“Expensive, frustrating, demoralizing”

Wheelchair users’ recent device purchase experiences

Mobility Device User Survey: A Full Report

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Cover Image: The cover image displays the words used by survey respondents to describe mobility devices or equipment that the respondents do not have the funds available or the insurance coverage to obtain, and how these would meet their home and community-based mobility needs.

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Introduction

Mobility assistive devices are necessities for persons with mobility limitations who need the functions of these devices to engage in activities at home and in the community. The primary mobility devices are wheelchairs and scooters, often with such necessary accessories as custom cushions, reclining functions, wheelchair casters, power assists, and seat elevation. Beyond their transport function, mobility devices are important to many users because they enable independence and autonomy.[1,2]

For some users their mobility device is an extension of their person. [2, 3] Therefore, the specific characteristics and functional abilities of a wheelchair or scooter are of great importance to its user.

Approximately 5.5 million persons in the U.S. are estimated to be mobility device users.[4] The acquisition of needed mobility equipment is affected by the equipment available to meet specific uses, the financial coverage offered by health insurance, and individual needs and preferences.[5] The major sources of funding of mobility devices are Medicare programs, Medicaid, and private health insurance and self-pay. Medicare and most private insurance have similar rules guiding covered device configurations, costs, and eligible uses. The Mobility Device User Survey (MDUS) reported here was stimulated by reports from mobility device users of the many problems, limitations, and long waits associated with the process of acquiring a mobility device, including problems attributed to Medicare and other insurers' policies. The aim of this study was to understand the recent experiences of users when they attempted to obtain new mobility equipment. An additional key motivation was to learn from long-term users with Medicare their views of the effect on device choice and utility of the 2005 Medicare coverage restrictions that created new barriers to getting devices appropriate for activities outside the home.

The main findings:

1. More than one mobility device often was required to accomplish both indoor and outdoor activities; for some people the characteristics of a single device posed limits in use, either at home or out in the community.
2. Medical insurance created complexity and frustration with the purchase experience; most purchasers experienced a denial of any, or of full, coverage for

a wheelchair or scooter purchase. Many users did not even try to use medical insurance to cover purchase costs.

3. Occupational or Physical Therapists, doctors, and equipment suppliers shaped equipment requests, but rarely assisted in appealing insurance coverage denials.
4. Most mobility device users rated their most recent purchase experience difficult or very difficult, regardless of the type of insurer.
5. Among persons who had purchased a wheelchair or scooter before 2005, a substantial proportion rated the most recent experience harder or much harder.
6. While the majority of users were satisfied with their recently purchased mobility device, this rated satisfaction was *after* their own additional actions or personal expenditures to configure the device to their needs.
7. The challenges and frustrations associated with barriers to mobility equipment acquisition had profound personal consequences from such circumstances as extended use of ill-fitting or poorly functioning equipment. Respondents explicitly mentioned increased pain or health risk, activity limitation at home, inability to leave home, or limitation of engagement in valued family, work, or community roles and associated social isolation and mental health/emotional challenges.

Policy context

Mobility devices such as wheelchairs and scooters are often covered by health insurance in the category of durable medical equipment (DME). While Medicaid, private insurance, and the Veteran's health system also cover DME costs, Medicare is a major source of DME funding. Medicare policies for DME that articulate user eligibility criteria, covered equipment, and restrictions strongly influence the standards adopted by the other insurers. Since 2005, the Medicare regulations define DME as equipment that is (1) durable (can withstand repeated use); (2) used for a medical reason; (3) typically only useful to someone who is sick or injured; (4) used in your home; and (5) expected to last at least 3 years.[6] Before the 2005 release of "Decision Memo for Mobility Assistive Equipment"[7] the Medicare coverage criteria referenced limitations in Instrumental Activities of Daily Living (IADL) which include activities outside the home. After the 2005 guidance, the applicable criteria are mobility-related activities of daily

living (MRADL) *in the home*, a change that has affected device options for persons with mobility needs at home and in the community. Informally, users express a lot of dissatisfaction with the narrower criterion. Some also express the belief that it has had an impact upon the quality and durability of the equipment broadly offered by the manufacturers since equipment for exclusive in-home use is now the largest market. [Appendix A contains a more detailed presentation of the Medicare DME regulations both pre- and post-2005 and their implications.] Other factors that affect equipment availability and spur long waits for repairs include the CMS Competitive Bidding Program, implemented in 2011, which requires DME suppliers to compete to become Medicare suppliers. Unintended consequences include smaller suppliers are driven from the market, supply shortages, and reduced access to services, especially emergency repairs.

Overview of Methodology and Sample

The MDUS was conducted online by the Disability Rights Education and Defense Fund (DREDF) in spring 2023 to capture the on-the-ground experiences of persons using Medicare, Medicaid, and/or private insurance and self-pay to purchase a mobility device. Questions focused on the setting where the mobility device is used, users' most recent experience requesting a device with features deemed necessary, the processes that occurred between request and receipt of equipment, and satisfaction with the equipment ultimately acquired. Questions were multiple choice, Likert scales, and open-ended in format. The survey was available online for respondents from mid-April to mid-June 2023. Notices about the survey, encouraging wheelchair and scooter users to respond, were distributed through national disability advocacy organizations, social media and online forums, organizational email lists, and personal networks. The analyses in this report are derived from the 307 valid responses received. Results are presented in tabular, narrative, and graphic format with illustrative quotations selected from participants' responses to open-ended survey questions.

The MDUS respondents were largely experienced mobility device users, with 60.9% reporting wheelchair or scooter use of more than 15 years. Approximately 75% of user respondents were over age 35, with 54.2% of respondents in the prime working age span 36-65 years and 20.4% of respondents over age 65. Respondents also were two-thirds female (68.2%) and predominately white (81%). Of those who answered the question about annual income, nearly two-thirds had an annual income at or below

$50,000 (20.3% below $10,000 and 41.6% between $10,000 and $50,000). Nearly equal percentages reported residing in a city-urban area or in a suburban area (45.4% and 41.4% respectively). [Appendix B offers detailed information about the MDUS methodology and respondent demographic characteristics.]

