

Spring 5-1-2021

## The Enterprise of Health: An Evaluation of the Accessibility of Durable Medical Equipment in Low-Income Households

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# **The Enterprise of Health: An Evaluation of the Accessibility of Durable Medical Equipment in Low-Income Households**

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University Scholar Thesis  
May 2021

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**Abstract:**

People with disabilities constitute a marginalized group in the United States and their experiences within the health care system are often unaccounted for in policy recommendations and reforms. This research aimed to provide general insights on the barriers that prevent access to durable medical equipment (DME) for people with disabilities. I developed a qualitative ethnographic study to capture how people with disabilities experience these barriers first-hand. I collected five in-depth semi-structured interviews with people with disabilities in need of DME. The findings are grouped into two large themes, the economic and the social. The goal of the research is to help tailor efforts in eradicating access disparities to quality health care services for individuals with disabilities in the current American health care environment.

**Keywords:** Disability, Durable Medical Equipment, Access Disparities, Medicare, Medicaid

## Introduction:

In our biotechnologically forward society, capitalistic principles have inverted our healthcare delivery philosophy: paradoxically, the highest need of care is met with the lowest access to care due to the inaccessibility of medical resources and high costs of medical devices. The disabled community carries a disproportionate burden of disease, notably in health care coverage for durable medical equipment, rehabilitative services, and care coordination (Breslin et al., 2019). In 2000 alone, private insurance paid approximately \$6 billion for healthcare coverage for over 6.9 million adults with disabilities, yet persons with disabilities or long-term illnesses and their families paid \$34 billion out-of-pocket (US Department of Health and Human Services, 2005). A privatization of medicine has propagated an expanding gap in the access to medical equipment between the wealthy and the lower income communities. Neoliberal ideals fuel this process by underscoring individualistic responsibility for one's health and discounting the social determinants of health which compromises access to disability health care services (Sakellariou & Rotarou, 2017). For people with disabilities unable to meet high wealth and career benchmarks, reliance on state provided benefits labels them as costly bodies draining limited health resources or financially burdensome (Rotarou & Sakellariou, 2016; Grover & Karen, 2013). By placing the responsibilities and obligations of health expenditure on individuals, the neoliberal agenda of market-based and deregulated health care reduces investment into welfare programs. Consequently, reduced health benefits has led to higher rates of deteriorating overall health: disabled people are more likely to be obese, smoke cigarettes, and be physically inactive (Iezzoni, 2011). Management of secondary health conditions further incurs significant health costs on individuals (Glynn et al., 2011).

The passage of the American with Disabilities Act (ADA) propelled the civil rights of people with disabilities to new heights, yet the right to health care for a growing number of disabled people remains relatively stagnant (Peacock et al., 2015; Kraus et al., 2018). While

public insurance programs are able to pay for 60% of health care expenditures, private insurance only pays for 6% of the costs, which means that out-of-pocket costs remain significantly expensive due to cost-sharing mechanisms (Brown & Finklestein, 2011). With care costs continually increasing, gaps in accessibility to care are inevitable. An amalgamation of social and economic barriers has successfully prevented people with physical disabilities from accessing durable medical equipment (DME), i.e., a category of durable and reusable equipment prescribed to patients with disabilities, or those with injuries and sickness, for in-home medical use (“Durable Medical Equipment”, n.d.). These supportive care technologies include wheelchairs, patient lifts, walkers, oxygen equipment, etc.

Background:

*Public Health Insurance Coverage for People with Disabilities in the U.S.*

A combination of high unemployment rates among people with disabilities and administrative recommendations for budget cuts of welfare programs cyclically threatens coverage for essential health services (Office of Disease Prevention, n.d.; Tankersley et al., 2020; Taylor, 2020). Health insurance coverage assures some manner of access to medical devices. Government programs, such as Medicare and Medicaid, provide people with disabilities significant funding in order to receive care and support to remain active members within their communities. “In 2008, the federal government spent an estimated \$357 billion dollars on programs for working-age people with disabilities,” yet many of the health risks still remain uninsured (Brault, 2012). Medicaid covers health services for 8 million people with disabilities and low incomes, most of which qualify through the Supplemental Security Income program (Breslin, 2009). However, this safety net is not without holes. Medicaid recipients often face poor coordination of care, reduced consumer choice, and limited ability to access specialists. Limited coverage on Medicaid fails to cover essential services, such as durable

medical equipment and rehabilitative services (Roberts, 2013). Home health benefits are often limited to medical necessities, an interpretation that often undervalues the need of assistive support for daily function.

Medicare provides health coverage for all people over the age of 65 and buying into Medicare Part B allows for DME coverage up to 80% of all costs. People with disabilities under the age of 65 can become eligible for Medicare benefits after a two year waiting period. During this time, they remain uninsured and receive monthly cash allowances from the Social Security Disability Insurance (SSDI). SSDI payments cannot offset mounting health expenditures as these cash allowances do not provide livable wages. Prior to Medicare's waitlist enrollment, SSDI beneficiaries must abide by an additional five month waiting period between the time of disability diagnosis and the first cash payment (Iezzoni & O'Day, 2006; Whittaker, 2005). A total 29-month gap in health coverage for people with disabilities results in sporadic access to medical technological interventions and complete abandonment of rehabilitation services. This quagmire of financial and health pressures increases feelings of depression and anxiety in those waiting as inaccessibility of care can hasten functional declines (Whittaker, 2005). Similar to Medicaid, Medicare does not cover a plethora of long-term care services thus increasing costs may lead to these beneficiaries forgoing necessary equipment. This is not an unexpected consequence, "as 46% of adults with disabilities live in households with \$30,000 or less in annual income," double the number of adults living in low-income households to their comparative counterparts without disabilities (Fox, 2011).

