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Transportation challenges for persons aging with mobility disability: Qualitative insights and policy implications



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ABSTRACT

Background: Persons aging with mobility disability (PAwMD) experience transportation barriers, which can hinder their ability to fully participate in society. Despite a vast infrastructure of federal laws and programs designed to ensure access to transportation, PAwMD remain a transportation-disadvantaged population.

Objectives: This paper presents detailed insights on transportation challenges experienced by PAwMD along with recent Federal programmatic initiatives designed to enhance access and mobility for transportation for older adults and people with disabilities. To identify policy gaps and opportunities to improve transportation services, we compared individual-level challenges from PAwMD to national survey data about barriers associated with delivering transportation services at state and local levels.

Methods: To assess individual-level transportation challenges, we conducted in-depth, structured interviews with sixty older adult participants with self-identified mobility disabilities for at least 10 years. We also conducted a content analysis of end-user transportation challenges and agency-level transportation coordination barriers to identify correspondences.

Results: Participants reported challenges utilizing public and private modes of transportation, related to availability; accessibility; safety; advanced planning; as well as societal attitudes. Barriers to the availability, delivery, and coordination of access and mobility services are linked directly or indirectly to the PAwMD reports of experiencing a shortage of accessible transportation options.

Conclusions: Findings highlight the complexity of federal transportation policies and programmatic initiatives designed to support older adults and people with disabilities, which contribute to implementation barriers and transportation challenges. Results highlight the importance of integrating end-user and state and local provider input into transportation policy development and program implementation.

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Participation is defined as "involvement in life situations" by the World Health Organization *International Classification of Functioning, Disability and Health* (ICF) model, and is an important component of health and quality of life for people with disabilities.^{1,2} Transportation plays a vital role for all people to facilitate participation in community-based activities, including those that are essential (e.g., healthcare, shopping) as well as desired (e.g., entertainment, recreation). An estimated 11.2 million older Americans (age 65+) have travel-limiting disabilities that make it difficult to leave home.³ Mobility disability is the most prevalent type of disability among older Americans, affecting over 15% of older adults

(ages 65–74), 26% of those ages 75–85, and 48% of those ages 85+.⁴ Many older adults with mobility disabilities lack access to adequate transportation, which can hinder their ability to fully participate in society.^{5,6}

Older Americans with mobility disabilities rely on personal vehicles, as drivers or passengers, for the vast majority of trips, with low utilization of local public transit, paratransit, or ‘other’ transit, such as taxis and rideshare.^{3,5} Low use of public transportation among older adults with mobility disabilities has been attributed to issues including: difficulty walking; inaccessible vehicles and facilities; restricted services; affordability; and availability, particularly in rural areas.^{5,7–9} Less is known about the factors contributing to low use of private taxi and rideshare services among this population. Despite a great dependence on personal vehicles among older adults with mobility disabilities, availability, affordability, and sustainability issues are common.⁵ Transportation challenges have the potential to be greater and more complex for older adults with long-term mobility disabilities, who are subject to unique circumstances at the intersection of aging and disability.

Persons aging with mobility disability (PAwMD)

Among older adults with mobility disabilities, a substantial number live with disabilities acquired in early to mid-life, and thus are ‘aging with disability’.¹⁰ This term has traditionally been used to refer to adults with lifelong and early onset of physically disabling conditions such as cerebral palsy, multiple sclerosis, and spinal cord injury, who are now in mid- or later life.^{11,12} However, with increased longevity, the concept and prevalence of ‘aging with disability’ can be expanded to include adults who acquire mobility disabilities in mid-to later-life due to disease, injury, and the cumulative effect of age-related and degenerative health conditions.^{13,14} Herein we refer to these two groups of individuals collectively as “persons aging with mobility disability” or PAwMD. National prevalence estimates of PAwMD are unknown due to gaps in national health surveillance systems using different measures of disability and failing to capture disability onset age or duration.^{15,16}

PAwMD are likely to experience secondary conditions related to their underlying impairment (e.g., pain, fatigue, depression; 12,17–19) as well as normative, age-related health conditions (e.g., hypertension, diabetes, arthritis, hearing loss, cognitive decline), which may occur either at earlier ages and/or have greater impact on quality of life compared to their non-disabled counterparts.^{17–21} Given the complex interaction between long-term mobility disability and aging, many PAwMD experience barriers in performing everyday activities.^{22,23} Socioeconomic disadvantages, such as lower income, higher unemployment, and less healthcare access, can further complicate the ability of PAwMD to live independently and participate in their communities.^{5,24} Collectively, these factors likely contribute to PAwMD being at increased risk of experiencing transportation barriers. More research is needed to understand the specific issues these individuals experience using various modes of public and private transportation.

Key elements of U.S. Legislative policy and programmatic initiatives regarding transportation for older adults and people with disabilities

To understand transportation challenges experienced by PAwMD, it is important to place them within the broader context of key federal civil rights legislation and program initiatives aimed at ensuring transportation access. Within the U.S., Section 504 of the Rehabilitation Act of 1973 (hereafter the Rehab Act), as amended, and the Americans with Disabilities Act (ADA, 1990), are seminal

acts that serve as the policy and legal framework for ensuring the rights of people with disability across all federal programs.^{25,26} Specifically, the Rehab Act ensured the right to protection against discrimination by reason of disability under any U.S. Department of Transportation (DOT)-conducted or funded program. The ADA clarified and expanded the Rehab Act by: 1) extending protection from discrimination to *all* public entities that provide transportation services, *whether or not they receive federal financial assistance*; 2) expanding the types of transportation systems covered; and 3) broadening the reach of accessibility requirements.

