportation services, you may want to contact the Community Transportation Association of America www.ctaa.org.

Considerations for State Respite Coalitions

Promoting access to transportation services is also congruent with the mission and the work of the state respite coalitions. State respite coalitions are most often grassroots membership organizations composed of state and local, public and private organizations, which represent individuals with disabilities or chronic conditions of all ages; family caregivers; community and faith-based organizations; and respite, social service and health care providers. Most often their activities are focused on advocacy, networking, and public education, although several are engaged in direct service delivery.

State respite coalitions can work to eliminate transportation barriers to respite care by:

- Advocating for and educating on how to include transportation in the respite care planning process
- Advocating for and educating on providing referral services to transportation, particularly as it relates to respite care
- Joining the statewide transit and human services transportation coordination process. For more information on human services transportation, coordination, visit the National Resource Center for Human Service Transportation Coordination website at <http://web1.ctaa.org/webmodules/webarticles/anmviewer.asp?a=8>

For more information on your state's efforts, contact the State Transportation Association at <http://web1.ctaa.org/webmodules/webarticles/anmviewer.asp?a=256>

- Becoming involved in state transportation planning efforts (i.e., state transportation

improvement program, STIP). For more information, contact the State Department of Transportation at <http://ntl.bts.gov/tools/statedot.html>

When weighing in on transportation planning and funding decisions, remember to include youth and adults with disabilities, older adults, and caregivers in the feedback and public involvement process.

Involvement in state level transportation planning and funding decisions that affect respite care recipients, caregivers, and providers is essential to ensuring that respite-related transportation needs across the states – not just in the urban centers – are met. To learn more, contact your State Transportation Association and ask how you can get involved in your state's human services transportation coordination efforts and how you can provide input on the state transportation improvement program.

Considerations for Lifespan Respite Care Grantee Programs

Lifespan Respite Care programs bring together Federal, state and local resources and funding streams to help support, expand and streamline the delivery of planned and emergency respite services while also providing for the recruitment and training of respite workers and caregiver training and empowerment. The Lifespan Respite Care Program is intended to accomplish multiple objectives including "improving access to programs by streamlining the means by which consumers access programs and by filling gaps in service where necessary." As transportation service gaps can be a barrier to respite care, Lifespan Respite Care programs can help address this critical service gap by:

- Obtaining information from family caregivers and respite providers during the needs assessment process about existing barriers to transportation services and including available transportation options in an environmental scan of the respite services landscape.

Oklahoma Lifespan Respite Program's Mobile Respite Program

To overcome transportation barriers in rural isolated areas of Oklahoma, the state Lifespan Respite initiative funded a mobile respite program. The **Mobile Respite Program** is designed to bring respite services, staff and materials to new locations across Oklahoma and to provide respite for full time caregivers in an existing respite program. A vehicle that had been used for the Federal Transit Administration's Section 5310 transportation program was released for use to the state's Lifespan Respite Program. The van was then provided to the Mobile Respite Program. The van may be kept by the local grantee to ensure sustainability of the program once funding ends.

- Identifying and drawing attention to transportation service gaps as they relate to respite
- Developing training materials for family caregivers, respite providers, volunteers, and peer mentors on strategies and resources to best access transportation options for respite services
- Sharing information on best practices in overcoming respite transportation issues.
- Identifying possible funding sources and sustainability plans to ensure inclusion of transportation services or strategies when necessary in development of respite programs
- Partnering with state agencies or community-based organizations to develop new strategies for overcoming respite barriers related to transportation. See description of the Oklahoma Lifespan Respite Program's partnership with state transportation authorities to develop a mobile respite program.

Conclusion

Reliable, accessible and affordable transportation services can be critical to the successful receipt of respite care regardless of whether it is provided inside or outside the home of the caregiver. Through ensuring that transportation needs are addressed in the respite care planning process, caregivers and respite care providers work together to assure the needed respite care happens. Through advocating for transportation options that meet the needs of individuals with disabilities across the lifespan, caregivers, respite care volunteers/workers, and respite care providers, state respite coalitions and lifespan respite care programs promote further use of respite care. And through work at the local, regional, and state level, transportation barriers can be replaced with transportation solutions.

Resources

The following resources may be helpful to State Respite Coalitions, Lifespan Respite Programs, respite providers, respite recipients, and their family caregivers.

Administration on Aging AAA Directory

http://www.aoa.gov/AoA_programs/OAA/How_To_Find/Agencies/find_agencies.aspx

To locate a State and/or Area Agency on Aging (AAA) start by clicking the state on the map or select the state from the drop down list. State and/or Area Agencies on Aging may be able to refer you to transportation providers in your area.

Aging and Disability Resource Center Locator

<http://www.adrc-tae.org/tiki-index.php?page=ADRCLocator>

If you are looking for information or assistance with long-term services and supports for yourself or for a friend or family member, you can use the map on this website to locate the Aging and Disability Resource Center (ADRC) nearest you.

ALLIANCE National Parent Technical Assistance Center (NPTAC) Directory

<http://www.parentcenternetwork.org/parentcenterlisting.html>

Parent Centers provide training, information and assistance to families of children with all disabilities ages birth to 26 years and the professionals who work with them. This link brings you to a directory of Parent Centers listed by state.