#### *Conceptual Framework: Social Model of Disability*

To analyze the reduced care opportunities for people with disabilities, the anthropological lens of the social model of disability is adopted. An analysis on the structural and social failings of the health care delivery system in access to DME is nestled in a larger debate of disability

rights— a fight for equal opportunity, full community participation, independent living, and economic self-sufficiency (Peacock et al., 2015). The social model of disability provides the political impetus to disability rights. Disability is viewed as a social construct imposed upon those with impairments, leading to isolation and exclusion from society because of oppression and discrimination faced across all social dimensions of an individual's life. In this perspective, the disabled body is reflective of its environment. Theoretically, the notion of disability can be expunged from society through appropriate and equitable accommodations of goods, services, attitudes, or other socio-cultural strategies (Rogers & Swadener, 2001). In contrast, an impairment is a personal functional limitation that may or may not be perceived as disabling. Historically, the medical model of disability abused the concept of impairments to create a hierarchical health paradigm that placed disabled bodies inferior to biologically normal ones. Scientific conceptions of normality spread stigmas of *abnormal* bodies and created unequal power dynamics between disabled and abled bodies (Olkin, 1999). In the medical model, the body, if possible, was subject to corrective medical treatments, otherwise individuals remained on the outskirts of society (Reddy, 2011; Reid-Cunningham, 2009). The social model of disability calls for a critical evaluation of legislations, social barriers, and built environments that degrade health statuses of individuals with disabilities and emphasizes the development of compensatory measures. Understanding barriers to access of DME through the social model allows the discussion to reframe poor health outcomes in patients with disabilities and shift attention from their impairments to significant disparities faced in the social, political, and economic sphere.

#### Methodology:

The data presented in this paper is based on five months of ethnographic fieldwork conducted between August 2020 and December 2020. The purpose of this IRB-approved study was to broadly investigate factors that influence medical device accessibility and to collect these

experiences from people with physical disabilities in low-income households. Income thresholds were measured based on Medicaid insurance status. Participants were recruited through advertisements electronically distributed via UConn's Center for Excellence in Developmental Disabilities and Citizens Coalition for Equal Access' emailing networks. All participants filled out a Qualtrics survey with their socio-demographic information to convey interest in a virtual interview. After signing of the IRB-approved consent form, two hour in-depth interviews were scheduled. In this qualitative study, a total of five semi-structured informal interviews were conducted among adult people with disabilities who use or require durable medical equipment. Types of DME were restricted to wheelchairs, patient lifts, or any mobility assistive technologies. There was no distinction established between an acquired disability or a disability present at birth. This study focused explicitly on individuals with mobility impairments, such as difficulty walking, as those specific disabilities would be particularly well-suited to DME intervention. Once informed consent was provided, participants were asked to reflect on device access based on their personal experiences with any mental, physical, economic, or social challenges.

Audio data collected from participants were transcribed and analyzed through reflective notetaking of emerging themes and concepts. Thematic analysis of this data is particularly useful as the paradigm facilitates the recognition of salient patterns between participants' lived experiences, perspectives, and behaviors (Clarke & Braun 2017). The use of memos enabled the researcher to identify preliminary themes and development of an emic coding scheme. Generation of an initial list of themes helped organize the entire dataset into groups and meaningfully extract information (Birks et al., 2008; Porcia & Turner, 2015). These emerging themes were grouped into subcategories that fell under two overarching dimensions found to influence DME accessibility: the economic and the social. Characterizing subcategories was an iterative process of using both interview data and secondary sources. Several subcategories were redefined or combined to establish clear distinctions between groups and overlapping patterns. Direct quotations from participants supplemented the refinement of subcategories. All

participants' names and identities have been redacted from this paper to protect their anonymity. Data analysis was further substantiated by extensive literature reviews of secondary sources. The body of peer-reviewed academic literature specific to durable medical equipment is limited in both breadth and depth. Therefore, analyses from government policy briefs, newspapers or other sources of health journalism, and novels by disability advocates were mandatory to contextualize the presented critiques.

#### Results and Discussion:

Analysis of raw data unveiled an array of both indirect and direct barriers to accessibility of DME. The economic dimension of accessibility delves deeper into health insurance policies, insurance plan benefits, and structural inequities related to purported cost-savings programs. The discussion on the financial motives behind DME regulations follows a top-down approach to demonstrate the physical, emotional, and economic barriers faced by people with disabilities downstream. Extensive utilization of secondary sources was imperative to this section as many participants were unable to pinpoint the roots of their problems, but rather spoke of their difficulties managing the resulting consequences. On the other hand, the section on the social dimension of accessibility highlights the direct factors that hinder access to DME within each participant's social environment. This discussion presents prevalent stigmas, prejudices, and discriminations against those with disabilities within the care delivery process. The social dimension section will further address the physical and emotional barriers that limit a person's ability to choose their DME and to participate in their own health decisions. In both discussion sections, barriers will not be presented as isolated factors that compromise access to DME, since the reality of health care delivery intersects the economic and social domains.

#### ECONOMIC DIMENSION

##### *Current Insurance Policies*

Our health care system faces many challenges in appropriately addressing questions to adequate insurance coverage for people with high health care needs and limited financial resources. The third-party payer system in the United States is the dominant health care services payment structure. For 27.5 million people who fall outside this umbrella of insurance coverage or remain underinsured, seeking preventative services or purchasing prescription drugs is not a financially sound decision until often their delay has already compromised their health (Berchick et al., 2019).

One participant speaks to this experience which resulted in her hemiplegia:

I had a stroke on December 14th of 1978. I suppose a stroke came because I was stupid and I neglected to take my blood pressure pills. Now, I will tell you, I had a wonderful doctor, Dr. Pitt. We still exchange correspondence, and he continues to tell me, "... if you don't take your pills, you're going to have a stroke" ... I had no idea what a stroke was, absolutely nothing. So, because I wasn't really feeling terrible, and I just didn't have the insurance to pay for these pills. I neglected sometimes to get the bottle refilled when it went empty... I had a stroke, and that stroke took me to losing the left-side control over my left side of my body.