Comprehensive federal initiatives to implement the assurances of the Rehab Act and the ADA at state and local levels have lagged far behind. The Fixing America's Surface Transportation (FAST) Act (Pub. L. 114-94;²⁷), or FAST Act, signed into law in 2015, was the first federal legislation in over a decade to provide predictable and long-term funding (FY16– FY20) for infrastructure planning *and* investment to address the lack of access to reliable transportation experienced by millions of “transportation-disadvantaged” Americans, including older adults, people with disabilities, and low-income individuals.

Table 1 provides an overview of three key programmatic provisions of the broader FAST Act directly focused on improving access and mobility for people with disabilities and older adults at state and local levels, along with examples of specific initiatives. The first two consist of 1) the [Pilot Program for Innovative Coordinated Access and Mobility](#) (ICAM Pilot Program), a discretionary grant program available to state and local agencies and service providers aimed at improving coordination of transportation services, including non-emergency medical transportation services²⁸; and 2) the [Enhanced Mobility of Seniors & People with Disabilities Program](#), a formula grant program available to states and tribal organizations for projects to assist private nonprofit groups with removing transportation service barriers and expanding mobility options.²⁹ The third key FAST Act provision is the Interagency Coordinating Council on Access and Mobility (CCAM) to provide a coordinating infrastructure to implement activities and issue policy recommendations that support transportation disadvantaged populations.

Despite the assurances of the Rehab Act and the ADA and the complex array of innovative programs and initiatives funded under the FAST Act, older adults and people with disabilities, particularly PAwMD, remain transportation-disadvantaged. This ongoing disparity is likely fueled by barriers to coordinating and implementing transportation programs and services at state and local levels. Specific barriers identified from focus groups and a nationwide survey on transportation coordination were included in the CCAM September 2020 Report to the President.³⁰ There is a need to understand more about the relationship between these barriers and the specific transportation challenges experienced by PAwMD.

ACCESS study

The Aging Concerns, Challenges, and Everyday Solution Strategies study (hereafter ACCESS) is a mixed-method investigation of user needs for PAwMD that offers a unique opportunity to explore the lived experiences of transportation challenges, across both public and private modes.³¹ Covering a broad range of everyday activities, including transportation, the ACCESS interview obtained PAwMD detailed insights about task performance challenges as well as their strategies for responding to these challenges. ACCESS data collection occurred in 2015–2019, overlapping with timing of the FAST Act transportation provisions described here.

Table 1

Fixing America's surface transportation (FAST) Act of 2015 – key provisions and examples of program initiatives aimed at improving access and mobility for people with disabilities and older adults.