Beverly Foundation

www.beverlyfoundation.org

The Beverly Foundation's mission is to foster new ideas and options to enhance mobility and transportation for older adults. They offer a number of excellent resources related to volunteer driver programs. **The Turnkey Kit** is a free, practical, "how to" technical assistance tool for organizations and agencies who are ready to plan and implement user friendly, convenient, and economical transportation services for older adults who are unable to use standard public transportation alternatives. The kit includes materials that can be downloaded to assist not only in planning and implementation of a service, but also to help with evaluation of planned or existing programs.

Centers for Independent Living Centers Directory

<http://www.ilru.org/html/publications/directory/index.html>

The term "center for independent living" means a consumer controlled, community based, cross disability, nonresidential private nonprofit agency that is designed and operated within a local community by individuals with disabilities and provides an array of independent living services. This directory lists Centers for Independent Living by state. Your local Center for Independent Living may be able to refer you to transportation resources in your area.

Easter Seals Project ACTION

www.projectaction.org

Easter Seals Project ACTION promotes universal access to transportation for people with disabilities under federal law and beyond by partnering with transportation providers, the disability community and others through the provision of training, technical assistance, applied research, outreach and communication.

Eldercare Locator

<http://www.eldercare.gov>

The Eldercare Locator, a public service of the U.S. Administration on Aging, connects you to services for older adults and their families. You can also reach the Eldercare Locator at 1-800-677-1116. This is another good place to go to find out more about transportation services for older adults in your area.

ITN America

www.itnamerica.org

The mission of ITN America is to support sustainable, community-based transportation services for seniors throughout the world by building a senior transportation network through research, policy analysis and education, and by promoting lifelong safety and mobility. ITN provides rides with door-to-door, arm-through-arm service to thousands of seniors nationwide. Its unique programs allow older people to trade their own cars to pay for rides, and enable volunteer drivers to store transportation credits for their own future transportation needs.

MAP-21

<http://www.fta.dot.gov/map21>

MAP- 21 is the authorizing legislation that provides funding for transportation including funding for public transit and transportation services for people with disabilities and older adults that go beyond the requirements of the Americans with Disabilities Act (ADA). You can also sign up for updates on MAP-21 from the Federal Transit Administration on this website.

Metropolitan Planning Organization Search

<http://www.planning.dot.gov/mpo.asp>

Federal transportation legislation requires that a Metropolitan Planning Organization (MPO) be designated for each urbanized area with a population of more than 50,000 people in order to carry out the metropolitan transportation planning process, as a condition of Federal aid. This search page will help you find your local MPO. Your local MPO can help you learn more about opportunities to get involved in transportation planning, human services transportation coordination, funding opportunities, and transportation resources in your area.

National Center on Senior Transportation

http://seniortransportation.easterseals.com/site/PageServer?pagename=NCST2_homepage

The National Center on Senior Transportation's mission is to increase transportation options for older adults and enhance their ability to live more independently within their communities throughout the United States. The Center includes on its website a guidebook for family caregivers, *Transportation Solutions for Caregivers: A Starting Point*, and related training materials http://seniortransportation.easterseals.com/site/PageServer?pagename=NCST2_tsc_toolkithome

National Resource Center for Human Service Transportation Coordination

<http://web1.ctaa.org/webmodules/webarticles/anmviewer.asp?a=8>

The fundamental purpose of the National Resource Center for Human Service Transportation Coordination is to provide states and communities with the support they need to better integrate public transportation services with the services and demands of their human services networks.

State Transportation Association Directory

<http://web1.ctaa.org/webmodules/webarticles/anmviewer.asp?a=256>

Many of the most important decisions about public and community transportation are made at the state level. State departments of transportation administer most public transit grant programs, and often offer training and technical assistance, as well. State transit associations are among the most important resources for information, advocacy, training and assistance in the ongoing improvement of community transportation.

United Way 211 Call Center

<http://www.211.org>

2-1-1 provides free and confidential information and referral. Call 2-1-1 for help with transportation, food, housing, employment, health care, counseling and more. Learn more about your local 2-1-1 by looking it up on this website.

Veterans Transportation and Community Living Initiative

http://www.fta.dot.gov/grants/13094_13528.html

The Federal Transit Administration (FTA) awards competitive grants to help veterans, military families, and others connect to jobs and services in their communities by improving access to local transportation options. All funded projects are displayed, with descriptions, on the map on this web page based on the location of service.

Veterans Transportation Resources

<http://web1.ctaa.org/webmodules/webarticles/anmviewer.asp?a=2693>

The National Resource Center for Human Service Transportation Coordination has a web page devoted to transportation resources for veterans.

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Easter Seals Transportation Group promotes universal access to transportation for people with disabilities and older adults under federal law and beyond by partnering with transportation providers, the disability community, and others through the provision of training, technical assistance, applied research, and outreach and communication.

Easter Seals is the leading non-profit provider of services for individuals with autism, developmental disabilities, physical disabilities and other special needs. For more than 90 years, Easter Seals has been offering help and hope to children and adults living with disabilities, and to the families who love them. Through therapy, training, education and support services, Easter Seals creates life-changing solutions so that people with disabilities can live, learn, work and play. Support children and adults with disabilities at www.easterseals.com.

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