Now her private insurance plan covers almost all her costs, paying for diagnostic imaging exams and equipment replacement for her wheelchair. Saving money by splitting pills, skipping medication doses, or deliberately failing to fill prescriptions is unsurprising when out-of-pocket costs are exorbitant for low-income people with chronic illnesses, like hypertension (Kennedy & Erb, 2002). At the time, this individual did not qualify as a beneficiary for Medicare and her private health insurance provided restrictive coverage (Cubanski et al., 2016). Although now she has more comprehensive insurance coverage that better matches her

care needs, arguably her well-being declined as “before [her] stroke... [she] didn't have to wait for other people to go through their routines... if something needed doing, [she] would just get up and do it”. The skewed financial incentives of the American health care system has forced her to pay for coverage by trading in her health and well-being. Lack of affordability to comply with treatment plans are not limited to prescription medications but also DME.

Poor federal regulation of private insurance allows for differential coverage of people with disabilities between employers. Although the ADA prohibits discriminating against employees with disabilities in the Terms and Conditions, the boundaries of such provisions are unclear. As long as limitations apply to all plan members, an employer's health insurance plan can exclude coverage for certain services, e.g. home health care which makes paying for DME very difficult (Institute of Medicine, 2007). Physical or occupational therapies typically accompany DME prescriptions in order to capitalize on the device's benefit. Most health insurance plans in the United States do not cover maintenance therapies that ensure independent living for people with disabilities by preventing deterioration of a person's functional status, and instead cover rehabilitative therapies that restore or improve function. In addition, coverage for DME is often limited to a predetermined number of visits over a certain time period, e.g. 20 visits over a year, or to a set dollar amount if the specific DME is deemed as an unessential health benefit (Neri & Kroll, 2003; Iezzoni & O'Day, 2006). This means that people with disabilities may not always be able to receive these services when they need them, or to the extent that they need them:

“They tend to give you the cheaper product, not necessarily what you need... Everything has to be submitted to insurance, so they decide whether they're going to pay for it, and then you have to write more stuff, as far as why you need it. What you would think would take a couple of days, takes six months to two years.”

Insurers limit reimbursement to the least expensive equipment which may not provide great safety, functionality, and independence to the user as the more expensive higher-tech model. Significant delays are associated with the assessment and documentation of DME requests as the process is not straightforward nor efficient. A face-to-face exam by a health practitioner is required to obtain a prescription or a certificate of medical necessity for orthotics, prosthetics, or wheelchairs in order to be authorized by Medicare, Medicaid, or private insurance. General requirements for DME approval include a comprehensive patient history and conditions relevant to functional difficulties, a musculoskeletal and neurologic exam, and how activities of their daily living are impacted. In completing a wheelchair exam, additional documentation is required that includes how a wheelchair would compensate for an individual's physical impairment that would not otherwise be satisfied by a cane or walker (Short, 2020). The paperwork increases when providing proof of necessity for a power wheelchair over a manual one. Replacement of wheelchairs will be considered only after three years or longer, which is not ideal for someone with a progressive chronic condition as the technology would need to evolve with care needs (United Way, 2020). A similar and detailed process is required in request for a prosthetic or orthotic.

### *Medical Necessity*

Before the Centers for Medicare and Medicaid Services can reimburse costs of DME, under the Social Security Act they must evaluate whether the item is "reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member" (42 U.S.C. § 1862 (1)(A)). The purpose of determining medical necessity is to save Medicare expenses from covering convenience technologies. The problem in accessibility of DME in part lies in Medicare's vague definition of medical necessity. Inconsistent or incorrect applications of this policy leads to an improper denial of equipment coverage for people with disabilities. For example, Medicare regards bathroom grab bars as medically unnecessary even though falls are the leading cause of injury and death among the elderly and annually cost

Medicare \$31 billion (CDC 2016). Even a power wheelchair may be denied to someone who can operate a manual wheelchair despite the potential for exacerbation of secondary medical conditions. One participant speaks to her struggles with her provider in approving a prescription for a manual wheelchair based on the medically necessary criteria:

When I told my physician that if the pain got any worse, I was going to need a wheelchair, she laughed at me... I told my therapist that I was looking into wheelchairs, and she was like, "Well, maybe now is not the time to be doing something that extreme because you don't know if any of this stuff is going to get better." ... Everyone thinks that I'm being dramatic at this point.

Medical necessity determinations can be highly subjective decisions. This person was disabled from a Traumatic Brain Injury, complicated further by a range of chronic disorders such as Ehlers-Danlos syndrome, Chronic Fatigue Syndrome, and Postural Orthostatic Tachycardia Syndrome. The necessity of a manual wheelchair might be obvious from her limited mobility, yet she faces condescension and rejection at every turn. A manual wheelchair is not simply a personal comfort or convenience item when she lives day-to-day in pain from her many physically debilitating disorders.

#### *Affordable Care Act and Disability Coverage*

Obtaining a DME prescription is oftentimes not as challenging as gaining approval from insurance, especially a state-provided insurance. Even after the Affordable Care Act's expansion of Medicaid, which provided broader coverage than private plans, people with disabilities can have serious difficulties financing their durable medical equipment needs (National Council on Disability, 2016):

It's been harder and harder and harder with the state ... It's very difficult to get, in most cases, a new wheelchair because there's a lot of paperwork ... that you need to process.

Even then, maybe a certain part won't come in or the wrong part will come in and everything has to be reapproved. For example, I needed a lift... I literally could not get one from the state. They pay for one kind, but the kind I needed, they wouldn't pay for... They make it extremely difficult, in some cases, to get what you need.