Overview of Key Provisions	Examples of Program Initiatives
<p>1. ICAM Pilot Discretionary Grant Program to Improve Coordination: Section 3006 (b), under Title III Public Transportation of the FAST Act, created the Pilot Program for Innovative Coordinated Access and Mobility (ICAM Pilot Program) administered by the Federal Transit Administration (FTA). Purpose: assist in financing innovative projects for the transportation disadvantaged that improve the coordination of transportation services and non-emergency medical transportation (NEMT) services, such as deployment of coordinated technology projects. Requirements: All ICAM discretionary grant funds must be used for capital-only projects. Funding: levels ranged from \$3.5 million to \$7.3 million across fiscal years FY 2016 to FY 2020.</p>	<p>Rides to Wellness Demonstration and Innovative Coordinated Access and Mobility Grants. Goal: foster local partnerships between health, transportation, and home and community-based services and test promising practices to support increased access to care, improved health outcomes and reduced costs. Eligible Activities: mobility management; health and transportation provider partnerships; technology. Result: 11 projects funded totaling \$7.2 million. For a listing see: FY2016 Rides to Wellness Demonstration Grants. Access and Mobility Partnership Grants Goal: foster transit coordination projects that improve access to healthcare. Eligible Activities: innovative coordinated access and mobility projects that improve transportation services and NEMT. Result: 23 projects were funded for a total of \$7.4 million across FY 2016 through FY 2019. For a listing see: Grants FY2019 Project Selections. Mobility for All Pilot Program Goal: improve mobility options and access to community services for transportation disadvantaged populations by funding projects that enhance connections to job, education and health services. Eligible Activities: mobility management strategies, vehicle purchase, IT purchase, leasing equipment or a facility for use in public transportation etc. Result: 17 projects were funded with \$3.5 million in FY 2019 and FY 2020. For a listing see: FY2020 Mobility for All Selections.</p>
<p>2. Enhanced Mobility of Seniors & Individuals with Disabilities (5310) Formula Grants to States: U.S.C. Section 5310 Reauthorized Under/Section 3006 of the FAST Act. Purpose: provide formula grants to states to assist private nonprofit groups in meeting the transportation needs of older adults and people with disabilities when the transportation service provided is unavailable, insufficient, or inappropriate to meeting these needs. Goal: improve mobility for seniors and individuals with disabilities by removing barriers to transportation service and expanding transportation mobility options. Funding: Funds Awarded: ranged from \$258.3 million to \$285.6 million across FY 2016 to FY 2020. Funds are apportioned based on each state's share of the population for these two targeted groups (older adults and people with disabilities) and varies based on rural or urban areas Matching Funds can come from other Federal (non-DOT) funds, which can allow local communities to implement programs with 100% federal funding (e.g. Older Americans Act (OAA) Title IIIB Supportive Services Funds)</p>	<p>Traditional Investments: At least 50% of recipient funds must be used on capital or "traditional" 5310 projects. For example: buses and vans; wheelchair lifts, ramps, and securement devices; information technology systems, including scheduling/routing; mobility management programs; acquisition of para-transportation services under a contract or lease, both capital and operating costs, including user-side subsidies. Nontraditional Investments: The remaining 45% of recipient funds is for other "nontraditional" projects beyond those required by the ADA, designed to assist individuals with disabilities and seniors. Examples include: Travel training; volunteer driver programs; accessible paths to bus stops (e.g., curb-cuts, sidewalks); improved signage and wayfinding technology; same day or door-to-door service; vehicle purchases to support accessible taxis, rides sharing and/or vanpooling programs; and mobility management. Examples of Innovative Tools Created with Section 5310 Funds: A New Engagement Resource for Mobility Managers: The Inclusive Walk Audit Facilitator's Guide, Minnesota Department of Health (MDH). Purpose: assist mobility managers in bringing together people with mobility challenges and government officials to identify solutions to walkability issues; and assess how well pilot transportation improvements are working. NCMM Framework to Develop a Continuum of Mobility Services. Purpose: help mobility management professionals identify potential transportation services that can be included in a continuum of mobility services to ensure safe, reliable, and accessible transportation options; and identify public and private funding sources; and support continuous evaluation. Inventory of Federal Programs Providing Transportation Services to the Transportation-Disadvantaged Select Research Reports and Products Pilot Program for Innovative Coordinated Access and Mobility Grants (FY2018 Report to Congress). CCAM Strategic Plan 2019–2022. Barriers and Solutions to Complete Trips for All National Online Dialogue (2019). Public Transportation: Enhanced Federal Information Sharing on Coordination Could Improve Rural Transit Services (Report to the U.S Government Accountability Office, 2020). CCAM Report to the President (September 2020). CCAM-Funded National Resource Centers: National Center for Mobility Management (NCMM). Primary activities support mobility management professionals, Federal Transit Administration (FTA) grantees, and partners in adopting proven, sustainable, and replicable strategies that achieve its mission to advance good health, economic vitality, self-sufficiency, and community. Since 2015 NCMM has provided community grants that increase partnerships and breakdown silos (see: https://nationalcenterformobilitymanagement.org/grants/community_grants/) National Aging and Disability Transportation Center (NADTC), since 2017 has provided grants to support communities to assess their transportation needs and develop and implement innovations and new models for increasing availability of accessible transportation services for older adults and people with disabilities. To view the grants funded visit: https://www.nadtc.org/grants-funding/nadtc-grant-opportunities/nadtc-awarded-grants/.</p>
<p>3. Interagency Coordinating Council on Access and Mobility (CCAM) - incorporated and funded in the FAST Act; initially established in 2004 through Executive Order 13,330: Human Service Transportation Coordination. Purpose: undertake interagency efforts to help implement requirements of Sections 3006(b) and 5310 (described above) to improve the availability, accessibility, and efficiency of transportation and to support States and communities in assessing needs and developing innovative transportation solutions. Mission: issue policy recommendations and implement activities that improve the availability, accessibility, and efficiency of transportation for targeted populations (i.e., older adults, people with disabilities, individual with low incomes, and rural populations). CCAM Membership: Departments of Transportation, Health and Human Services, Agriculture, Education, Housing and Urban Development, Interior, Justice, Labor, Veteran Affairs, National Council on Disability, and Social Security Administration.</p>	

Objectives

To understand potential gaps in policy, as related to personal experiences, we interdigitated the micro-data on transportation challenges reported by PAwMD from ACCESS with U.S. transportation policies and initiatives designed to support this population. Specific research questions included:

RQ1) How do key barriers experienced by state and local providers in implementing and coordinating transportation services for older adults, people with disabilities, and individuals with low income compare to transportation challenges reported by ACCESS PAwMD?

RQ2) How can insights on transportation challenges among ACCESS PAwMD highlight gaps in current government policies and programs as well as point to new opportunities to improve transportation services?

Method

ACCESS overview

ACCESS comprised self-report questionnaires and a structured interview assessing challenges with a broad range of everyday activities, as well as responses to those challenges.^{31,32} The ACCESS study included 180 individuals with long-term disabilities, including 60 in each group: vision, hearing, mobility. The focus here is the mobility disability group ($N = 60$). This study was conducted at the University of Illinois Urbana-Champaign and the Georgia Institute of Technology with Institutional Review Board approval from each university. Participants were compensated \$30.

Participants. ACCESS participants were 60–79 years old; self-identified as having a mobility disability (serious difficulty walking or climbing stairs) that began prior to age 50; fluent in English; and resided in the U.S. Participants were recruited through local and national disability organizations, flyers, social media posts, participant registries, and word-of-mouth referrals.

Procedures. Participants completed questionnaires assessing demographics, health, and characteristics of their mobility disability.^{23,32} Structured interviews lasted 60–90 min and covered six broad activity categories, including outside the home, around the home; shopping/finance; transportation; health; and basic activities. Participants rated their difficulty with specific activities, using a 3-point scale. For their 'most difficult' activities, participants answered open-ended follow-up questions probing for the specific challenges they experienced and how they managed them (e.g., assistance from others, use of tools, own methods).

Data analysis

ACCESS Data. This paper is focused on identifying challenges related to transportation activities, including: arranging transportation via taxi, Uber or Lyft; driving; getting a ride from a friend or family member; and taking a bus. Our analysis focused on transportation systems and modes for local community participation relevant to U.S. policy (thus excluding flying, walking, way-finding). Although we did not explicitly ask about paratransit, paratransit challenges emerged in the interviews and are reported here as a distinct mode to convey unique challenges.

