

Caregivers and Transportation

NADTC’s Transportation Diversity, Equity and Inclusion (DEI) Initiative began in 2020 and collected information to identify transportation needs of older adults, younger adults with disabilities from historically marginalized and underserved communities and their caregivers; identify promising practices and education; and provide guidance and support for communities and providers. This Equity Brief centers on learnings derived from the DEI Initiative about the role of caregivers from marginalized communities, gathered as part of the 2021 Transportation DEI Survey as well as focus groups and stakeholder meetings held in 2022.

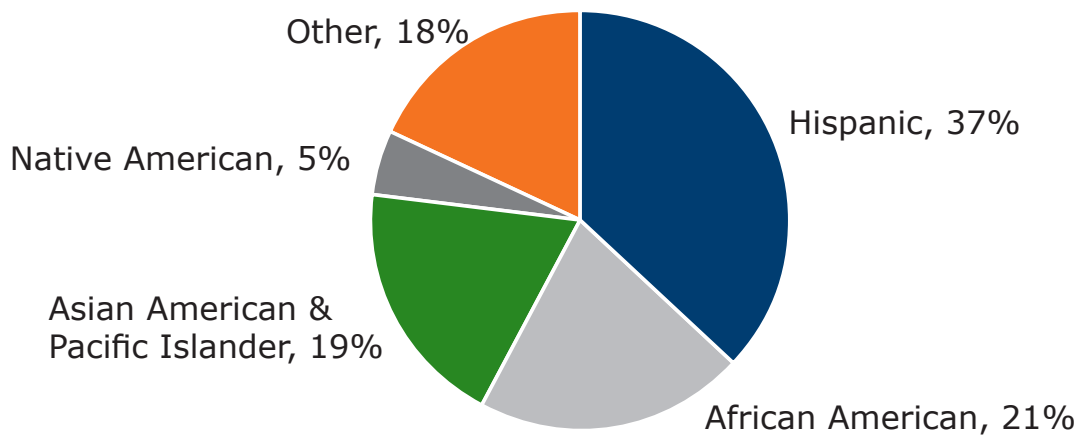


Providing or arranging transportation is often a responsibility for family caregivers, who often are family members or friends who provide unpaid care to assist their loved ones to live independently in the community. Caregivers play a critical role in helping older adults and younger adults with disabilities live well in their homes and communities, and nearly one in five adults in the U.S. provides unpaid care to an adult with health or functional needs.¹ As Former First Lady Rosalynn Carter said, “There are only four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need a caregiver.”² Yet despite their important and life-sustaining role, caregivers are too often undervalued or ignored.

Family caregivers typically take on their role by necessity. Someone they love or know may no longer be able to adequately dress, bathe, or eat without help, or simply be unable to get to the places they need and want to go. Caregivers often become the lifeline to socialization and community for an older adult or younger adult with a disability. Without a caregiver’s support to access health care and other needed services, many who receive care would become isolated and at risk of failing health. However, being a caregiver can be physically and emotionally demanding and can lead to negative health consequences for long-time caregivers.

According to the *Caregiving in the U.S. 2020*³ report from National Alliance for Caregiving and AARP, family caregivers from historically marginalized communities and are on average between 43 and 49 years old. Many of them are also employed: Asian American and Hispanic caregivers work approximately 36.7 hours per week while African American caregivers average 37.5 hours of work each week. More than non-Hispanic whites and Asian American caregivers, African American and Hispanic caregivers feel that their caregiving role gives them a sense of purpose or meaning in life. African American caregivers are more likely to experience financial impacts as a result of providing care.⁴

NADTC 2021 Transportation DEI Survey Percentage Respondents by Race/Ethnicity



The family caregivers who responded to NADTC’s 2021 survey reported that transportation is a major responsibility, with about 80 percent reporting that they provide rides for the people for whom they care. More than 40 percent of older adults and younger adults with disabilities rely on family, friends and neighbors for rides.

Transportation Options for Older Adults and Younger Adults with Disabilities

Transportation is closely tied to independence. Many older adults fear losing their independence when faced with giving up their car keys, so making the decision to no longer drive can be heart-wrenching for older adults and their families. Still, the primary way older adults and younger adults with disabilities travel is by car. In fact, there may not be another option or limited options for helping older adults and younger adults with disabilities reach needed destinations, so family caregivers are critical for transportation to health care appointments, jobs, grocery stores, day programs and social outings.