Findings from the Mobility Device Users Survey

The survey findings offer important insights into the factors that influence a mobility device user's purchasing experience and satisfaction with the equipment's support of their home and community activities. Key factors involved in purchase and satisfaction are desired use; the role of doctors, occupational and physical therapists, and device manufacturer representatives; and restrictions, limitations, and interactions associated with medical insurance DME coverage.

1. More than one mobility device often was required to accomplish both indoor and outdoor activities; for some people the characteristics of a single device posed limits in use, either at home or out in the community

"Manual wheelchair is good at home, but away from home I get so worn out with my manual wheelchair. I'd love a motorized wheelchair but insurance will not cover it."

Most respondents reported using a wheelchair both indoors and outdoors, with 51% using their chair 13 or more hours per day (see Table 2 Appendix B). While the specific type of wheelchair used varied, most respondents used a powerchair. Table 1 shows the distribution across types of equipment used for indoor versus outdoor activities. Table 1 does not total 100% because respondents could report the use indoors or outdoors of more than a single device. The use of canes was much higher indoors compared to outdoors, and the use of a mobility device with power (e.g., manual chair with power assist, scooter, or powerchair) increased for outdoor activities. Of note is that the data analysis found that among people who used no device or a cane and walker indoors, over half reported using a powered mobility device for outdoor travel in the community. The greater reliance on a powered mobility device for outdoor use reflected the need for a device to able to go greater distances over potentially variable terrain, while use of this equipment indoors was problematic for some due to inadequate

space and turning radii. Smaller indoor spaces and better floor surfaces enabled indoor movement by cane, walker, or manual chair for some people. These differences in equipment used indoors compared to outdoors indicate that many users relied upon more than a single mobility device to enable daily activity at home and activities requiring trips from home.

Table 1. Mobility devices used indoors and outdoors

Mobility Device	Device used indoors (No.=307)		Device used outdoors (No.=307)	
	No.	%	No.	%
Cane or walker	70	22.8%	44	14.3%
Manual wheelchair	72	23.5%	62	20.2%
Ultralight wheelchair	35	11.4%	33	10.7%
Manual wheelchair with power assist	10	3.3%	26	8.5%
Scooter	13	4.2%	35	11.4%
Powerchair	166	54.1%	183	59.6%
Dependent pushed by others chair	20	6.5%	35	11.4%
No mobility device used	35	11.4%	8	2.6%
Other	11	3.6%	8	2.6%

2. Medical insurance created complexity and frustration with the purchase experience; most purchasers experienced a denial of any, or of full, coverage for a wheelchair or scooter purchase. Many users did not even try to use medical insurance to cover purchase costs.

The cost of a wheelchair or scooter may be covered (partially or totally) by medical insurance as "durable medical equipment." Medicare, Medicaid, Veterans health benefits, and private insurance offer coverage of the cost of a mobility device, with conditions. These conditions generally specify the accepted purposes for which equipment will be covered, and require a professional (doctor, occupational or

physical therapist) who has evaluated the individual to submit a "prescription" for the equipment's configuration. Because the suggested equipment may not be readily available from manufacturers, a manufacturer representative may also influence the equipment specifications sent to the insurance company for coverage approval. The insurance provider determines whether to cover the purchase as proposed, cover it partially, or deny coverage altogether.

"It [device] partially meets my needs. If I did not have other devices, it would not. I need multiple devices to have my needs fully met. Insurance does not recognize this."

We asked respondents about their experiences with this process because informally there are many complaints. One specific area of interest for the survey was the reported sense of ease with the process, rated satisfaction with the outcome, and whether these varied by type of insurance coverage.

Types of insurance. Table 2 shows the percentage of respondents who used each type of insurance, as well as the percentage that did not use medical insurance to purchase their most recent device. Because some people have multiple insurance providers, for example Medicare with a private insurance supplement, the table cells report the percentage of the total sample that reported use of each type of insurance.

Table 2. Type of insurance used

Type of insurance	No. of respondents	% of total (n=307)
Traditional Medicare	36	11.7%
Medicare Advantage	25	8.1%
Medicaid	55	17.9%
Medicare-Medicaid Combined (Dual MC-MA)	46	15.0%
Veterans Health Insurance	1	0.3%
Private insurance	113	36.8%
Did not use medical insurance	76	24.8%

Surprisingly, in nearly 25% of recent purchases medical insurance was not used. Most of these respondents reported that their purchase was funded by paying out of

pocket, although some had a funding source other than medical insurance (e.g., accident insurance payment, vocational rehabilitation support, GoFundMe, or donation from supplier or non-profit organization). Paying privately enabled purchasers to acquire the equipment they thought best met their needs and with fewer delays, thus providing more choice and flexibility. Medicare, whether Traditional (Part B), Medicare Advantage (Part C), or in combination with Medicaid, was used by 34.8% of the respondents. Thus, Medicare regulations likely played an important role in respondents' purchase experiences. Private insurance, alone, was used by 24.1% of respondents, but an additional 12.7% used private insurance in combination with Medicare or Medicaid.

> *I didn't even try for insurance because I knew I would be denied. I've purchased one scooter and two lightweight power wheelchairs. All of them are purchased on the internet sight unseen because I had no other way to do it.*

Coverage denials. A device-related insurance denial within the past 5 years was reported by 43.3% of respondents (n=130). Nearly sixty percent (59.5%) of those denials were a denial of a device component (e.g., seat elevators, power assist, specific seat cushion or wheels, or better motor). However, 35.1% were a denial of a specific wheelchair and 5.3% the denial of a scooter. There were small differences in the denial experience by insurance type with the lowest denial rate reported by Medicare Advantage users (32.0%) and the highest denial rate by dual Medicare-Medicaid users (45.7%). Since Medicaid frequently pays for prescribed mobility equipment, these denials likely originated within Medicare. Of those using private insurance, 37.5% reported a denial. No single insurance source appeared to deny the recommended equipment at a substantially lower rate than the others.

Table 3. Denial within the past 5 years by type of insurance

Experienced denial within past 5 years	Traditional Medicare	Medicare Advantage	Medicaid	Dual MC-MA	Private Insurance
No	58.8%	68.0%	63.0%	54.3%	62.5%
Yes	41.2%	32.0%	37.0%	45.7%	37.5%
Total %	100.0%	100.0%	100.0%	100.0%	100.0%
No.	34	25	54	46	112

Had to appeal insurance denial with the insurance commissioner office. I did not have the 18K the medical supply company was requesting of me.