Transportation challenges were identified through a review of participants' responses to select interview questions, including those assessing: 1) challenges and response strategies for their 'most difficult' transportation activity; 2) satisfaction with transportation overall, and 3) difficulty ratings for all transportation activities. Drawing on our general coding scheme,³³ we reviewed

all 'transportation challenge' code segments related to community-based activities in ACCESS (e.g., entertainment; healthcare; shopping).

Two researchers independently reviewed the interview segments and developed a list of distinct themes. Challenge themes were primarily derived from an existing ACCESS challenge coding scheme (e.g., safety, financial; 31,33). Additional themes were added to encapsulate specific challenges identified in the current review (e.g., societal attitudes). The full research team (the four authors) consulted to resolve discrepancies and refine challenge themes.

Policy Analysis. To identify provisions and program initiatives of the FAST Act (Table 1) we conducted extensive internet research on the FAST Act and U.S. Department of Transportation websites. We report top-ranked barriers to state and local transportation coordination for older adults, individuals with disabilities, and low-income persons, as reported in the 2020 CCAM Report to the President.³⁰ Data come from: 1) a DOT series of virtual and in-person focus groups conducted in 2018 including 200 transportation and human services stakeholders representing 22 states and funding recipients from CCAM agencies; and 2) a 2018 nationwide survey on transportation coordination best practices and barriers conducted by the National Center for Mobility Management. Respondents included 527 transportation and human services organization employees (public, private, nonprofit), across 47 states.

We then conducted a content analysis of the CCAM barrier descriptions (Table 2) and the contextual information provided about transportation challenges from ACCESS participants to identify correspondences. The research team compared key words and concepts between the agency-level transportation coordination barriers (CCAM) and consumer-level transportation challenges (ACCESS), respectively. Linkages were based on two criteria: 1) cause and effect relationships 2) and similar language or concepts.

Results

Sample description

The 60 community-dwelling participants had a mean age of 69 years ($SD = 54$), were mostly female (58%), and most had an education level of 'some college/associate's degree' or higher (85%). Race distribution was 87% White/Caucasian, 8% African American, and 3% Other; 2% declined to report. Annual household income was distributed as follows: 20% < \$25,000; 22% between \$25,000–49,999; 18% \$50,000 - \$74,999; and 32% > \$75,000; with 8% not reporting. Causes of mobility disabilities varied: 50% post-polio; 18% neurological (e.g., multiple sclerosis, cerebral palsy); 23% accident or event; 7% were congenital condition or abnormality (e.g., spina bifida), and 2% other (e.g., adverse drug reaction). Age of disability onset ranged from birth to age 45, with mean onset age of 19 years old ($SD = 16$) and a mean duration of 55 years ($SD = 15.4$). With regard to mobility aids, 57% of participants used power wheelchairs; 47% manual wheelchairs, 18% walkers, 17% canes, 13% scooters, and 13% crutches.

Participants reported if they had access to a variety of transportation modes, including a car they drive (71% had access); someone who drives them (51%); paratransit bus (48%); public bus (43%); public train or subway (32%); taxi service (30%); complimentary shuttle (10%). Most reported driving themselves (67%) as their primary mode of transportation. Other reported transportation modes were: riding with a friend or family member (12%); public transportation (e.g., subway, bus, 12%); other (e.g., paratransit, taxi; 8%); and residential facility transportation service (1%).

ACCESS: challenges with transportation activities

The qualitative analysis of participants' transportation challenges revealed several themes (Fig 1), including those related to: availability; accessibility; safety; physical limitations/health concerns/pain; financial limitations; advanced planning and waiting; as well as societal attitudes. Table 3 includes challenge themes and illustrative participant quotes.

Participants described challenges related to availability, or lack there-of, for all transportation activities except driving. Several individuals reported issues related to living in rural areas, where access to public transit as well as taxi and ride-share services such as Uber and Lyft are limited, if available. Other issues included not having access to family or friends who can provide rides and not knowing how to access paratransit services.

Specific accessibility issues included: transferring; steps and stairs; limited access to accessible vehicles; wheelchair access and storage; and lack of handicap accessible spaces. Transferring was only discussed as an issue for transportation activities involving cars. Several participants described needing assistance with car transfers and detailed how getting into vehicles with high seats, such as vans or SUVs, can be difficult to impossible. Steps and stairs were an accessibility issue for public transit. Many participants shared how they are unable to get into standard cars and thus rely on wheelchair accessible vehicles. Taxi and ride share services were desired, but unused, due to the lack of wheelchair accessible vehicles in operation. Several reported using a single wheelchair accessible vehicle, driven by themselves or a family member, as their sole mode of transportation. Wheelchair access and storage was a challenge for taking a bus, utilizing taxi and ride-share services, and getting a ride

from friends and family. Specific issues included limited car storage space and the cumbersome process of disassembling and reassembling wheelchairs. Limited availability of wheelchair accessible bus spaces and vehicle parking spaces was described as creating inconvenient, 'first come first served', circumstances.

Participants expressed safety concerns about their driving ability due to functional limitations, such as slow reflexes and limited dexterity. Experiences of injury and discomfort due to improper wheelchair securement on public buses and paratransit were also described. Participants reported challenges related to physical limitations (e.g., mobility, strength) as well as health concerns. The process of driving, particularly transferring in and out of the vehicle, was described by some as physically demanding and exhausting. Long-distance travel by car was reported as a rare event due to exceptional fatigue and slow travel time due to stops and transfers.

