

Statement for the Written Record from the

Independence Through Enhancement of Medicare and Medicaid (ITEM) Coalition

Ways and Means Committee Subcommittee on Health United States House of Representatives

Hearing on:

"Bridging Health Equity Gaps for People with Disabilities and Chronic Conditions"

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Chairman Doggett, Ranking Member Buchanan, and Members of the Ways and Means Health Subcommittee:

On behalf of the Independence Through Enhancement of Medicare and Medicaid (ITEM) Coalition, we appreciate the opportunity to submit this statement for the record regarding the Subcommittee's hearing on addressing health equity gaps for people with disabilities and chronic conditions. We are grateful for the Subcommittee's attention to this critical issue. As you well know, people with disabilities face major disparities in accessing health care and other services.

As your offices and the rest of Congress continue to identify and develop solutions to these inequities, we urge you to consider key issues impacting individuals with disabilities, particularly regarding inequitable access to assistive technologies and devices.

The ITEM Coalition is a national consumer- and clinician-led coalition advocating for access to and coverage of assistive devices and technologies for persons with injuries, illnesses, disabilities, and chronic conditions of all ages. Our members represent individuals with a wide range of disabling conditions, as well as the providers who serve them, including such conditions as paralysis, spinal cord injury, limb loss, multiple sclerosis, cerebral palsy, brain injury, stroke, spina bifida, ALS, low vision and visual impairments, hearing and speech impairments, and other life-altering conditions.

I. Health Equity for People with Disabilities

On behalf of the ITEM Coalition and the consumers and providers we represent, we greatly appreciate Congress' and the Administration's renewed focus on advancing health equity. In particular, we thank the Subcommittee for its recognition during this hearing that people with disabilities and chronic conditions must be included in the health equity conversation, as this population often faces severe inequities and disparities in health. In fact, President Biden's Executive Order 13895, *Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*, explicitly recognizes people with disabilities as an underserved population for federal equity efforts.

People with disabilities face significant inequities and disparities in both their health status (inclusive of and beyond their individual disabling condition(s)) and access to health care, employment, education, community participation, independence, and more. These inequities are exacerbated when considering the intersection of race, ethnicity, and other identities, as well as social determinants of health. Of course, there are also higher rates of disability among minority communities, making disability an integral part of any effort to understand and address disparities.

Unfortunately, as the Subcommittee heard during this hearing, there are numerous barriers faced by people with disabilities in accessing the care and support they need. The ITEM Coalition, in particular, has focused on access to and coverage of assistive devices and technologies, which are critical to maximizing the ability of people with disabilities and chronic conditions to be independent, meet their medical and functional needs, improve their health outcomes, reduce their reliance on caregiver and attendant support, and save on avoidable medical costs. When coverage through federal programs or private payers is unavailable, inequities become even more apparent; those who have the means to pay out-of-pocket for medically necessary technologies

are able to reap their benefits, while those who cannot afford to purchase such equipment on their own are often left without access. Below, we have identified some key areas where policymakers can make meaningful improvements, though there are many other critical gaps in access for people with disabilities.

II. Access to Seat Elevation and Standing Systems for Individuals with Severe Mobility Impairments

Individuals with mobility impairments, such as spinal cord injury, muscular dystrophy, paralysis, ALS, cerebral palsy, and other permanent disabilities and significant medical conditions, may use complex rehabilitation technology (CRT) wheelchairs to meet their medical and functional needs. For Medicare beneficiaries with significant mobility conditions who spend the majority of their days in a wheelchair, power seat elevation and standing systems are critical for their health and independence. However, the Medicare program does not currently cover these systems, deeming them "not primarily medical in nature."

The medical benefits of these systems are beyond dispute. Spending one's life unable to stand or ambulate, restricted to a bed, chair, or wheelchair 24 hours a day, seven days a week, dramatically inhibits the ability to participate in daily life and causes countless complications and secondary conditions. These medical complications are often almost entirely avoidable with access to seat elevation and standing systems in power wheelchairs, which help the user transfer more safely from their chair to other surfaces, reduce skin breakdowns and muscle contractures, and decrease injurious falls. Standing systems in particular improve joint mobility and muscle tone, increase strength and bone density, assist bladder and bowel management, enhance cardiovascular and respiratory function, and reduce neck and spine injuries associated with long-term wheelchair use.