My insurance only covers mobility aids if you need them to get from your bedroom to your bathroom or kitchen. I can walk about 15 minutes at a time, so my insurance will not cover anything. But if I want to have a life and actually leave my house sometimes, then I need a wheelchair.

Most respondents who received a denial did not appeal it (63.3%); however, 17.5% appealed the denial and lost their appeal, while 19.2% appealed the denial and won. Table 4 shows that among those who did not appeal or appealed and lost, the major follow-up action was to pay out of pocket (58.9%). A sizeable proportion of denied mobility device users (42.3%) also engaged in other actions, including: applied for a grant; received returned equipment from supplier or donated equipment; changed insurance plans and resubmitted; compromised on component; crowd funded; won partial coverage; funded by donation or 3rd party; gave up on component; 3rd party paid for denied parts; delayed purchase until qualified; purchased acceptable "fix;" rented the equipment; worked with Medicare to correct order with supplier; reapplied/restarted the process.

Table 4. Action taken after lost appeal or did not appeal insurance denial

Action taken	No.	% of Total No.=97
Paid out of pocket	58	58.9%
Accepted what was approved	18	18.6%
Canceled order	11	11.3%
Took other actions	41	42.3%

Some respondents took multiple actions.

Among persons who used insurance, half (50.2%) reported that their insurance did not fully cover the cost of their mobility device. However, as a group, persons of color had a higher percentage reporting full coverage (62.9%) compared to white respondents (46.7%). Among persons whose insurance did not fully cover costs are persons who were granted coverage for a wheelchair but denied coverage for a requested wheelchair component. Many of those whose insurance did not fully cover costs made out of pocket expenditures to cover part of the device's full cost or received financial assistance from other sources (e.g., a donation from individuals or organizations or

sources named above). Out of pocket expenditures ranged from $100 to over $20,000 with the majority spending under $5,000 (14.7% of respondents spent between $500-$1000, 44.8% spent $1,000-$5,000). Respondents also reported long delays in both the approval process and in actually receiving their devices.

The entire process has taken three years now. My insurance has finally covered it, but I have still not received the new wheelchair. I went through two different-insurances because [of my] employer, and both put me through a difficult year long appeal process.

It is an expensive, frustrating, demoralizing experience. I went 15 years between chairs because I had to save for the out of pocket costs.

DME is expensive, I don't qualify for Medicaid, and I wish Medicare covered the equipment I need.

3. Occupational or Physical Therapists, doctors, and equipment suppliers shaped equipment requests, but rarely assisted in appealing insurance coverage denials

The characteristics of a user's mobility device resulted from a complex and often lengthy process. Occupational therapists (OT), physical therapists (PT), or doctors were often required to provide an assessment of what was needed. OTs or PTs were involved in the process of getting the most recent device for 73.8% of respondents. Suppliers also offered advice about device options and features (57.1%), often shaping options by indicating what they thought insurance was likely/not likely to cover. Despite the work of OTs, PTs, or doctors in configuring the recommendation, 43% of respondents had a denial. It seemed that in some cases an error in how the paperwork was completed affected what device or which components would be allowed for insurance coverage. However, respondents' qualitative comments also indicate a disconnect between what the user and OT, PT, or doctor deemed necessary and what medical insurance will cover.

Table 5. Actions of OT, PT, and Supplier

Assistance received	Yes	No	Total No.
OP or PT involved in process of getting most recent mobility device	73.8% (220)	26.2% (78)	Missing=9 No.=298
Did supplier or clinician advise re products/features, including those potentially not covered by insurance	57.1% (173)	42.9% (130)	Missing=4 No.=303
Did supplier or clinician inform you of your rights to appeal a written denial	45.2% (56)	54.8% (68)	Missing=183 No.=124
Did supplier or clinician offer to connect you to someone to assist with an appeal	14.3% (18)	85.7% (108)	Missing 181 No.=126
Did you ask your supplier or clinician for help filing an appeal	28.5% (35)	71.5% (88)	Missing 184 No.=123

OTs, PTs, and doctors rarely advocated or assisted in an appeal of denied equipment. It was not clear whether respondents reached out for help that was not given, or did not ask for help because they did not consider it part of the professionals' role. Nor is it clear how often these professionals initiated an offer of assistance with a denial.

> *Trying to obtain a new wheelchair has been a long frustrating process which I finally gave up on. I have reached out to the Nurse Advocate at the insurance company She was working on the issues of obtaining the Letter of Medical Necessity as my doctor's letter and the Physical Therapist eval were not sufficient for the Wheelchair Provider. I was seen by the MD, PT, and 2 ATP, and still no one would complete the paperwork for a new Rehab lightweight Wheelchair after months Aug to Feb I gave up.*

> *Vendors should not be in charge of the components that patients are prescribed, and PTs should advocate for those patients if the evaluation/patient opinions seems to [be] getting steam-rolled by the vendor. This is especially true when the vendor's motivations are profit-driven.*

4. A majority of mobility device users rated their most recent purchase experience difficult or very difficult, regardless of the type of insurer

Approximately two-thirds of users reported that the recent process for acquisition of their mobility device was difficult or very difficult. There was little difference in the difficulty assessment by insurance type--private, Medicare, or Medicaid.

Table 6. Ease of most recent acquisition by type of insurance coverage

Level of ease	Traditional Medicare	Medicare Advantage	Medicaid	Dual MC-MA	Private Insurance
Very Easy or Easy	33.3%	48%	29.1%	33.3%	31.3%
Difficult or Very Difficult	66.6%	52%	71.0%	66.7%	68.8%
Total %	99.9%	100.0%	100.1%	100.0%	100.1%
No.	36	25	55	45	112

Missing= 1 private insurance, 1 dual MC-MA
Values are rounded and may not sum to 100%

Seventy percent of persons who indicated serious mobility limitation in walking or climbing stairs, unable to walk or climb stairs, or difficulty doing errands alone such as visiting a doctor's office or shopping rated their most recent mobility device acquisition as difficult or very difficult. The rating of ease of acquisition did not vary by the number of hours per day that the respondent used the mobility device.