With the exception of getting a ride from friends and family, financial challenges related to cost and affordability were reported for all modes of transportation. Wheelchair accessible vehicles were described as 'prohibitively expensive', with regard to personal ownership as well as arranging rides via medical transport. Advanced planning and amount of waiting required was a reported challenge for getting a ride and utilizing paratransit. Participants described being at the mercy of someone else's schedule, which limits their ability to go places spontaneously, and expressed concerns about being a burden to others. Paratransit rules (e.g., advanced reservations, lengthy drop-off/pick up windows), constrained participants' ability and desire to use services.

Lastly, participants described instances where they encountered ableist attitudes among drivers and other passengers while using

Table 2
Interagency transportation coordinating council on access and mobility (CCAM) top 10 ranked barriers to coordination of state and local transportation services for three target populations of older adults, individuals with disabilities, and low-income persons based on state and local focus groups and a national survey of transportation and human services organization employees conducted in 2018.⁽¹⁾

CCAM Top Ranked Barriers to Local Transportation Coordination Rank	Barriers	Description of Barriers
1	Limited Awareness	A lack of awareness of the federal funding sources available for human service transportation, the policies that enable transportation coordination, and/or the community's transportation options for targeted populations
2	Unengaged Stakeholders	Challenges associated with establishing and maintaining the organizational and community partnerships necessary to pursue transportation coordination
3	Program Restrictions	Reporting obligations, eligibility criteria, trip purpose restrictions, and other program rules that make it difficult to coordinate across different transportation programs.
4	Insufficient Incentives	A lack of incentives or financial motivation for human service providers to pursue transportation coordination initiatives
5	Limited Federal Guidance	An absence of federal guidance that states and local communities need to coordinate transportation in compliance with federal law
6	Jurisdictional Boundaries	City, county, or other regional lines that define an organization's service area and prevent that organization from coordinating with other entities beyond the service area
7	Administrative Burden & Staff Shortages	Shortage of staff to handle the accounting obligations, logistical responsibilities, implementation work, and other administrative tasks that consume an excessive amount of time and resources Lack of time and staff Complexity of reporting and other administrative requirements related to providing transportation services.
8	Insufficient Data	A lack of the data that states and local communities need to increase the transparency of transportation spending, demonstrate the utility of transportation coordination, and allocate the costs of coordinated transportation equitably
9	Cost-Sharing Concerns	Lack of cost sharing arrangements and reimbursement combined with apprehension about sharing the costs of coordinated transportation across participating stakeholders in a way that is equitable and proportionate to the services received. Inability to secure local match funding.
10	Inaccessible Systems	Transportation vehicles and facilities that funding recipients cannot use for some coordination activities because they are inaccessible to people with functional limitations.

Note. Additional identified barriers from NCMM survey respondents beyond the top 10 included: Lack of time and/or staff; lack of available accessible transportation vehicles; lack of cost-sharing arrangements or reimbursement structures; inability to secure local match funding; complexity of reporting and other administrative requirements.

¹ Sources: A U.S. Department of Transportation series of focus groups conducted spring of 2018 with transportation and human services stakeholders on behalf of the Interagency Coordinating Council on Access and Mobility (CCAM) and a nationwide survey conducted by the National Center for Mobility Management (NCMM) as reported in the **CCAM Report to the President (September 2020)** In response to: Fixing America's Surface Transportation Act Section 3006(c)(4).

public buses and rideshare services. These attitudes, conveyed through remarks and/or body language (e.g., eye rolls), implied that wheelchair users should not be travelling independently.

Comparison of agency barriers and user challenges

Table 2 presents the top ten ranked barriers to coordination of state and local transportation services for older adults, individuals with disabilities, and low-income persons, as reported by agency and organizational representatives who participated in CCAM-sponsored focus groups or a national survey. At the top of the list is *Limited Awareness* of federal funding sources and policies that enable transportation coordination, followed by *Unengaged Stakeholders*, which includes difficulties establishing community partnerships; and *Program Restrictions*, referring to reporting obligations and restrictive rules. Additional barriers include: *Insufficient [financial] Incentives*; *Limited Federal Guidance*; *Jurisdictional Boundaries Among Cities, Counties and Regions*; *Administrative Burden and Staff Shortages*; *Insufficient Data to Demonstrate Utility*; *Concerns about Cost Sharing*; and *Inaccessible Systems*.

Fig. 2 displays the correspondence or lack of correspondence between barriers to coordination identified in the CCAM focus groups and national survey (Column A) and the transportation challenges reported by PAwMD in ACCESS (Column B). All the barriers in Column A corresponded directly or indirectly to ACCESS participants' reports of the *Shortage of Accessible Transportation Options*. The coordination barriers and personal challenges deemed to have direct links were as follows:

- A7: *Administrative Burden and Staff Shortages* and B6: *Amount of Advanced Planning and Waiting Required*;
- A9: *Concerns About Cost Sharing and Local Matching Funds* and B5: *Financial Costs/Affordability*; and
- A10: *Lack of Accessible Vehicles and Inaccessible Systems* with B1: *Shortage of Accessible Transportation Options* and B2: *Inaccessible Transportation Features*.

There were no apparent linkages between any of the ten coordination barriers and three of the end-user transportation challenges including *Safety*; *Physical Limitations and Health Concerns*; and *Societal Attitudes*.

Discussion

Given the complex interaction between long-term mobility disability and aging, PAwMD are likely to experience barriers to community participation, including transportation challenges, which can hinder their ability to participate in society. Our goal was to compare insights from PAwMD on their lived experiences of transportation challenges with relevant U.S. transportation policies and programs. We also explored how individual-level transportation challenges compared to organizational-level barriers to coordinating transportation services and programs for this population.