After the passing of the ACA, there were several provisions that improved access and affordability of health services for people with disabilities. Preceding implementation of the ACA in 2014, exclusionary insurance practices were rampant. Employers would avoid hiring workers with disabilities fearing a rise in their health insurance premiums, or employees' health insurance plans would fail to cover for conditions predating their employment. The ACA significantly changed the guaranteed issue laws, eliminating exclusionary policies on pre-existing medical conditions and outright coverage denials (Rosenbaum et al., 2011; National Council on Disability, 2016). In an effort to provide a level of coverage standardization in the health insurance market, the ACA broadly defines essential health benefits that need to be covered in both individual, small-employer groups, and qualified health plans- including rehabilitative and habilitative services and devices such as DME. The problem with comprehensive DME coverage lies in the determination and design of the essential benefits packages, such as its scope of benefits.

#### *Scope of Benefits*

How a particular benefit class is defined affects its coverage availability in particular cases. For example, a power wheelchair can be generally categorized as a DME or as a subcategory, complex rehabilitation technology (CRT). An equipment that qualifies as a CRT is designed to meet the very specific medical and functional needs of each person with a disability by offering highly customized systems and accessories (Stanley, 2015). This implies that fixing malfunctioning hardware can be more difficult than in a manual wheelchair. Theoretically, Medicare covers reasonable repairs of DME until it's serviceable. Due to complex

reimbursement procedures, definitions of equipment serviceability may differ between the user and technician resulting in improperly fitted wheelchairs. With delays in equipment parts, users may have to use technology ill-fit to their bodies and mobility needs for longer periods of time. Mechanical adjustments to DME are only possible if patients have the knowledge and resources to contact vendors in the first place, which is not always apparent:

This lift broke and it's getting a little bit more worn out because I use it every day. They tell me that I should look into this, look into that, but I don't know where to go to get it updated... Older things need to be refurbished over time. Everybody [I ask] says, "I don't know."

Medicare also maintains restrictive purchasing coverage over electric wheelchairs, requiring people to prove that the requested equipment is not merely for their convenience. Intensive reviews of power wheelchair prescriptions have only increased since 2007 after Medicare lost \$27 million to fraudulent supplier claims (Office of Inspector General, 2010). Due to reimbursement cuts, competitive bidding, and policy changes accessing these more specialized wheelchairs becomes more difficult than for a typical DME:

In my experience, I've called the wheelchair company and said, "I need X, Y, Z," and they'll say, "Oh, they don't cover those anymore. You have to get A, B, C." ... I've [called the wheelchair supplier but]... They show up many times with the wrong part for the wheelchair. I say to them, "Don't you think you should carry some parts with you?" They say, "No, we don't carry any parts with us. Everything has to be ordered."... That doesn't make sense, because it makes the process longer than it really has to be.

CRT power wheelchairs are often classified as capped rental DME because Medicare does not have a unique device coverage for more complex and long-term needs of individuals

with disabilities. Capped rental DME is a category of DME for devices priced higher than \$150 and required for short-term use during which Medicare contractors pay DME suppliers on a 13-month fee schedule, until total rental prices reach the allowed amount of purchase of the item (Blue Cross Blue Shield, 2020; Office of Inspector General, 2010). After 13 months of rent, the ownership of the DME transfers to the Medical beneficiary at no further cost, barring any modifications that might renew the rental period or any addition of accessories that might also add capped rental plans to existing ones. Not only does administrative paperwork and cash flow become more complicated through these monthly installments, but also there are no cost-savings in expenditure. The Centers for Medicaid and Medicare Services predicted an eight-month time frame for most capped rentals that would help significantly reduce device costs for beneficiaries (Kopf & Watanabe, 2013). Under the assumption that individuals dependent on these highly specialized technologies will retain their disabilities for the rest of their lives, corresponding DME usage will likely exceed the estimated eight months revealing no real cost benefit from this arrangement.

Yet, this is often the best case scenario. With advancing technologies in the consumer market, insurers cannot keep pace with coverage options for every device or associated needs. Certain technologies can fall outside these payment boundaries, as seen with an individual who could only had access to a manual hooyer lift instead of the sit-to-stand hooyer lift that she preferred:

[Public insurance programs] pay for something called a Hoyer lift, which transfers you...I needed one that would stand you up... [Currently] mine has a crank. The state only pays for the [manual] Hoyer, which is the less expensive one. No matter what I did, I went to Mount Sinai Rehab Hospital and I thought they would be able to help me get [sit-to-stand] one. We tried a couple of different places. Then in the end [the state] said, no... it was very difficult... I happened to find one through a friend of mine at the Loan

Closet at the Senior Citizen Center...for \$20, which is great because if I wasn't able to get it from them, I don't know what I would have done... I got very lucky. Some people I know here, have actually found these- they call them Sara lifts...Some people I know have actually gone online and got them for a discount, but I didn't have to do that.

Notably, there is the lack of transparency in coverage denials for people with disabilities. In the past, every participant has at least once received a blanket rejection to their device prescriptions, despite inquiries for clarifications “they don't give you a reason, it's just, ‘we don't cover that anymore,’ period.” Denial letters rarely explain what coverage policies were applied or the overall decision-making procedure and guidelines. Unknown reasons for denials are a significant challenge in addressing difficulties to DME accessibility. It strands individuals in a limbo where they do not receive the required technology yet cannot do anything about it. This makes navigation of their health care plans obscure leading to a sense of loss of control in their health decisions: “It's like they say, ‘Jump,” and I'd jump’.”