Why is it so hard to get what I NEED!

It takes a ridiculous amount of time and effort to get a new wheelchair.

5. Among persons who had purchased a wheelchair or scooter before 2005, a substantial proportion rated the most recent experience harder or much harder

The specific interest in the evaluation of the purchase experience by persons who had purchased a wheelchair or scooter prior to 2005 was stimulated by a change in the eligibility wording in the CMS regulation after that date (see Appendix A for elaboration). Concerns raised by this change are that it made the purchase process

more difficult and that it resulted in a narrower range of equipment options and lower quality equipment overall. One survey question asked respondents to rate the ease of the recent purchase experience compared to the pre-2005 experience, with a follow-up to qualitatively share further comments about the purchase experience.

There were 178 respondents (62.2%) who reported being a mobility device user prior to 2005. Of this group, 15.7% assessed their recent experience as easier or much easier compared to the past, and 32.6% said it was about the same. However, a large proportion of these users, 45%, rated the most recent experience as harder or much harder compared to their pre-2005 experience.

Table 7. Most recent purchase experience compared to pre-2005

Comparison rating of recent experience to pre-2005 experience	Frequency	Percentage
Much easier	13	7.3%
Easier	15	8.4%
About the same	58	32.6%
Harder	32	18.0%
Much harder	48	27.0%
I cannot recall	12	6.7%
Total	178	100.0%

Missing=129.

I answered questions based on my current 15 month attempt at getting a new chair. It's still not ordered. The current chair is causing me progressive nerve damage and pressure points. I can't understand why this process is so complex. I have used power chairs since 1978 and it has never been this complex with so many gate keepers. I am using large books to provide lateral support in my chair because my muscles [have] weakened and my scoliosis has progressed.

I have been a wheelchair user since 1990 and it was easier to get a chair that met my needs in 1995 than it is now!

6. While the majority of users were satisfied with their recently purchased mobility device, this rated satisfaction was after their own additional actions or personal expenditures to configure the device to their needs

Overall, users reported they were satisfied or very satisfied with the ability of their mobility device to meet their needs at home and in the community (48.8% satisfied, 23.2% very satisfied). There were some differences in level of satisfaction by type of device acquired. The most satisfied or very satisfied were persons who acquired a scooter (84.6%). Persons who acquired a manual wheelchair with power assist or dependent chair pushed by others expressed the highest rates of being dissatisfied or very dissatisfied (33.4% and 42.9%, respectively). There were no differences in satisfaction by race/ethnicity.

People who had experienced a denial had higher levels of dissatisfaction compared to those who had not experienced a denial (dissatisfied was 18.5% among not denied to 22.7% among denied; very dissatisfied was 4.2% among not denied to 11.7% among denied). There was no association between level of satisfaction and source of funding. While there are procedural differences associated with using the different types of insurance, the final rating of satisfaction did not show differences by source of funding, including the satisfaction rating of persons who did not use insurance funding.

Table 8. Level of satisfaction with device recently purchased by type of insurance

Level of Satisfaction	Traditional Medicare	Medicare Advantage	Medicaid	Dual MC-MA	Private insurance only	Did not use insurance
Very dissatisfied	6.3%	9.5%	13.5%	8.5%	4.2%	5.4%
Dissatisfied	21.9%	23.8%	17.3%	25.5%	12.7%	25.7%
Satisfied	46.9%	33.3%	53.8%	40.4%	57.7%	47.3%
Very satisfied	25.0%	33.3%	15.4%	25.5%	25.4%	21.6%
Total	100.1% (No.=32)	99.9% (No.=21)	100.0% (No.=52)	99.9% (No.=47)	100.0% (No.=71)	100.0% (No.=74)

Values are rounded and may not sum to 100%

While these rates of satisfaction with the ultimate acquisition are high, they come with a caveat. In qualitative comments elaborating on their satisfaction, respondents indicated they were satisfied *after* their own additional actions to enable the equipment to meet their needs. The additional actions included out-of-pocket purchase or additional financial assistance for the accessories that insurance denied.

> *My options basically boiled down to paying out of pocket to immediately receive the perfect wheelchair for my needs - or going through insurance which would involve many months of waiting; tons of my time and energy on the phone to coordinate between insurance, my doctor, and my OT, plus following up on endless forms and paperwork; only to ultimately receive a chair that would not meet my needs or work for my lifestyle. For the sake of my health, I bypassed insurance and went into debt to purchase what I needed.*

> *The process is really long and tedious and the insurance makes you go through several hoops. I'm lucky I got everything I needed, but I practically had to beg for everything.*

7. The challenges and frustrations associated with barriers to mobility equipment acquisition had profound personal consequences from such circumstances as extended use of ill-fitting or poorly functioning equipment. Respondents explicitly mentioned increased pain or health risk, activity limitation at home, inability to leave home, or limitation of engagement in valued family, work, or community roles and associated social isolation and mental health/emotional challenges.

In addition to describing the steps in acquiring their most recent mobility device, respondents' answers also described the life consequences of inadequate equipment. They noted that lack of appropriate equipment, such as seat elevation, sometimes limited their ability to carry out activities of daily living in their homes, including reaching the stove or into kitchen cabinets or transferring from chair to bed safely or independently. Respondents also observed that inadequate or unreliable equipment made it difficult or, in some cases, impossible for them to leave their homes and carry out everyday tasks such as shopping, socializing, and even working.

I just wish I didn't have to depend on people in order to get around my own home and outside. Since acquiring this new type of wheelchair, I no longer go outside… and could almost be considered a shut in because I never want to leave my home.

They also said that lack of appropriate equipment, such as customized seating systems or reclining and leg elevation functions, affected their health by limiting their ability to shift their weight during the day and therefore contributed to the development of pressure ulcers, swelling of lower limbs, and increased back, neck, and leg pain.

A dominant theme among respondents' open-ended remarks was pervasive frustration stemming from their inability to move freely in their communities because they lacked appropriate mobility devices that were available but unaffordable and not covered by insurance. They also frequently mentioned their profound frustration with qualifying for and arranging repairs to their mobility equipment and the time it took for repairs to be made. Some reported being confined to their homes and even their beds for weeks or months while waiting for suppliers to order replacement parts and repair their devices.