Many older adults and younger adults with disabilities from marginalized communities who responded to the NADTC survey rated the transportation in their households “not good” or “poor.” It is also worth noting that households headed by people of color overall are less likely than white households to have access to a vehicle in both highly urbanized

and rural states.⁵ About 40 percent of caregivers arrange transportation rather than, or in addition to, providing rides themselves. As described by focus group participants, other caregivers may choose *not* to drive under certain circumstances, such as being unable to find parking close enough to the destination or concern about traffic in an unfamiliar area. Older family caregivers or those living in rural areas, for example, may be uncomfortable driving in the city.

Community transportation options—from fixed route buses and demand-response paratransit to human service transportation, transportation network companies (TNCs) and volunteer services—often are needed to help family caregivers ensure older adults and younger adults with disabilities have transportation to and from appointments. However, 84 percent of caregiver survey respondents indicated that it would be “mildly” to “very difficult” to find alternative transportation. This may be due to a lack of community transportation services that meet the needs of the person for whom they provide care or because they are unaware of the transportation options available.

It is critical to recognize that underserved and marginalized populations face unique challenges in accessing transportation. The older adults, people with disabilities and family caregivers who participated in NADTC’s focus groups identified several transportation inequities that they have encountered, including frustration getting to adjoining jurisdictions, having to schedule rides too far in advance, lack of availability of long-distance trips and transportation costs. Providing transportation can be cost prohibitive. Even though many family caregivers are working, they still may have difficulty helping their loved one pay for transportation needs. Furthermore, dealing with discrimination based on race, immigration status or sexual orientation, as some focus group participants reported, can impact the caregiver’s willingness to use available transportation services.

Lack of Awareness of Transportation Options

Because older adults and younger adults with disabilities may have never used transportation services, they and their family caregivers frequently do not know all the options available in their area. Additionally, they may not know where to turn to learn about transportation services.

Transportation providers and those who work in transportation are familiar with eligibility requirements, fare reductions based on age or disability, ADA regulations, Title VI, service boundaries, fixed route vs. demand-response vs. on-demand, Medicaid NEMT and more. But to older adults, younger adults with disabilities and caregivers, these terms sound like restrictions that prevent them from getting where they need and want to go. When considering older adults, younger adults with disabilities and caregivers from marginalized communities, the restrictions can be an even greater challenge to overcome.

Educating the public is essential to ensuring that underserved and underrepresented populations receive the services they need and deserve. In fact, a family caregiver in

one focus group expressed her desire for training about various transportation options so she can help the people for whom she provides care choose the best option. Since there may not be a single place where consumers can find transportation information, many different community organizations—including transportation providers, mobility managers, travel trainers, Area Agencies on Aging, Centers for Independent Living, Aging and Disability Resource Centers, senior centers, libraries, health care programs and facilities, and even places of worship—can play a role in disseminating transportation information.

Travel Training and Engaging Caregivers

During NADTC's stakeholder meetings, transportation providers spoke about travel training as a vehicle for outreach, education, relationship building in the community and including caregivers as partners. Travel training offers comprehensive instruction designed to give new riders the confidence they need to travel safely and independently on public transportation. Since family caregivers have a close relationship with older adults and younger adults with disabilities, equipping them with knowledge may help ease access barriers for many riders, enabling caregivers to assist their loved ones with using available transportation services.

A stakeholder meeting participant and general manager of Denver Regional Mobility Access Council pointed out that her travel training program educates family caregivers and the riders for whom they care about options for multi-modal transportation. She reviews bus routes to see if there is another route or service that would get them closer to home or their destination. As a former caregiver, she understands the importance of including caregivers in the travel training process to ensure riders are safe.

Why Providers Should Work with Caregivers

While travel training with family caregivers may be a conduit to someone who needs to learn and use transportation, there is another benefit for providers of working with caregivers: caregivers can become transportation information partners. Because they often arrange transportation or manage issues with scheduling transportation on behalf of the people for whom they care, family caregivers can identify riders' mobility issues and specialized needs. One caregiver in the NADTC focus groups pointed out that older adults with health concerns may have difficulty using transportation services because of wait times or long rides. However, a family caregiver can make sure the provider is aware of rider needs, making it more likely that an accommodation will be made.

In addition, when providers design or revise transportation programs for older adults and younger adults with disabilities, family caregivers should be included in planning committees, program pilots and evaluation. This is especially true for caregivers from marginalized and underserved communities, many of whom live in areas that have

experienced decades of community neglect, disinvestment and lack of opportunities for engagement and inclusion. It is important not to assume what barriers exist for individual riders. Instead, explore how riders' experiences might be impacted by their race, ethnicity, culture, sexual orientation or other personal characteristics. Caregivers can offer valuable insight into how their loved one is impacted by scheduling, driver relationships, accessibility, transportation policies and affordability of the service. One family caregiver who participated in the NADTC focus groups was frustrated by a policy in her community requiring caregivers to not only ride with the people for whom they care but to pay for the ride as well.