#### *Use-in-Home Provision*

One of Medicare's concrete stipulations for DME coverage is appropriate use of equipment at home. The home-use provision limits the availability of assistive mobility equipment to ones that help beneficiaries move inside their homes. Seemingly innocuous, through this statute a person can be denied coverage based on equipment that they will only need outside their homes for activities of daily living. This violates the basic tenets of disability rights calling for increased community participation and independent living of people with disabilities. In many instances, substandard implementation of universal design are cited for coverage denials, meaning a home's size and floor plan determine access to these technologies:

The house I live in is the house that my grandparents built, so it was built in the '50s. It's mostly a one-level house, which is lovely. The doorways are regular doorways, there's still ledges to get in the house, and I live on a dirt road...The insurance I have would only pay for a wheelchair if they could come in and look at my house to say that a wheelchair could fit in the house, but whose house could [normally] fit a wheelchair? Because you'd have to look and [check] your doorways going into the bathroom... nobody's bathroom can fit one. [Their response] would be like, "Renovate your house then." ... I think about all the places that I would go, and then I think about [how] they're not wheelchair accessible either.

Universal design principles emphasize human-centered architectural designs of buildings and homes, with everyone across the full spectrum of functional ability in mind (Lid, 2013). Many homes fail to meet criteria that structurally accommodate those with DME, i.e. wheelchairs. For this person, renovations would have to include widened doors, wheelchair-accessible paths, and spacious bathrooms. Medicare and other health insurers do not cover home renovations which can add thousands of dollars to out-of-pocket costs, therefore DME remains unaffordable to many individuals with low-incomes.

#### *Competitive Bidding Program*

Medicare introduced a competitive bidding program (CBP) for all Durable Medical Equipment, Prosthetics, Orthotics, & Supplies (DMEPOS) to replace the previous standard rates of fees for various equipment that were based on prices from the 1980s ("DMEPOS Competitive Bidding", n.d.). Congress mandated this change through the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 in response to the Health and Human Services (HHS) Office of Inspector General (OIG) and the Government Accountability Office's (GAO) report on Medicare's significant overpayment for DMEPOS. In an effort to reduce paying above-market rates for devices and saving an estimated \$19.7 billion, Medicare established a

program under which prices for specific DMEPOS sold in specific geographic areas would be determined by suppliers' bids (GAO, 2018). These bids would be evaluated by Medicare and contracts would be selectively awarded to suppliers based on their bid prices and financial stability. In the past, small-scale demonstrations of CBP showed significant savings with little changes experienced in product availability and quality, yet in large-scale implementation there were significant challenges faced by beneficiaries (Katron et al., 2004; Newman et al., 2017).

### *Navigating Multiple Suppliers*

There is a high population prevalence of secondary medical conditions among people with disabilities (Kinne et al., 2004). Many patients who use DMEPOS might have comorbidities, chronic conditions, or expansive needs that require management through multiple types of DME. CBP is structured so that a bid winner is limited to providing a single type of device, unless more bids are won. Consequently, beneficiaries would need a corresponding number of suppliers to the number of health conditions they have. Management of different suppliers further convolutes the insurance procedures and bottlenecks access to DME for many users, especially if some are not familiar with the basics of their available device selections to begin with: "Well, I think I don't ever actually get enough information on what is available, and I'm not sure who to ask or where to find more."

### *Competition and Geography*

An inevitable consequence of CBP is the reduction of available DME suppliers (Institute of Medicine, 2010). Vendors not selected for Medicare contracts lose a large portion of their customer base potentially leading to their business shutdown, more so if they are a small-scale business therefore unable to cater to a large geographic region. Since CBP relies on competition among suppliers to produce lower payments, if insufficient competition exists then the program will not produce cost-savings for either Medicare or the beneficiaries. Additionally, removal of local suppliers will force people with disabilities to travel greater distances to access a Medicare-approved supplier: "I think there are ones that are a little farther out like Harvard,

Worcester, but they're much farther out and it would not be worth it to either rent or ... buy one [from them]." As of now, Connecticut has one vendor supplying standard power wheelchairs and three supplying manual wheelchairs for the whole state. Finding proper transportation accommodations to these locations is not always easy, which increases geographic isolation and worsens access to health care for patients with disabilities: "I remember... sometimes my wheelchairs wouldn't fit where I wanted to go, or it was hard to use the bus to get to where I wanted to go."

### *Poor Supplier Standards*

Even with Medicare contracts, vendors will likely suffer a loss in profits with the driving down payments of DMEPOS to match market DME prices, thereby affecting the quality and coverage of services provided to beneficiaries. HHS initially launched a trial of Medicare's CBP between 1999 and 2002 in County, FL and San Antonio, TX. The Secretary of Health and Human Services' report summarized the bidding demonstrations as having no appreciable change in the quality of DME (Katron et al., 2004). Despite alleged successful demonstrations, participants' experiences in-present time speak otherwise:

I have an older model wheelchair that I still have [but] I don't use anymore because it's very old. I can tell you that [old] chair still works better than this [new] one does, and I've only had this chair... [for three months], I think, and it's been broken a couple of times already...my old one that I'm no longer able to use...still works better than this one. The footplates are better. Just in general, the equipment is of better quality.

This discrepancy can be explained by the technical interpretation of the survey responses in HHS's progress report that concluded there were no systematic quality problems. Yet, there were early warning signs in poor supplier standards that would not encourage the maintenance of quality in DME. In San Antonio, some wheelchair suppliers attempted to cut

costs by providing fewer accessories, charging beneficiaries for accessories typically covered by Medicare payments, or using less-qualified staff for fitting. Even instances of follow-ups were poor or missing. At the time, these quality concerns were deemed a minor issue.