My insurance told me that a power chair is only covered if needed for mobility within my home. I can walk those sorts of distances, but need a power chair for indoor and outdoor distances over 100 meters or so. But evidently my insurance (and most others I've heard) believe that I don't need to leave my home ever - to go to medical appointments, to shop, to socialize, to enjoy nature.

Respondents also observed that even equipment suppliers and medical professionals with whom they interacted about their equipment needs sometimes failed to grasp the profound impact of inadequate mobility devices and long repair delays on their lives and well-being. They said that they felt unseen and unheard. They thought that suppliers disrespected them and didn't treat them as full-fledged customers. This observation likely stems from the fact that health insurers, rather than the disabled beneficiary, determine what mobility devices and accessories will be covered and the payment rates for those devices. Suppliers owe their primary allegiance to payers rather than equipment recipients.

It's currently clear that there is no attempt to understand the CONSUMER perspective by insurance or DME manufacturers because the CONSUMER isn't the "customer" - the "customer" is the insurance company.

The Figure 1 word cloud shows the words most frequently used by respondents when asked "Is there anything else you would like to share about your experience acquiring or purchasing your wheelchair or scooter?" Responses often touched on the impact of devices on their lives at home and in the community, and effects of denials and lengthy insurance approval processes.

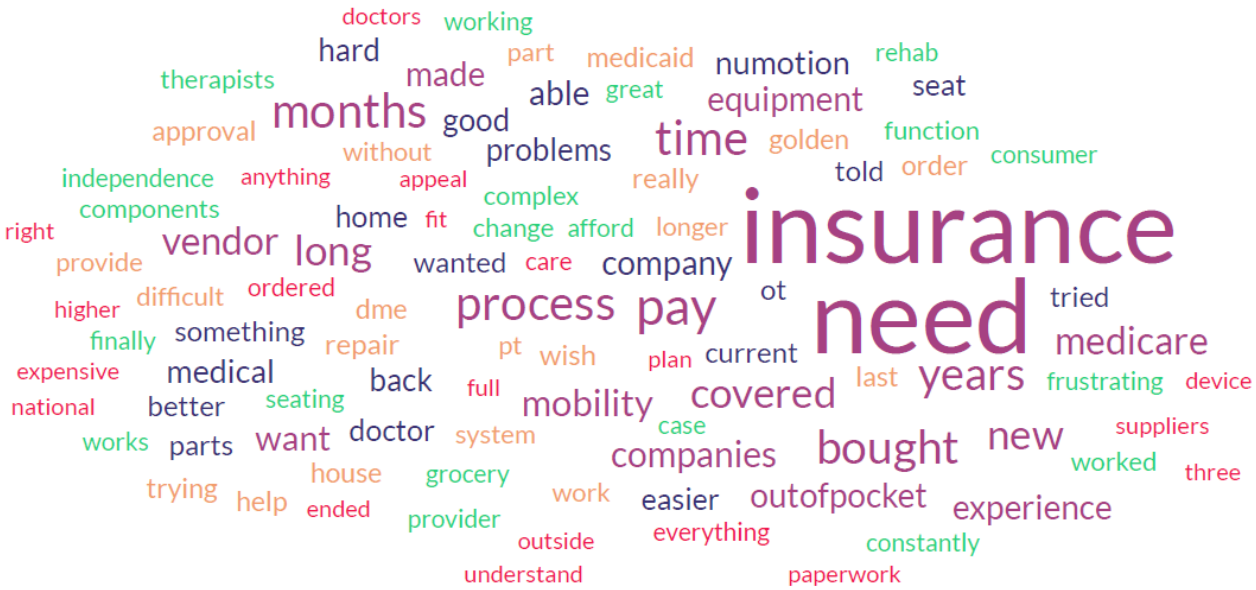

Figure 1. Mobility device users' words for the device's impact on their lives and acquisition barriers

Conclusion

For people with functional mobility limitations, mobility devices can make the difference between confinement and dependency and agency and control over activities of daily living at home and in the community. These devices do more than make life easier or save time; their primary purpose is to address functional mobility limitations that hinder essential human activities such as sitting, standing, walking, reaching, running, and even dancing. They achieve this by offering advanced electronic and mechanical tools that compensate for these capabilities. Such devices include manual and motorized wheelchairs, scooters, wheelchair power assists, seat elevators, robotic arms, sophisticated control systems, and seating systems designed to support and cradle the body in positions that facilitate functionality. These mobility

aids restore agency, promote healthy living, help prevent institutionalization, and encourage and enable users to lead engaged lives.

Yet MDUS results revealed that Medicare beneficiaries encountered significant barriers to acquiring their most recent mobility devices, including ineligibility determinations, even when occupational or physical therapists thought the equipment was medically and functionally necessary. Forty percent of respondents reported that Medicare had denied payment for the mobility devices or accessories they had requested. Many survey respondents noted long waits for approvals, difficulty getting broken chairs or scooters repaired, and limited device options. They reported paying burdensome out-of-pocket copayments for approved devices and needed but disapproved equipment and accessories or having to go without what they needed because of the expense. Moreover, most users said their recent device acquisition experience was more challenging than their pre-2005 experience. Medicare DME rules also affected others with mobility limitations despite not having Medicare. Many private insurers have adopted Medicare policies restricting mobility device use to the home as a cost cutting strategy. Even states that require Medicaid to pay for mobility devices appropriate for community use sometimes deny the needed devices, incorrectly deferring to the Medicare requirement that the device must be solely for use in the home.

The MDUS results raise fundamental questions concerning the impact of restraining disabled mobility device users' community participation and functional independence at home and in the community by limiting their access to needed equipment. The MDUS has shown that CMS's attempt to rein in costs, beginning in 2005, has had the added effect of reducing some Medicare beneficiaries' ability to function in their own homes and travel safely in their communities without concern about equipment failures, breakdowns, and lack of repair options. Specific CMS policies appear to deliberately limit access to community engagement, which runs counter to the full community participation and integration mandate of federal disability rights laws, including Section 504 of the 1973 Rehabilitation Act, the 1990 Americans with Disabilities Act (ADA), and the U.S. Supreme Court ADA decision in the *Olmstead* case.