ACCESS findings demonstrate that many transportation barriers PAwMD experience were related to accessing modes of transportation that can safely and effectively accommodate mobility aids. With regard to public transportation, there is an apparent need to expand wheelchair seating availability and provide evidence-based best practices and wheelchair securement training for drivers. Additionally, training programs for public transit drivers designed to increase empathy and understanding of aging and disability populations could help address the ableist societal attitudes experienced by PAwMD.⁹ Although paratransit services are specifically designed to accommodate mobility aid users, service restrictions are limiting the ability of PAwMD to participate in community-based activities.⁸ In comparison to urban and suburban counterparts, PAwMD in rural communities are likely to experience greater transportation-related restrictions, as accessible transportation options are much more limited with longer travel distances to and from destinations.

Providers of private taxi and rideshare services are explicitly not required by ADA to purchase, or have a minimum number of, wheelchair accessible vehicles for their fleets. Not surprisingly, ACCESS participants described challenges of not being able to use these services. Rideshare companies such as Uber and Lyft are increasingly popular and available around the country, but are missing an important sector of the population—people with mobility disabilities. Smartphone-based rideshare services hold great potential to support customized, on-demand transportation for PAwMD. In addition to increasing availability of accessible vehicles on rideshare services, ACCESS data suggest that the addition of vehicle selection options on apps, such as 'wheelchair accessible', 'offers wheelchair storage' and 'lower level (e.g., standard sedan)',

Challenge Category	Specific Issue	Arranging transport via taxi/Uber/Lyft	Driving	Getting ride from friends/family	Riding train or subway	Taking a bus	Using paratransit ^a
Lack of availability		X		X	X	X	X
Accessibility	Transferring	X	X	X			
	Steps and stairs				X	X	
	Limited access to accessible vehicles	X	X	X			
	Wheelchair access and storage	X		X		X	
	Lack of handicap accessible spaces		X				
Safety			X		X	X	X
Physical limitations and health concerns			X			X	
Financial limitations		X	X		X	X	X
Advanced planning and amount of waiting required				X			X
Societal attitudes		X				X	

Note. An "X" indicates the challenge was reported for the corresponding transportation activity.

^aWe did not ask about paratransit explicitly in the interview as a transportation activity. Paratransit challenges emerged under different activities, but are presented as a separate activity here to convey distinct challenges associated with that mode.

Fig. 1. Challenges reported across transportation activities from ACCESS.

Table 3
Transportation challenge examples from ACCESS.