Unfortunately, Medicare beneficiaries face severe uphill battles to access these critical systems. While many payers (including some state Medicaid programs, the Veterans Health Administration, and a limited number of private insurers) recognize the need for these systems and cover them for enrollees with qualifying conditions, Medicare beneficiaries receive no support from the largest health care payer in the country to access this medically necessary technology. Some beneficiaries can afford to pay for these technologies out-of-pocket or obtain them through charitable grant programs or other avenues, but many are simply unable to do so, severely impacting their health, function, and ability to participate in community living. This exacerbates pre-existing inequities faced by people with disabilities and runs counter to the Administration's goal of advancing health equity for underserved populations and enhancing independent living in the community.

In September 2020, the ITEM Coalition submitted a comprehensive Request for Reconsideration of the National Coverage Determination (NCD) for Mobility Assistive Equipment (MAE), seeking a new determination that these systems are, in fact, primarily medical in nature and therefore qualify for Medicare coverage under the Durable Medical Equipment (DME) benefit. This request was developed in collaboration with a group of experts and stakeholders across the

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¹ Full NCD Reconsideration Request available here: https://itemcoalition.files.wordpress.com/2020/09/item.-request-for-reconsideration-of-ncd-for-mae.pdf

disability and rehabilitation continuum, including wheelchair users, disability advocates, and clinicians serving patients with disabilities. Despite being deemed "complete" by the Centers for Medicare and Medicaid Services (CMS) in November 2020, this request has yet to be opened for public comment and has been stalled at the agency for more than 15 months.

Recently, many of your colleagues in the House and Senate, including 7 members of the Ways & Means Committee, urged CMS to move forward with this process. On October 6, Reps. Jim Langevin (D-RI) and Don Young (R-AK), co-chairs of the Bipartisan Disabilities Caucus, led 75 other Representatives in a letter seeking a timely opening of the NCD for public comment. Later that same month, Sens. Tammy Duckworth (D-IL), Marsha Blackburn (R-TN), and Bob Casey (D-PA) issued a letter calling on the agency to issue an affirmative coverage policy for these systems. This request has also been echoed numerous times by the leadership of the National Council on Disability, and by 60 national organizations from the ITEM Coalition membership. It is long past time for the Medicare program to cover these systems.

We urge members of the Subcommittee to join in calling on CMS to open this pending NCD immediately for public comment and to advance a coverage policy to fix this serious gap for Medicare beneficiaries with severe mobility impairments.

III. Access to Assistive Devices for Individuals with Low Vision and Visual Impairment

Low vision and blindness significantly impact Medicare beneficiaries, as well as the general population. In fact, low vision has been noted as one of the most prevalent causes of disability across the country. According to the National Health and Nutrition Examination Survey (NHANES), there were nearly 1.85 million individuals with low vision or worse in 2017. This represents a significant percentage among the Medicare population in particular, with beneficiaries developing low vision from a range of common conditions including macular degeneration, cataracts, glaucoma, and more. This population is also growing quickly, with nearly half a million new cases of mild low vision or worse arising each year.

Reduced visual function impacts individuals' lives in myriad ways, reducing participation in activities of daily living, employment, and in community participation; decreasing individual safety and function, and reducing the ability to manage other health conditions. Clinical literature also suggests a significant association between visual impairment and a variety of mental health conditions, including depression, social isolation, anxiety, and dementia. Low vision has a disparate impact on underrepresented groups, especially racial and ethnic minorities; for

² Letter available at: https://itemcoalition.files.wordpress.com/2021/10/10.6.21-langevin-young-ncd-reconsideration-request-letter.pdf

³ Letter available at: https://itemcoalition.files.wordpress.com/2021/10/duckworth-blackburn-casey-joint-letter-to-cms-standing-seat-elevation-ncd.pdf

⁴ See August 31, 2020 and August 4, 2021 letters.