Transportation providers should consider focusing outreach directly to caregivers, especially caregivers from marginalized communities, through the spaces and places they are most likely to frequent. For example, worship settings have served as a central aspect of community among African Americans for centuries and could provide an inroad for reaching and engaging family caregivers and promoting local transportation services that would especially benefit caregiver parishioners and the people for whom they care. Overall, intentional efforts to be more inclusive in program development can advance transportation services and result in a more equitable service for all older adults and younger adults with disabilities, especially those who historically have been underserved.

Resources on Caregiving

Transportation Needs and Assessment of Diverse Older Adults, Younger Adults with Disabilities and Caregivers, Sept. 1, 2021, National Aging and Disability Transportation Center, www.nadtc.org/wp-content/uploads/NADTC-Transportation-Presentation-long.pdf.

Webinar: Transportation Needs and Assessment, Feb. 14, 2019, National Aging and Disability Transportation Center, www.nadtc.org/resources-publications/resource/nadtc-national-poll-webinar-transportation-needs-and-assessment.

Dementia, Caregiving and Transportation, January 2018, National Aging and Disability Transportation Center, www.nadtc.org/wp-content/uploads/Dementia_Caregiving_and_Transportation.pdf.

Caregiver Needed: How the Nation's Workforce Shortages Make it Harder to Age Well at Home—Data from Area Agencies on Aging, 2022, USAging www.usaging.org/Files/Workforce-Issues_508.pdf.

Community Care Corps, a national program of the U.S. Administration for Community Living (ACL), cooperatively operated by the Oasis Institute, Caregiver Action Network (CAN), USAging and Altarum Institute to foster innovative local models in which volunteers assist family caregivers, older adults, and adults with disabilities with nonmedical care to maintain their independence.
<https://www.communitycarecorps.org/about>

References

USAgging, Caregiver Needed: How the Nation's Workforce Shortages Make it Harder to Age Well at Home, 2022, www.usaging.org/Files/Workforce-Issues_508.pdf.

National Alliance for Caregiving and AARP, Caregiving in the U.S. 2020, www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf.

National Equity Atlas, www.nationalequityatlas.org/indicators/Car_access#.

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Endnotes

1 <https://www.caregiving.org/research/caregiving-in-the-us/caregiving-in-the-us-2020/>

2 USAgging, Caregiver Needed: How the Nation's Workforce Shortages Make it Harder to Age Well at Home, 2022, https://www.usaging.org/Files/Workforce-Issues_508.pdf.

3 <https://www.caregiving.org/research/caregiving-in-the-us/caregiving-in-the-us-2020/>

4 Caregiving in the U.S. 2020

5 National Equity Analysis, https://nationalequityatlas.org/indicators/Car_access#/



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Who We Are

Established in 2015, the NADTC is a federally funded technical assistance center administered by Easterseals and USAging based in Washington, DC.

The **National Aging and Disability Transportation Center** is funded through a cooperative agreement of Easterseals, USAging, and the U.S Department of Transportation, Federal Transit Administration, with guidance from the U.S. Department of Health and Human Services, Administration for Community Living.

USAgings is the national association representing and supporting the network of Area Agencies on Aging and advocating for the Title VI Native American Aging Programs. Our members help older adults and people with disabilities live with optimal health, well-being, independence and dignity in their homes and communities. USAging and our members work to improve the quality of life and health of older adults and people with disabilities, including supporting people with chronic illness, people living with dementia, family caregivers and others who want to age well at home and in the community. Together, we are ensuring that all people can age well. Our members are the local leaders that develop, coordinate and deliver a wide range of home and community-based services, including information and referral/assistance, case management, home-delivered and congregate meals, in-home services, caregiver supports, transportation, evidence-based health and wellness programs, long-term care ombudsman programs and more. www.usaging.org

Easterseals is leading the way to full equity, inclusion, and access through life-changing disability and community services. For more than 100 years, we have worked tirelessly with our partners to enhance quality of life and expand local access to healthcare, education, and employment opportunities. And we won't rest until every one of us is valued, respected, and accepted. Through our national network of affiliates, Easterseals provides essential services and on-the-ground supports to more than 1.5 million people each year — from early childhood programs for the critical first five years, to autism services, to medical rehabilitation and employment programs, to veterans' services, and more. Our public education, policy, and advocacy initiatives positively shape perceptions and address the urgent and evolving needs of the one in four Americans living with disabilities today. Together, we're empowering people with disabilities, families and communities to be full and equal participants in society. www.easterseals.com