Challenge	Quotes from Participants	Context of Quote (activity being discussed)
Transportation not available	<p>"There is one taxi that is sometimes in existence. Usually Uber doesn't cover, there is no public transportation, there's no rail, there's no bus. In the last twenty years, a local transport system for the aged and disabled has been developed. I know virtually nothing about it, I've never used it. All transportation that I use is self-provided."</p> <p>"Getting a wheelchair and getting somebody's vehicle and going anywhere. I can't do that, so I stay home."</p>	<p>Arranging transportation via taxi, Uber or Lyft</p> <p>Getting a ride from friends or family</p>
Accessibility: Transferring	<p>"There is very limited public transit available where I live, like train transportation. There are no taxi services, and any kind of private passenger service, such as Lyft or Uber, does not provide any accessible vehicle."</p> <p>"There's been times I've called for a taxi and explained [that I need] a vehicle that is a standard sedan where the seat is pretty level with where my wheelchair seat... I get out there and it's a minivan or a van and there's just no way I can transfer that high into a seat."</p> <p>"So many people have SUVs, you know, and things that are really hard for me to get in now- you know, the strength I need, so I usually will need them to help boost me in."</p> <p>"If it's a van, if it's up and high, forget it... Sometimes I'd sit on the floor of the vehicle. I'd make a joke out of it to make everybody comfortable... I worry more about how other people feel than trying to explain the challenge."</p>	<p>Transportation activities (overall)</p> <p>Arranging transport via taxi, Uber or Lyft]</p> <p>Getting a ride from friends or family</p>
Accessibility: Steps and stairs	<p>"I have no leg power I have to slide out of there and a lot of unless people have leather seats you can't really slide on the upholstery in the car so I have learned to bring a plastic bag with me and use that to slide on."</p> <p>"Oh, the bus challenge is the big step."</p> <p>"A lot of [train] stops would not be wheelchair accessible... I don't think I'm going to walk down subway stairs... it would have to have a lift... If you're talking about the greyhound, the same thing that applies to the train is actually getting on the bus, and then not being able to use a restroom while you're traveling in that bus."</p>	<p>Taking a bus</p> <p>Riding a train or subway; taking a bus</p>
Accessibility: Limited access to accessible vehicles	<p>"Calling and scheduling Uber and Lyft or taxis is very simple because it's only a phone call. Getting the service is a difficult aspect, because it's dependent on the number and the existence of accessible vehicles."</p> <p>"No matter where I'm going I'm going in my own van... but you know it's not going to last forever and I don't know if I'm going to be able to afford a second one."</p> <p>"Getting a ride somewhere from a friend or family member... that is equally impossible, unless that friend or family member is willing to drive my parents' accessible van."</p> <p>"It's going long distances. I use the bus and train around [my city] and I can get to most places I want to go, but if I have to leave the city, or going out of town, I can't go unless there's a vehicle that's accessible for me."</p> <p>"There is no way to throw a 350 pound [wheelchair] in the trunk. I recently took a drive with my family in my friend's convertible... I couldn't take my chair so once we got to where we were going I just had to stay in the car."</p>	<p>Arranging transportation via taxi, Uber or Lyft</p> <p>Driving</p> <p>Getting a ride from friends or family</p> <p>Visiting family and friends</p>
Accessibility: Wheelchair access and storage	<p>"When the bus pulls up to the curb, and there's another wheelchair on there, I cannot get on. I have to wait for the next bus. That's an inconvenience."</p>	<p>Taking a bus</p>
Accessibility: Lack of handicap accessible spaces	<p>"I have to plan the activity and then I have to rely on the availability of parking. Accessibility is another issue. Store location, store layout all becomes part of the consideration in engaging in that activity."</p> <p>"When I'm driving... in the parking lot I'm trying to figure out okay, where's the ramp, so I can park closest to that instead of just being out somewhere and then say 'gosh, I can't even get in here.'"</p>	<p>Going shopping in-person</p> <p>Visiting friends and family</p>
Safety	<p>"The slow reflexes... I'm afraid of causing a wreck. I've decided it wasn't right for me."</p> <p>"With the loss of my dexterity in my hands... I think now if I try to drive I'd be having an accident every day."</p> <p>"I [need to] know where the entrance is and where the train or subway stops... [If] they decide to pull up forever down the track, and then everyone is rushing down to get it... that could be dangerous."</p> <p>"I've been injured several times using that service, so I'm afraid of it. There are all these signs about how you have to be tied in, locked in, or whatever, but those are just signs, the people that actually drive the bus don't care about that at all, so I've been thrown from my wheelchair every time I've used that service."</p>	<p>Driving</p> <p>Riding a train or subway</p> <p>Using paratransit</p>
Physical limitations and health concerns	<p>"I break the chair down and put it in the car. Now, the shoulders being shot, it hurts a little bit every time I do it."</p> <p>"Transportation in and out of my van. I try to conserve my energy to the extent that I can."</p>	<p>Driving</p> <p>Going shopping in-person</p>
Financial limitations	<p>"Going some distance, going out in weather, maybe parking, opening doors... just the physical challenge of it."</p> <p>"It costs too much money for me to use public transportation. A cab here in town will run you about forty bucks in town, no matter where you want to go. Busses are anywhere from five to ten dollars... I can't afford them."</p> <p>"I would like to not have to get in and out [of my car] using my arms. I would like to have a van I could roll into, but I cannot afford that."</p> <p>"Sometimes the only accessible transportation in town is like a wheelchair van, medical type service and those are prohibitively expensive, like unbelievably expensive."</p>	<p>Transportation activities (overall)</p> <p>Driving</p> <p>Using paratransit</p>
Advanced planning and amount of waiting required	<p>"I can't do too much stuff spontaneously. You know, everything pretty much has to be something that's scheduled."</p> <p>"[I] have to call [the paratransit company] a day or two ahead of time for when I need them to pick me and when I need them to come back and get me and bring me back to the facility of where I live. If I don't call in time, I can't make the reservation."</p> <p>"I have to be ready at the designated area at least a half an hour before the time that I scheduled for them to pick me up. It's the same way for coming back... If I'm not at that designated area, they'll wait just a couple of minutes and then they leave. And there's no guarantee that they will come back if I call."</p>	<p>Transportation activities (overall)</p> <p>Going to entertainment events</p> <p>Using paratransit</p>
Societal attitudes	<p>"I don't think they're used to somebody with a disability traveling, and then traveling alone. Cause every time I go somewhere they say, 'Who's with you?', and I say I'm by myself! They make it seem like, 'oh, somebody let you out? In public by yourself? Oh no!'... No, you know, I'm independent, I want go when I want to go."</p>	<p>Arranging transportation via taxi, Uber or Lyft</p>