### *Consequences of Poor Quality Equipment & Services*

The premise of CBP is a race to offer only the cheapest product to beneficiaries. The danger in drastically low bid prices is the impossibility of coverage for highly advanced and customized equipment. Vendors will refuse to supply unprofitable products leading to supply shortages or might instead offer inferior quality products. This will further constrain access to appropriate DME for low-income individuals who in the best of circumstances might be forced to pay for necessary technologies out-of-pocket. Otherwise, if the price of DME is similar to that of a power wheelchair, costs can rise upwards of \$3,000 which is simply unaffordable for the majority of Medicare beneficiaries who fall below the 200% FPL in Connecticut (KFF, 2019; BraunAbility, n.d.). Poor quality of service can translate into delays in obtaining medically-necessary equipment or a smaller range of choices in selection of equipment or suppliers (Ramsey, 2014). Delays in equipment access are not brief: “Sometimes [the wheelchair accessory replacement is] not the right one so then they got to send it back. You can wait two or three months sometimes for just a simple part for your wheelchair.” Even placing orders for replacements is tedious:

“There is a supply place called Doyle Medical Supplies... Only they’ve decided they don’t really like coming [here], I’m not sure why... So, now they only come...once a month, so I have to wait until it’s convenient for them to get new things like a new reacher or new armrest for my manual chair.”

Participants can find themselves going months without access to a properly operating technology which hinders their social participation in routine life. During this gap, some might try to find cheaper alternatives:

I have been looking into backdoor solutions and looking at Craigslist and eBay to find used [wheelchairs] at this point, which may seem like a better solution because I think that I might be able to find one that will be smaller... I can't renovate my house [but insurance would only cover] this massive electric wheelchair that I just don't have the need for. If I'm just going to use it for ambulatory use, I need a more affordable one.

Participants might find moderate success in obtaining an equipment that better fits their needs than the insurance-provided equipment, but this may be tempered by the quality of the substitute. Only state-provided wheelchairs receive modifications, resizing, and repairs. A wheelchair bought from a third-party does not automatically guarantee suitable device configurations as parts may be worn out or incorrectly sized. The ergonomics of wheelchair matter as they can have adverse health consequences. Improper configurations lead to poorly seated body postures which contributes to back pain or spinal deformities in users (Barks et al., 2021; Samuelsson, 2009). Moreover, mobility can be reduced and accompanying risks include pressure ulcers and wheelchair tip-overs (Brienza et al., 2018; Nelson et al., 2010).

#### *Out-of-Network DME Suppliers*

The allowance for DME suppliers to remain non-participating, meaning they can accept assignment on a claim-by-claim basis or not, is an economically unfriendly pitfall for beneficiaries in Medicare's health insurance policies. An assignment is when a supplier contractually agrees to Medicare-approved amounts as full payment for rendered services and devices, therefore beneficiaries only have to worry about paying the coinsurances and Part B deductibles as determined by Medicare ("Lower Costs with Assignment", n.d.). A

non-participating DME supplier can accept Medicare, but not necessarily assignment. Non-participation statuses effectively narrow the network of DME vendors available to patients at no cost incurred to the supplier, unlike for physicians who face a 5% payment reduction for a nonparticipating status (Medicare Rights Center, n.d.). The burden falls on beneficiaries to check the status of their supplier's participation, which they may not always be aware of. Furthermore, it is the patient's responsibility to cover the difference in costs between what Medicare will pay and what the supplier will charge, which has no legal limitation (Medicare Rights Center, n.d.). Competitive bid program contractors are always required to accept assignment, but those with no contracts have no mandate to follow similar stipulations.

Non-participating DME vendors can artificially raise prices because they have no cap placed on their ability to balance bill patients in excess. Balance billing allows them to bill beneficiaries beyond Medicare's standard 20% coinsurance rate in the instance assignment is not accepted by the vendor, since they are not contractually bound by Medicare's DMEPOS fee schedule. Dangers of balance billing are evident as the Office of Inspector General (2001) disclosed that beneficiaries were charged \$41 million above Medicare allowed amounts for medical equipment and supplies in payment for the 3 million non-assigned claims. Before implementation of CBP, the most recent survey revealed that 62% of DME suppliers were non-participating Medicare suppliers thereby allowing them to accept assignment case-by-case (Office of Inspector General, 2001). Many cited delayed payments and low reimbursement rates from Medicare for their participation status. Although Medicare reported no changes in assignment rates in 2016 after implementation of CBP, depending on the goodwill of suppliers to not excessively balance bill patients is a financial liability and proven to not work ("Fee Adjustment Monitoring", n.d.). Under this new DME pricing system, vendors are threatened by a loss in revenue due to reduced reimbursement rates of DMEPOS to match market value. To account for shrinking profit margins, vendors are now more likely to balance bill a greater

number of beneficiaries. This means even higher coinsurance and deductibles paid out-of-pocket by beneficiaries.

Yet, balance billing is a careful balancing act in competitive bidding areas because those less-efficient will lose business to vendors who can profitably provide products on an assignment basis. Outside of competitive bidding areas, free-market competition may not be enough to curtail costs for patients due to limited suppliers in rural areas with limited access to specialized technologies (Centers for Medicare & Medicaid Services, 2020). Generally, with no ceiling placed on device costs, suppliers can inflate prices to soaring heights and significantly increase out-of-pocket costs for users. Competition cannot enhance quality of healthcare services and quantity of device availability when consumer choices are stymied by an individual's economic status, physical barriers, and missing underlying safeguards in regulatory policies (McGregor, 2008).

## SOCIAL DIMENSION

### *Self-determination*

Complicated health insurance practices and many bureaucratic hurdles limit patients' ability to self-determine their health technology needs. The right to self-determination refers to efforts to ensure that people with disabilities have the skills, opportunities, and support to be the main drivers in their own lives (Shogren et al., 2006). Self-determination and positive health outcomes are closely tied together (Heller et al., 2011). For patients, the highest possible level of decisional autonomy in device selection would ensure that their prescribed DME are appropriately satisfying their needs and are well-modified to their physical environments. Across all interviews, every participant believed they did not have majority control over their DME selection. Patients are the experts about living with their disabilities, and should be consulted accordingly. The care team needs to listen and value their input to a greater degree than is presently done. Participants currently find this respect lacking:

The vendors and doctors, they think they know what a person needs. They give you what's the hot item for the year and not necessarily what you need or want...I find when you typically go for an appointment, it's you and the doctor and the person from the durable medical equipment [company]. They all meet together and you go from there. In other words, the doctors tend to sign off on whatever the vendors tell them would be best... The vendor and the [physical] therapist tell the doctors what's best, [but] they don't know the person... The doctors just sign off on what the vendors tell them to sign off on.