⁵ See ITEM Coalition letter accompanying formal NCD request here:

⁶ Chan T; Friedman S; Bradley C; Massof R. Estimates of Visual Impairment, Low Vision, and Blindness in the United States. JAMA Ophthalmol. Doi: 10.1001/jamaophthalmol.2017.4655. Published online Nov. 2, 2017.

⁷ Chan, et al. Estimates of Visual Impairment, Low Vision, and Blindness in the United States.

⁸ 9 See, e.g., Court H, McLean G., et al. (2014). Visual Impairment is Associated with Physical and Mental Comorbidities in Older Adults: A Cross-Sectional Study. BMC Med. 12:181. Doi: 1001186/s12916-014-0181-7.

example, diabetic retinopathy, glaucoma, cataracts, and all-cause visual impairment affect minority populations at much higher rates than white individuals.

There are a wide range of clinically indicated technologies, known as "low vision aids," that can improve individuals' functional capacity and address the effects of vision loss. They are typically not available over-the-counter and are prescribed by vision treatment professionals; they are not intended for those with simple refractive error typically treated with eyeglasses or contact lenses. These can be "low-tech" or "high-tech," and may include devices such as optical magnifiers, telescopes, head-borne digital displays, video magnifiers, minifiers, prisms, and more. Low vision aids, when paired with vision rehabilitation services provided by qualified medical professionals, are effective for improving health-related quality of life, mental health, and independence for those with low vision.

Despite the availability of low vision devices and the numerous benefits they can afford individuals with low vision, the Medicare program currently denies coverage of any technology that uses "one or more lens for the primary purpose of aiding vision" under a 2006 regulation known as the "Low Vision Aid Exclusion." This restrictive policy goes far beyond congressional intent in broadly interpreting the statutory "eyeglasses" coverage exception and denies critical and medically necessary assistive devices for an entire diagnostic category of beneficiaries with medical and functional needs.

As with seat elevation and standing systems in wheelchairs, this exacerbates existing inequities by creating a two-tiered system where those who are able to afford such devices out-of-pocket can benefit medically and functionally from their use, while those without the financial capacity to do so are largely unable to access these technologies. *In fact, researchers have found that significant racial and ethnic disparities exist in the use of low vision aids, while no such disparities exist with reported use of low vision rehabilitation services, which are covered by Medicare.* ⁹

The Medicare Vision Act of 2021, co-led by one of the members of this Committee (Rep. Suzan DelBene), would direct CMS to undergo a review of low vision aids currently available and determine which are appropriate for coverage. While we greatly appreciate all Congressional efforts to address this serious gap in coverage, new legislation is not mandatory to begin to address this equity gap. The ITEM Coalition has called on CMS to rescind the Low Vision Aid Exclusion under its regulatory authority and allow beneficiaries to seek individualized coverage of low vision aids under the Medicare appeals process, and for stakeholders to seek broader coverage policies under the existing NCD and Local Coverage Determination pathways. Removing this discriminatory regulatory barrier is a critical first step to addressing the inequities in access to care for individuals with low vision.

We urge members of the Subcommittee to encourage CMS to lift the low vision aid exclusion and remove this preemptive barrier to coverage for beneficiaries with vision loss, low vision, and visual impairment.

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⁹ Choi S, Stagg BC, Ehrlich JR. Disparities in Low-Vision Device Use Among Older US Medicare Recipients. JAMA Ophthalmol. 2018 Dec 1;136(12):1399-1403. doi: 10.1001/jamaophthalmol.2018.3892.