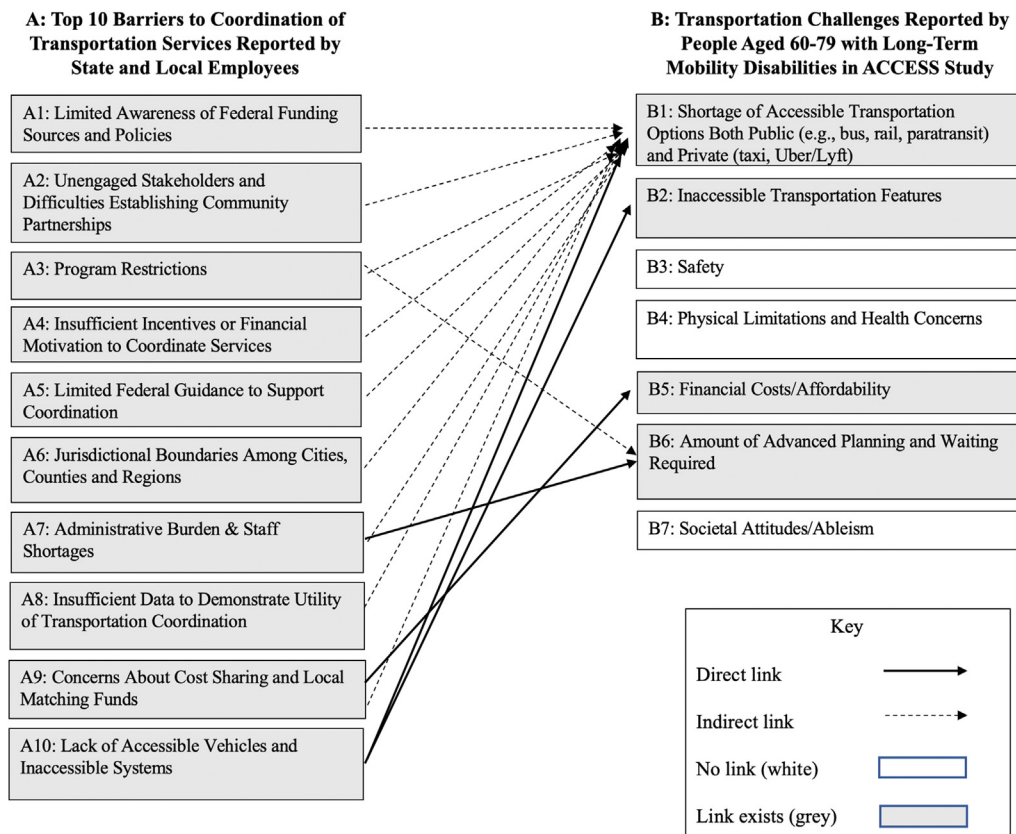


Fig. 2. Areas of potential correspondence between (Column A) barriers to coordination of state and local transportation services for older adults, people with disabilities, and individuals from low-income backgrounds (Column A) and personal challenges to accessing and utilizing transportation reported by individuals aged 60–79 with long-term mobility disabilities in the ACCESS study (Column B). Linkages were made based on two criteria: 1) cause and effect relationships 2) and similar language or concepts. Linkages with an explicit cause and effect relationship AND similar wording were labeled as ‘direct’, whereas linkages with either an explicit cause and effect relationship OR similar wording were labeled ‘indirect’.

would help address their individualized transportation needs.

One’s ability to access a vehicle, as a driver or passenger, is not within the domain of U.S. policy. However, the fact that many PAwMD rely on driving or getting a ride from a personal contact, in lieu of public transit and paratransit, is a reality that cannot be ignored.^{3,5} The cost of purchasing and maintaining a wheelchair accessible vehicle is much higher than an average car and cost prohibitive for many PAwMD. Driving is not a sustainable option for these individuals who are likely to experience health conditions (co-morbid and chronic) and limitations.

The analysis of the correspondence between the CCAM-identified organizational barriers to public transportation coordination and the transportation challenges reported by PAwMD in ACCESS highlighted a few important issues. First, all top barriers to implementation at the state and local contribute (directly or indirectly) to the shortage of accessible transportation experienced by PAwMD. Second, the comparison highlighted the lack of end-user input in the policy development and program implementation process. “Limited understanding of end user support needs” is not identified as a top barrier within the CCAM survey, but it is likely obstructing implementation across multiple fronts. Engaging end users as stakeholders can help create awareness of ‘missing links’, such as concerns about safety and physical limitations, that can help close the gap in effectively supporting transportation needs for PAwMD.

Table 1 underscores the complexity of eligibility and funding requirements associated with federal initiatives, such as the FAST Act, designed to implement provisions of the Rehab Act and the

ADA, ensuring protection from discrimination in access to transportation services for older adults and people with disabilities. This complexity contributes directly to the significant barriers state and local transportation, health providers, and organizations report in complying with regulations and delivering services to transportation disadvantaged-populations; and, even more so, to the challenges experienced by people with mobility disabilities in accessing mobility services. Many transportation challenges reported by ACCESS participants are, in fact, covered under various provisions and initiatives of the FAST Act, such as wheelchair lifts, ramps, and securement devices; transit-related information technology systems to aid in scheduling and routing; and funding to expand access to paratransit services.

To close this gap, there is not only a need for continued federal funding, but also for strategic public awareness campaigns, information dissemination, and training programs to better equip public and private transportation providers, their partners, and end-users with knowledge regarding the availability of federal programs and resources to aid in meeting the goal of mobility access for all. Moreover, such initiatives may be important focus areas for advocacy groups. Finally, to better meet the needs of the growing numbers of PAwMD in the U.S. and increase effectiveness of federal programs, findings from our research underscore the importance of engaging both service providers and end-users with disabilities into the transportation policy development and program implementation process at all levels of decision-making. Additional insights from allied health professionals such as physical and occupational therapists would be valuable.

Limitations

There are a few limitations of our analyses to acknowledge. First, ACCESS participants were predominately White/Caucasian with higher education, which limits generalizability of findings. Transportation challenges are likely even greater for minority and low-income populations, for whom there are known disparities in income, employment, education, and healthcare access.^{5,34} The sample included individuals ages 60–79; findings are not reflective of older PAwMD who are even more likely to be transportation disadvantaged. Future research identifying transportation user needs with more inclusive samples of people with disabilities is needed. The mix of diagnoses/causes and time of onset of mobility disability is a unique strength of this study within the larger arena of ‘aging with disability’ research and was selected to capture a broader range of sources of physical disabilities.

The ACCESS interview was structured so that participants were only asked in-depth questions about their ‘most difficult’ activity; as such, identified challenges do not represent all modes of transportation participants used. This analysis only focused on local transportation modes, excluding airline travel, for which numerous accessibility issues exist.³⁵ Lastly, the linkages in Fig. 2 based in part on the potential for transportation implementation barriers at the state and local level to lead to consequential transportation challenges at the consumer level among PAwMD; we cannot be certain of the extent of the actual cause/effect relationship.

Conclusion

This study integrated individual-level accounts of transportation challenges experienced by PAwMD with barriers to implementing transportation services and programs for this population reported by state and local employees. This intersection of micro and macro data revealed the complexity and fragmentation of the federal policy infrastructure, which consists of multiple laws, a vast array of regulatory requirements, inconsistent program initiatives, lack of federal guidance, and insufficient funding. Together, this complex infrastructure combined with inadequate implementation mechanisms contribute directly and indirectly to barriers to transportation coordination at the state and local level; and, to the challenges reported by individuals with mobility disabilities, who are the desired beneficiaries of these policies and programs. Collectively, results highlight the importance of integrating user input in transportation policy development and implementation to identify opportunities for improvement.

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Disclaimer

The contents of this publication do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

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