Policy Recommendations

Legislative and regulatory action is required to improve access to needed devices and reduce inequities experienced by many mobility device users. Congress should amend

the Social Security Act to clarify that the Medicare DME benefit is intended to enable disabled beneficiaries to function at home and in the community. It is crucial that CMS internally evaluate the extent to which its current implementation of the Medicare DME benefit violates the community integration mandate of Section 504 of the Rehabilitation Act as it applies to federally conducted programs. CMS also should issue regulations indicating that healthcare practitioners and DME suppliers should evaluate Medicare beneficiaries requiring mobility devices for the best device to meet their functional needs in their homes and the community. CMS should review its mobility device repair policies and revise them using various incentives and penalties to ensure Medicare beneficiaries have timely access to repairs. Additional evaluation by CMS is needed to determine the durability and reliability of currently approved mobility devices because many are no longer designed or manufactured to withstand daily use in the community.

Many private healthcare insurers follow the Medicare coverage policy for mobility devices. These limitations affect all disabled policyholders who need mobility devices. However, disabled people who have insurance through their employer are especially hard hit because they might depend on the devices to enable them to travel to their jobs. By ending the 'in-the-home-use' policy, CMS will signal that Medicare, the largest healthcare payor in the US, recognizes that disabled people require mobility devices for all activities of daily living in their homes and in the community, thus setting the stage for industry-wide reforms. Furthermore, private insurers should stop following the Medicare mobility device rule. They should review and revise onerous exclusions and benefit caps on payment for mobility devices in light of the 2010 Affordable Care Act requirement to include meaningful coverage for devices such as wheelchairs and scooters.

Even in states where the Medicaid agency pays for mobility devices for community use, providers often determine eligibility for a mobility device based on the Medicare rule, which is inconsistent with the state's policy and does not meet the beneficiary's community-based mobility needs. State Medicaid agencies should enforce the integration provisions of federal disability rights laws by requiring their healthcare providers and DME suppliers to provide mobility equipment suitable for home and community use. They also should track mobility device authorizations to ensure that healthcare and DME providers do not incorrectly deny beneficiaries the right to devices intended for use in the home and community. State Medicaid agencies should proactively educate DME suppliers with whom they or their healthcare providers

contract to ensure they understand and implement the policy of approving mobility devices disabled people require for community participation.

The CMS DME Competitive Bidding Program, implemented in 2011, requires DME suppliers to compete to become Medicare suppliers. While the program has touted fraud reduction and cost savings, it also has generated unintended consequences for mobility device users. Research suggests that suppliers bid artificially low to ensure competitiveness, driving smaller suppliers from the market and limiting access to services, especially emergency repairs. Mobility device users report that this bidding process also encourages suppliers to offer lower-quality products, exclude certain products, and cause supply shortages, resulting in long delays in getting repairs or acquiring new equipment.[8] CMS should thoroughly evaluate the program to fully understand how it has limited access to mobility devices and repairs, especially for people with complex functional limitations. The agency should also revise the program, at a minimum, to exclude complex rehabilitation mobility devices and establish a separate process for purchasing and repairing these devices.

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Appendix A
Medicare policies for insurance coverage of wheeled mobility equipment

By Silvia Yee

Part B of the Medicare Act generally authorizes payment for Durable Medical Equipment (DME), which includes the following:

> *"…wheelchairs (which may include a power-operated vehicle that may be appropriately used as a wheelchair, but only where the use of such a vehicle is determined to be necessary on the basis of the individual's medical and physical condition and the vehicle meets such safety requirements as the Secretary may prescribe) used in the patient's home . . ., whether furnished on a rental basis or purchased… [emphasis added] (42 U.S.C. § 1395x(n).*

The emphasized portion of the definition, "used in the patient's home," which should be seen as merely describing coverage for devices that are primarily used in an out-patient rather than an in-patient context and has been turned over the years into a de facto gatekeeping requirement that substantively limits Medicare coverage of medically necessary DME.

U.S. Department of Health and Human Services (HHS) regulations on Medicare Part B payment further requires DME to meet five conditions: (1) withstand repeated use; (2) have an expected life of at least 3 years; (3) primarily and customarily be used for a medical purpose; (4) not be useful to an individual in the absence of an illness or injury; and (5) Is appropriate for use in the home (42 C.F.R. § 414.202). This last condition adds a seemingly subjective 3rd party evaluation element to DME since it must not only be used in the home, but it must be "appropriate" for use in the home.

CMS added a further layer of interpretive details to Medicare coverage of wheelchairs in May 2005 with the release of a "Decision Memo for Mobility Assistive Equipment"[*] [7]

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[*] This includes canes (section 280.1), crutches (section 280.1), mobile geriatric chairs (section 280.1), motorized wheelchairs (section 280.1), quad-canes (section 280.1), rolling chairs (section 280.1), safety rollers (section 280.5), walkers (section 280.1), manual wheelchairs

and clinical guidance incorporated into the Medicare National Coverage Determination Manual (NCD) on mobility assistive equipment (MAE).[9] The Decision Memo makes it clear that the primary motivation for updating guidance on mobility devices was a concern with "allegations of wheelchair fraud and abuse,"[7] which might explain CMS's reluctance to adopt a broader "function-based" approach to covering wheelchairs. The compromise position put forth in the NCD acknowledges that authorization for a wheelchair does not require the beneficiary to have a medical status of being "bed or chair confined," but instead they must have a "mobility limitation that significantly impairs his/her ability to participate in one or more mobility-related activities of daily living (MRADLs) *in the home*." CMS made the deliberate decision to use MRADLs rather than instrumental activities of daily living (e.g., shopping, performing errands) as its clinical criteria stating, "because the IADL focuses on activities that can be performed outside of the home, we believe that consideration of those broader activities would be inappropriate."[7] The Decision Memo further stated that "[m]obility is not included in the definition of MRADL because, by itself, it does not serve a medical purpose."[7]

The original Medicare language that enabled coverage under Part B of "wheelchairs used in the patient's home" did not require *exclusive* use of the wheelchair in one's home. Moreover, it did not prohibit consideration of the beneficiary's medical and physical needs outside of the home. Yet CMS's interpretation of the "in-home use" requirements is now so narrowly focused on in-home use that disabled individuals are being denied DME who would otherwise be eligible for a mobility device that meets their mobility needs at home and in the community.

