



Adults with Disabilities Need Sustainable Long-Term Care

There is a significant need for long-term services and supports (LTSS) for older adults and people with disabilities.

LTSS refers to both institutional care and home- and community-based-services (HCBS). Policy-makers have been aware of and grappled with this challenge for decades with many policy proposals put forward by both legislators and policy-focused organizations, but none of these proposed solutions have ultimately been enacted.

Medicaid provides coverage for LTSS, while Medicare only covers short-term care needs, not long-term care needs. This leaves many adults who have worked and contributed throughout their professional lives without the services they need as they age or should they become disabled. These adults require assistance with activities of daily living (ADLs). ADLs include things like bathing, eating, and toileting – very basic needs which those with certain disabilities may need assistance to complete.

Americans with Disabilities and Their Caregivers Need a Long-Term Care Benefit

Adults covered by Medicare who are severely disabled and need assistance with ADLs struggle to access LTSS without either spending down funds or using other tactics to qualify for Medicaid. Yet, people who become disabled as adults and do not qualify for Medicaid due to their income and/or assets often have also contributed to Medicare and paid taxes during their professional lives and should not be penalized for their time in the workforce. Adults who require assistance to conduct basic ADLs should have a path to receive home

care assistance, which would allow them to continue to live in their homes with their families and, in many cases, continue working.

Proposed policies to achieve coverage of LTSS for disabled Americans have included long-term disability insurance programs and Medicare expansion. Unfortunately, long-term disability insurance has not been a successful option for most Americans. Challenges include denials of people with chronic illnesses, and disabilities; unpredictable and unaffordable premiums; and many carriers dropping out of the marketplace.¹

Broadening Medicare coverage to LTSS is costly to the federal budget and has generally been proposed as a policy solution for all Medicare beneficiaries. A narrow Medicare benefit for LTSS could apply to only individuals with serious disabilities.

Provide Long-Term Care for Those Who Need It Most

The Speak Foundation proposes exploring a narrow Medicare LTSS benefit to ensure those with severe disabilities can access the assistance they need with ADLs.

A benefit providing a small number of hours of weekly care (8-10 hours) to individuals with severe disabilities – those who require help with at least 3 ADLs (for example – toileting, bathing, and eating) could be a pragmatic way to provide care to those who need it most. This solution would be less costly than a broad LTSS benefit for all Medicare beneficiaries and more reliable than long-term care insurance.

1. https://bipartisanpolicy.org/download/?file=/wp-content/uploads/2021/09/BPC_Health_Long_Term_Care_RV4-min.pdf



The Speak Foundation (TSF) was established in 2008 to address the unmet needs for individuals living with LGMD and other neuromuscular diseases. TSF is a patient-led and patient-focused organization dedicated to those who often do not have a voice in regulatory, legislative, and pressing issues regarding the lack of systemic care for those living with catastrophic forms of muscular dystrophy. Improving the quality of life for those living with LGMD is an important mission to all of us. Our organization was founded on the principle: "Speak up for those who have no voice." (Proverbs 31:8). [TheSpeakFoundation.com](https://thespeakfoundation.com).