A patient's improved physical function does not always correlate with their perception of improved quality of life, indicating that DME selections solely based on a clinical gaze may not adequately provide the intended benefit (Chan, 2011). An unequal power dynamic between the patient and care team contributes to patients' impressions of feeling sidelined. Conceivably, communications between provider and patient can become stilted. When conversations largely circle between the vendor, physician, and physical therapist, there is little space for the patient with the disability to actively participate and outline their own expectations. Shifting the balance of power during clinical encounters becomes challenging when clinical expertise completely displaces the patient's views.

During medical appointments, the apparent stratification of power results in patients feeling invalidated. Despite sitting in the same room, patients who require DME remain largely unacknowledged by health professionals in the decision-making process. That is, until they must choose an equipment:

The process takes about an hour, and they expect you to make these life decisions like comfortably in [that] time. You live with the equipment every day for [the next] five, six

years, but they expect you to know exactly what you need within that hour's worth of time just by answering questions.

Generally, patients are not provided adequate resources or time to carefully appraise the benefits and disadvantages of each potential technology. Unless they are familiar with the process from years of prior struggle, following Medicare's DME-related procedures is never easy. Sometimes even familiarity with the system is not enough to make the process quick and painless, "Every time you think something's going to be one way, they throw in a new kink into the system so that you have to deal with those. Don't assume anything, because the more you think you know something, the more kinks they throw at you." Knowledge on changing health insurance policies and device availability is critical to a patient's ability to direct their care in accordance to their needs. Often times, this knowledge base may be absent:

Well, I think I don't ever actually get enough information on what is available, and I'm not sure who to ask or where to find more. I have a lot of good people helping me. I have a caseworker who has always looked out for my best interests. But still, I don't know that she could get me a medical catalog of what's available, and what I would be qualified to use.

A weak knowledge base can prevent patients from achieving the best possible health outcomes as there might be dissonant expectations between health professionals and themselves. Overwhelming patients during appointments is counterproductive to properly managing disability care. Pressure of time may not allow participants to adequately define their health goals and find the optimal equipment. All participants expressed feelings of frustration and hopelessness on their receipt of health care delivery, partially stemming from missing strong and clear dialogue between patients and clinicians. Patients must be allowed to engage in conversations asserting their health needs, beyond the physical therapist or DME vendor,

because they have a more detailed understanding of participating in daily activities with a disability. Their words should be weighted more heavily than they currently are.

### *Patient - Physician Relationships*

Collaborative patient care practices improve the quality of health care delivery by sharing the responsibility of care between the caregiver and recipient. When both the patients and health professionals successfully work in cooperation with each other to problem solve difficulties in DME access, the process eases the burdens and stress on patients:

I'm very fortunate. I have a good relationship with [my doctor], and through our appointments and our getting to know each other, she understands that I don't ask for something I don't need. She takes very good care of me. I have never had a problem getting anything I need from her.

The goal of collaborative care is to have clinical care plans and health management goals better accommodate a patient's functional limitation, including conversations on options for DME best-suited to the user. Patients' experiences with their physicians range and some are not as optimistic about their relationships:

At [the] meeting with the therapist, the vendor, and the doctor, to a much lesser degree, will ask you what you want, but... they'll only take about an hour. You wind up dealing with the salesman more than you deal with the doctor or the therapist. They just tend to sign off on stuff. A similarity that I could come up with for you is like when you buy a car, you get more time to decide what you want for your car than we get to decide what we need for our [wheel]chairs.

When patients are prematurely passed along the next steps in formal procedures, they are cheated of the tools and knowledge to make decisions for themselves. A company vendor

may not always be a trusted source for patients to openly discuss their personal health information, especially if the vendor regards them more like a customer rather than a patient. Participants were cognizant of when they were treated like commodities rather than people.

Collaborative care creates spaces for patients to make informed health decisions, but only when communication is clear. If patients were provided productive opportunities by their physicians to have conversations without a countdown, then maybe patients would know who to ask for help about their DME or know what a stroke is and adhere to their hypertension medications. An unapproachable relationship dynamic, established between the patient and physician, can result in detrimental communication barriers. Physician competencies in treating people with disabilities also need to be carefully assessed as one participant reported having her physician laugh at her request for a wheelchair. Disparaging behaviors can alienate patients away from resources that would otherwise assist them to acquire a medically necessary technology.

### *Stigmas*

Patients with disabilities often have to disprove stereotypical preconceptions of their bodies when it comes to seeking care:

It is tricky because [I am] chronically ill and disabled, [but] I'm sitting here talking to you, and I look completely fine. This is very complicated for the medical community to work around because I look fine, I act fine, I can have a conversation, and the two don't connect very well for the medical community.

On the surface level if someone looks fine, that does not insinuate that they actually are. There can be a disconnect between health practitioners and patients in understanding the nuances of living with a disability. While physicians are experts in curing diseases, disabilities cannot be treated like pathologies. A disability can be a cultural identity appropriately

accommodated in an individual's social environment, implying that impairments do not need to cripple individuals from fully participating in their communities (Reid-Cunningham, 2009). Impedance to medical care arises when disabled bodies are stigmatized and discriminated against rather than accepted and accommodated.

In 2014, 14% of Medicaid enrollees were people with disabilities, yet 40% of Medicaid's expenditure was spent on their health care (KFF, 2017). People with disabilities have more specialized health needs than typical able-bodied individuals, and proportionally require greater government investment into their health. Still, many able-bodied individuals consider this an inequitable distribution of resources. Popular attitudes paint people with disabilities as cheaters, undeserving individuals, or a burden on the system (Hansen et al., 2014; Wong, 2017).