<u>Violation of Section 504's Community Integration Mandate</u>

The original Medicare language that enabled coverage under Part B of "wheelchairs used in the patient's home" did not require *exclusive* use of the wheelchair in one's home, nor did it prohibit any consideration of the beneficiary's medical and physical condition outside of the home. Yet CMS's interpretation of the "in-home use" requirements is so narrowly fixated on in-home use that it fosters an on-the-ground application of the rule that risks violating Section 504's requirement that HHS "administer programs and activities in the most integrated setting appropriate to the

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(section 280.1), power operated wheelchairs (section 280.1), specially sized wheelchairs (section 280.3), power operated vehicles (section 280.9).

needs of qualified individuals with handicaps (45 CFR, Part 85, § 85.21(d). The integration mandate is a fundamental tenet of disability nondiscrimination. The analogous provision in the Americans with Disabilities Act (ADA) was interpreted in *Olmstead v. L.C.* (527 U.S. 581 (1999), the seminal 1999 Supreme Court decision, which held that unnecessary and unwanted institutionalization of people with disabilities violates disability rights law. One can argue that institutionalization is inherently far more segregating than living in one's own home in the community but being exclusively confined to that home because one has a mobility device that is intended only for assistance with toileting, grooming, eating and other activities of daily living within the confines of that home is deeply isolating. The conclusion that mobility does not, by itself, serve any health-related purpose, is also incongruent with standard medical practice, even at the time of the NCD.[10,11] The current accepted application of the in-home use rule makes no more sense than Medicare covering a prosthetic leg only for its use in the home and requiring a beneficiary to take it off as soon as they cross the threshold into the community.

While not directly implicated by disability rights law, we also note that the Medicare Act's requirement that DME be used in the home for it to be covered under Part B particularly disadvantages people who need mobility assistance equipment and who also live in high density urban areas where affordable accessible housing is rare. Rental housing stock in such areas commonly have narrow doorways and spaces that lack sufficient turning radius for a wheelchair. Lower income Medicare beneficiaries in such areas are also often older persons of color or multi-generational families that include immigrants. In such instances, the beneficiary can have a clearly documented need for a wheelchair, but their primary reliance on personal care assistance within an existing home in which a wheelchair cannot fit should not disqualify them from Part B Medicare coverage of a mobility assistive device needed for any distance longer than a few steps.

Appendix B
Methodology and respondent demographic characteristics

Methodology

The Mobility Device User Survey was a 42-question survey that aimed to learn about a respondent's most recent experience purchasing a wheelchair or scooter. Questions focused on the device purchased, the interactions with occupational or physical therapists and equipment vendors in development of the device configuration requested, the role of insurance in funding the device, and the respondent's experiences with denials and appeals for the device or device components. From persons who were mobility device users prior to Medicare's 2005 change in the device purpose language, information was sought about whether they perceived a positive or negative impact of the change on the equipment available and the process of acquisition. Users also were asked what characteristics they ideally would like in their mobility device as well as their overall satisfaction with the device they recently acquired. Survey questions were a mix of multiple choice answers, Likert scales, and open-ended formats. The MDUS survey instrument can be obtained from DREDF by email at info@dredf.org.

The survey was conducted online using SurveyMonkey. It was pre-tested by four mobility device users before being opened for general response from April 11 to June 19, 2023. An outreach effort to encourage response to the survey was conducted by DREDF, the National Council on Independent Living, and United Spinal Association. These organizations distributed notices of the survey to their members via email and electronic newsletters and posted links to the survey on their social media platforms including Instagram, TikTok, and Facebook. A first survey question verified that the respondent was a mobility device user before proceeding with the subsequent questions. A total of 307 mobility device users completed the survey (24 additional persons answered the first mobility device question affirmatively but did not answer any subsequent questions). The activities that provided information for this report were conducted in accordance with sound ethical principles. Participation was anonymous and voluntary, and consent was obtained from participants. To protect anonymity, we did not collect personally identifiable information, personal characteristics that could enable deductive disclosure (the ability to identify someone

based on their responses), isp data, or location beyond self-identified urban/rural status.

Quantitative analysis

The survey responses were downloaded from SurveyMonkey into Excel and SPSS. Frequencies and tables derived from the closed-ended questions were produced using SPSS.

Qualitative analysis

The answers to the open-ended survey questions were hand coded by two coders. Two coders used deductive and inductive processes to develop a thematic coding scheme of pre-determined and emerging themes, comprising main- and sub-categories.[12,13] Coders compared their coding, and with a third person participating, the assigned codes were discussed leading to consensual agreement on final codes and quotations, which were entered into a preliminary data matrix. All authors selected typical quotes, which were organized into a final tabular matrix of quotations that was used to make consensus decisions about which were to be included in the report.[14] The quotations included in this report were edited for clarity, brevity, and to protect respondents' anonymity.

Graphic analysis

We used "Free Word Cloud Generator" word cloud software (FreeWordCloudGenerator.com, Salt Lake City Utah) to generate word clouds for answers to open-ended questions to identify the most frequently occurring words across the responses and to supplement our initial impression of the data. Word cloud software counts the frequency that a word appears in a document and creates visual representation in which words' relative frequency is represented by the size of the word in the "cloud."[15] Word clouds are used to efficiently categorize qualitative materials and enable researchers to develop a sense of concepts' salience to study participants. Because the participants' comments were in response to a structured survey with added open-ended questions, word clouds which can increase comprehensibility of this type of data, were particularly useful.[16]

The Free Word Cloud Generator "cleans" the data by removing unnecessary pronouns, articles, and prepositions. We reconciled duplicate words and redundant concepts. We then set the generator to display the first 100 words, in order of frequency, that appeared in the answers to selected questions. We used an iterative process of consensus to identify the most common narrative threads.

Limitations

The MDUS is not a survey based upon a random sample. Survey respondents were persons who were alerted by the existence of the online survey through their connection to a mobility device therapist or provider or through a disability advocacy organization or network. Thus, the set of respondents cannot be considered representative of all mobility device users. Respondents skewed to older white female experienced mobility device users, with few younger or new mobility device users or users from a marginalized population group. However, because over half of all respondents had used a mobility device for more than 15 years and for 13 or more hours per day, these respondents were persons with ample knowledge and experience with the purchase and use of a mobility device.