IV. Health Equity Concerns in Medicare Coding, Coverage, and Payment

Access to seat elevation and standing systems in CRT power wheelchairs and access to low vison aids are just two examples of more systemic concerns the ITEM Coalition has with CMS regarding coding, coverage and payment of assistive devices and technologies, particularly new technologies in the durable medical equipment, prosthetics, orthotics and supplies (DMEPOS) benefit. While advances in surgical equipment, medications, and other treatments have been routinely covered by the Medicare program over the past several decades, CMS has been slow to grant coding, coverage, and payment of new and innovative DMEPOS that Medicare beneficiaries with disabilities routinely rely upon to be functional and independent. In fact, the regulatory effort to create temporary Medicare coverage for "breakthrough" technologies, or more recent CMS efforts to cover "emerging" technologies as an alternative to the withdrawn Medicare Coverage of Innovative Technologies (MCIT) proposal, is a subset of a broader problem.

In order to serve the beneficiaries with disabilities and other needs enrolled in the Medicare program, CMS must improve its processes to determine appropriate coverage, specific coding, and adequate pricing of DMEPOS devices and technologies. This includes both the Healthcare Common Procedure Coding System (HCPCS) Workgroup as well as the National Coverage Determination processes. Unless CMS works with stakeholders to revise and enhance its policies with an emphasis on this acceleration, many Medicare beneficiaries will continue to live without the assistive devices and technologies they need. Without the ability of innovators to bring to market new technologies and reasonably anticipate a path to coverage, beneficiaries who rely on these assistive devices and technologies will continue to be inequitably served. The ITEM Coalition welcomes the opportunity to engage in further dialogue with the Subcommittee on this important and complex issue in the future.

We appreciate the opportunity to provide the Committee with our perspective on the importance of equitable access to assistive devices and technologies for people with disabilities. These devices, when paired with medically necessary health care services offered by qualified providers, can dramatically improve the health, independent function, and quality of life for individuals with disabilities. The ITEM Coalition looks forward to working with Congress to address these priorities and to advance health equity for individuals with injuries, illnesses, disabilities, and chronic conditions. Our members are committed to these issues and work in concert with other organizations and coalitions to advance health equity from a variety of perspectives and focuses.

If you have any questions or if we can be of any assistance, please do not hesitate to reach out to Peter Thomas and Joe Nahra, ITEM Coalition coordinators, at Peter.Thomas@Powerslaw.com and Joseph.Nahra@PowersLaw.com, respectively. Thank you for your consideration of our priorities.

Sincerely,

The Undersigned Members of the ITEM Coalition

ACCSES

Access Ready

ALS Association*

American Academy of Ophthalmology

American Academy of Physical Medicine & Rehabilitation

American Association for Homecare

American Association on Health and Disability

American Cochlear Implant Alliance

American Congress of Rehabilitation Medicine

American Council of the Blind

American Macular Degeneration Foundation

American Medical Rehabilitation Providers Association

American Music Therapy Association

American Occupational Therapy Association

American Physical Therapy Association

American Therapeutic Recreation Association

Amputee Coalition*

Assistive Technology Industry Association

Association of University Centers on Disabilities

Blinded Veterans Association

Brain Injury Association of America

Caregiver Action Network

Christopher & Dana Reeve Foundation*

Clinician Task Force

Cure SMA

Epilepsy Foundation

Institute for Matching Person and Technology

Lakeshore Foundation

Lighthouse Guild International

Long Island Center for Independent Living

Medical Device Manufacturers Association

Miami Project to Cure Paralysis

National Association for the Advancement of Orthotics and Prosthetics

National Association for the Support of Long Term Care (NASL)

National Association of Councils on Developmental Disabilities

National Association of Rehabilitation Providers and Agencies

National Association of Rehabilitation Research and Training Centers

National Coalition for Assistive and Rehab Technology

National Disability Rights Network

National Multiple Sclerosis Society

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National Registry of Rehabilitation Technology Suppliers

National Respite Coalition

Paralyzed Veterans of America

Prevent Blindness

Rehabilitation Engineering and Assistive Technology Society of North America

The Simon Foundation for Continence

Spina Bifida Association*

Team Gleason

United Spinal Association*

Viscardi Center

The Vision Council

VisionServe Alliance

^{*} ITEM Coalition Steering Committee Member