In a society that constantly devalues individuals with disabilities, internalization of ableist ideations is hard to escape:

[Society has] created this culture of, "I have to push myself. I cannot rest. I have to be doing more. I have to be doing something all of the time and getting any help, getting any type of assistance, is lazy." Even though [being] lazy is not a thing... There's always some reason that somebody is not living up to whatever made-up thing that we're comparing somebody else to. It really becomes such a different thing when people are not accepting the help from any medical equipment... We have attached so much of worth to health and then you put this medical equipment in somebody's hands, you've taken away their worth at that point... Internalized ableism is the number one hardest thing to get over for absolutely all of us. It is a daily thing.

Mainstream American culture heavily emphasizes the economy of the body, and socially sanctions individuals with disabilities who cannot keep pace in poorly compensated environments. Equating an individuals' worth to their functional capabilities is self-defeating

because people who fall short of meeting the functional capacities of *normative* bodies become undeserving of entitlements (Susan, 1994). This misconception can compromise the quality of an individual's life when instances that threaten that perception, e.g. the need for a DME, are disregarded. Learned prejudices against deviant bodies is a serious barrier to access of DME.

### *Advocacy*

Advocacy becomes critical to breaking down these barriers to care and increasing access to DME. More so, since the Centers for Medicare and Medicaid Services (CMS) do not conduct oversight of ADA's architectural and programmatic accessibility guideline compliance by states, health plans, and medical providers, nor assess health providers' disability cultural competence (Breslin et al., 2009). Patient advocates are a vital layer of protection for many patients with disabilities. For example, one participant was able to access legal counsel to stop extraneous billing of DME that she did not own any longer:

I did call an attorney once... There was something on the back of a church bulletin...about some product, and I wanted to discontinue it, and [the vendors] kept billing me anyway. So, I finally called an attorney here ... who had been very good about coming out here and making a will for me, and he called them for me, and they shut up.

Granted, accessibility to patient advocates is riddled with problems. One patient speaks to an experience of an unfortunate series of conversations she had with the local care facilities' staff:

We have a nurse here... [but] if you ask her stuff, she says, "Manage your own care." I asked these people, we have emergency [attendees] for like if you fall down or whatever. They were helping me while I didn't have my lift. I'd say, "Where do I go if I can't get this

lift approved and all this?" "I don't know, but you need one." I'd be like, "I can't afford it."  
"Really, you're a young lady, who's got \$2,000 in most cases, or more?"

It is nearly impossible for a patient to understand the intricate health insurance policies and related technicalities all alone. The network of support that is supposed to empower patients to be proactive with their care fails on many accounts beyond an unsympathetic ear. Notably, participants frequently encounter microaggressions throughout their interactions with their assigned support systems. Snide comments and mocking assumptions make clinical encounters uncomfortable and hostile, effectively ensuring that patients hesitate before seeking help. Self-doubt and reduced care seeking behavior inadvertently curb access to prescribed technologies.

Patients with disabilities can become adept at managing their own health, but part of the challenge includes learning self-advocacy when institutional support is inadequate. One participant has stepped into the role of educating and coaching new Medicare or Medicaid enrollees with disabilities. He describes his role as such:

[It's important to know] where to get started, what questions to ask, [and to who]. It could be the therapist. It could be the doctor. It could be the actual wheelchair vendor. Or because I've been doing it so long, [I] know what they ask. I have a lot of friends that just let their parents decide what's best, and the parents don't know. The more experience you have, the better off you do. You need to make sure that being the individual, being the consumer, that you know what you want. That's why sometimes I'll sit with friends and say, "Does this feel comfortable? Does that feel comfortable?" In other words, I take the [time]t to break down [the process] with the individual, what they don't know they ask. I have them ask me the questions as I would to the consumer.

Learning to advocate for oneself takes time, effort, and social connections. Experience, which eludes new enrollees, determines the access of quality care a patient receives. Albeit, patients who never initially receive guidance, from those more experienced with DME procedures, can feel embarrassment in asking for help and just as lost as new enrollees: “[The nurses] just give you the names and phone numbers of companies, and then it's up to you. I feel like a fish out of water sometimes because I don't know what I'm doing. I suppose I should, by my age, but I don't.” Appointment rehearsals and developing question lists ensure that a patient's health concerns are well-addressed, indicating that conversations without these precautions would otherwise not be as fruitful. Yet, one participant's ability to train others is bounded by their own human capabilities. They can only help a limited number of people when in reality there may be more groups who require similar aid. Community resources need to be more accessible to patients with disabilities requiring DME because the burden should not fall on the shoulders of single individuals. There needs to be a stronger partnership between health care providers and community-based organizations. These partnerships can facilitate best practices for disability care to ensure patients and family members are well-informed about DME and included in the care process.

#### Conclusion:

People with disabilities face considerable social and economic disadvantages in acquiring durable medical equipment. A myriad of factors such as subpar health coverage and antagonistic or neglectful treatments of people with disabilities affect device selection, coverage, and delivery. The challenges of today are widespread and intertwined. DME paves way for the social integration of those with disabilities, yet it is difficult to separate overlaps such as between employment, insurance practices, and community networks in the analysis of accessibility. Besides being difficult, these attempts are not worthwhile. It is the complexity of these connections between variables that as a whole showcases barriers, not seen at first glance, that make device access difficult.

The health and wellness of people with disabilities have not always been well-addressed in health care policies, programs, or training, which simply focus on rescuing the economics of lost productivity and health care dollars to human costs. Arranging smoother opportunities for health promotion or maintenance—as offered by DME—are as equally important as changes in health care financing (Rimmer, 1999). Evaluating the accessibility of DME showcases how advances in medicine and public health should better account for the direct and indirect health needs of the disability community. Without early interventions, the challenges of today will only coalesce and worsen the problems of tomorrow in upholding the right to quality health for people with disabilities.

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