Respondent demographic characteristics

These tables show the demographic characteristics of the respondents. Most respondents were over age 35, female, white, and nearly half had annual income below $50,000. Over half of all respondents had used a mobility device for more than 15 years and for 13 or more hours per day.

Table 1. Demographic characteristics of the MDUS Sample

Age	Frequency	Percent
0-5 years	1	0.4%
6- 15 years	8	2.9%
16-21 years	13	4.8%
22- 35 years	45	16.5%
36 – 65 years	149	54.8%
66- 85 years	56	20.6%
No answer	35	
Total	307	100.0%

Gender identity	Frequency	Percent
Female	182	68.2%
Male	76	28.5%
Transgender	3	1.1%
Other	6	2.2%
No answer & prefer not to answer	40	
Total	307	100.0%

Race/ethnicity	Frequency	Percent
American Indian or Alaska Native	1	0.4%
Asian or Asian American	4	1.5%
Black or African American	10	3.8%
Hispanic or Latino	15	5.7%
White	216	81.8%
Some other race, ethnicity, or origin	1	0.4%
Prefer to self-describe	17	6.4%
No answer	43	
Total	307	99.9%

Annual income	Frequency	Percent
Less than $10,000	47	20.3%
$10,001 – $50,000	96	41.6%
$50,001 – $100,000	52	22.5%
$100,001 – $150,000	24	10.4%
Over $150,000	12	5.2%
Prefer not to answer	40	
No answer	36	
Total	307	100%

Table 2. Mobility device use characteristics

Years using mobility device	Frequency	Percent
Less than 1 year	5	1.8%
1-5 years	38	13.9%
6-10 years	39	14.2%
11-15 years	25	9.1%
More than 15 years	167	60.9%
No answer	33	
Total	307	99.9%

Mobility device of recent purchase	Frequency	Percent
Manual wheelchair	44	14.3%
Manual wheelchair with power assist	18	5.9%
Ultralight manual wheelchair	26	8.5%
Power wheelchair	172	56.0%
Dependent wheelchair—pushed by others	14	4.6%
Scooter	27	8.8%
Other (identify)	6	2.0%
Total	307	100.1%

Hours per day using mobility device		
Hours per day	**Frequency**	**Percent**
0 to 4	54	19.6%
5 to 8	32	11.6%
9 to 12	49	17.8%
13-16	71	25.8%
More than 16	69	25.1%
Total	275	99.9%

No answer=32

All table values are rounded and may not sum to 100%

References

[1] Kemmis E, Ashby S, MacDonald-Wicks L. *The impact of a power mobility device on occupational participation and quality of life for people with chronic diseases: A scoping review*. Br J Occup Ther. 2021;84(12):745-64. doi: 10.1177/03080226211034420

[2] Stenberg G, Henje C, Levi R, et al. *Living with an electric wheelchair - the user perspective*. Disability and Rehabilitation: Assistive Technology. 2014;11(5):385-94. doi: 10.3109/17483107.2014.968811

[3] Fishleigh L, Taylor R, Hale G, et al. *Factors that affect powered wheelchair use for an adult population: A systematic review*. Disability and Rehabilitation: Assistive Technology. 2024;19(7):2651-64. doi: 10.1080/17483107.2024.2304122

[4] Secretary Buttigieg Announces Proposed Rule to Ensure Passengers Who Use Wheelchairs Can Fly with Dignity [press release]. February 29, 2024 2024. https://www.transportation.gov/briefing-room/secretary-buttigieg-announces-proposed-rule-ensure-passengers-who-use-wheelchairs-can

[5] Cuppett M, Schein RM, Pramana G, et al. *Investigation of factors from assistive technology professionals that impact timeliness of wheelchair service delivery: A cross-sectional study.* Disability and Rehabilitation: Assistive Technology. 2023;18(8):1522-6. doi: 10.1080/17483107.2022.2048099

[6] Centers for Medicare and Medicaid Services. Durable medical equipment (DME) coverage. Medicare.gov. https://www.medicare.gov/coverage/durable-medical-equipment-dme-coverage

[7] Centers for Medicare and Medicaid Services. NCA - Mobility Assistive Equipment (CAG-00274N) - Decision Memo. 2005. https://www.cms.gov/medicare-coverage-database/view/ncacal-decision-memo.aspx?proposed=N&NCAId=143&fromdb=true

[8] Christopher & Dana Reeve Foundation. Competitive Bidding 2024 [Available from: https://www.christopherreeve.org/get-involved/advocate-for-change/advocacy-issue-equipment/competitive-bidding-concerns/

[9] Centers for Medicare and Medicaid Services. *Medicare National Coverage Determination Manual*, Chapter 1, Part 4. 2024. https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/ncd103c1_Part4.pdf.

[10] Javed MJ, Davis DD. Assisting Patients with Mobility. Treasure Island, FL: StatPearls Publishing; 2022.

[11] Dicianno BE, Tovey E. *Power Mobility Device Provision: Understanding Medicare Guidelines and Advocating for Clients*. Arch Phys Med Rehabil. 2007;88:807-16.

[12] Creswell JW, Creswell JD. *Research design: Qualitative, quantitative, and mixed methods approaches*. 5th ed. Thousand Oaks, CA: Sage; 2018.

[13] Braun V, Clarke V. *Using thematic analysis in psychology*. Qualitative Research in Psychology. 2006;3(2):77-101.

[14] Elo S, Kyngas H. *The qualitative content analysis process*. J Adv Nurs. 2008;62(1):107-15.

[15] Mathews D, Franzen-Castle L, Colby S, et al. *Use of word clouds as a novel approach for analysis and presentation of qualitative data for program evaluation*. J Nutr Educ Behav. 2015;47(4). doi:10.1016/j.jneb.2015.04.071

[16] Bletzer KV. *Visualizing the qualitative: making sense of written comments from an evaluative satisfaction survey*. Journal of Educational Evaluation for Health Professions. 2015;12(12). doi:10.3352/jeehp.2015.12.12