Increase Funding for Spinal Cord Injury Care, Data, Research and Program Supports

BACKGROUND
For over 50 years, the Spinal Cord Injury (SCI) Model Systems program, sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), has been the backbone of a comprehensive, multidisciplinary system of care, research, and resources for people with SCI. The services they provide encompass the entirety of the rehabilitation process from emergency services at injury through a person’s return to full participation in the community. In addition to comprehensive care for individuals with SCI, these Model Systems conduct a wide range of research and provide information to patients, professionals, and the public both nationally and internationally.

Over time, however, federal funding for SCI Model Systems has not kept pace with the SCI community's needs. While the SCI community achieved a victory in 2022 by restoring the capacity of the SCI Model Systems program to include 18 Model Systems receiving funding as opposed to 14, the average amount of funding each individual Model System receives has barely changed. Prior to 2022, this funding had remained stagnant at $6.5 million total annual funding since 2006. In restoring the capacity of the SCI Model Systems program to 18 funded centers, overall funding now stands at $8.5 million, but the amount each SCI Model System receives still stands at approximately $463,000. The purchasing power of these federal funds has not kept up with inflation or the approximate 50% growth of the SCI community since 2000. While Congress has increased funding for medical research at the National Institutes of Health (NIH) between 2015 and now by an additional $15 billion annually, an increase of 50% to $45 billion, the SCI Model Systems program has not benefited from that funding because NIDILRR is housed within the Administration for Community Living (ACL) and not NIH.

The lack of a meaningful per-Model System funding increase since 2006 has resulted in stretched budgets and increased burdens for SCI Model Systems. As the spinal cord injury community has grown, the funding provided for the premier care, rehabilitation, and services provided by the SCI Model Systems has not kept pace. Overall, the amount of inpatient rehabilitation provided per patient has been dropping significantly nationwide over the past two decades, leaving many newly-injured individuals with an SCI less prepared to re-enter their communities (with the appropriate education, medical equipment and supplies, therapeutic interventions, and community supports and services than they otherwise would have been).

In the current FY22-FY26 funding cycle, there are SCI Model Systems located in Alabama, California, Colorado, the District of Columbia, Florida, Georgia, Illinois, Massachusetts, Michigan, Minnesota, New Jersey, New York, Ohio, Pennsylvania, Texas, and Virginia. SCI Model Systems were formerly located in Arizona, Kentucky, Louisiana, Massachusetts, Michigan, Missouri, Ohio, Pennsylvania, Virginia, Washington, and Wisconsin.

REQUEST TO POLICYMAKERS AND APPROPRIATORS
• Increase funding for SCI Model Systems, https://msktc.org/sci/model-system-centers. This program is long overdue for a significant funding increase that considers inflation and the approximate 50% growth in the SCI population since 2000 - $15.75 million.
  o Explicitly maintain the $2 million in funding provided in FY22 to increase the number of SCI Model Systems receiving funding from 14 to 18.
• Increase funding for the National Spinal Cord Injury Statistical Center (NSCISC), https://www.nscisc.uab.edu, which serves as the premier source of spinal cord injury-related statistical data in the United States - $1.65 million.
• Increase funding for the Model Systems Knowledge Translation Center (MSKTC), https://msktc.org/sci, the MSKTC works with the NSCISC and the SCI Model Systems on research and on translating the data collected into useful fact sheets on various topics related to spinal cord injury that are used not only in the United States but globally - $1.95 million.
Catheter Coding and Coverage under Medicare

BACKGROUND
There are hundreds of thousands of individuals living with neurogenic bladder whose medical conditions require long-term use of intermittent urinary catheters who know too well the challenges they face and the key risk factors associated with urinary tract infections (UTIs), hospitalization and possible death. The catheter using population includes individuals with benign prostate hyperplasia, bladder cancer, diabetes, spina bifida, spinal cord injury, multiple sclerosis, and Parkinson’s Disease. Intermittent catheters are used to drain urine through the urethra and when inserted, they are designed to drain the bladder all at once and then be removed approximately 5 times a day.

There are over 1,000 different types of catheters with multiple catheter differences, including surface material (e.g. hydrophilic technology/coating) and other features that aid with clean insertion of the catheter which are necessary to ensure patients receive a catheter that fits their individual needs. Unfortunately, intermittent urinary catheters are currently grouped into only one of three HCPCS codes under Medicare: straight tip, coude (curved tip), or sterile kit with insertion supplies included.

The current code set does not distinguish between hydrophilic coating, no touch functionality, protective features or any other advanced functions. These advanced functions are medically necessary for successful catheterization which, along with increased patient adherence, can lead to improved bladder health, the decrease of secondary complications and increased independence both at home and in the community. Individuals with physical disabilities and chronic illnesses are more than likely to be immunocompromised where catheter associated urinary tract infections can lead to sepsis and death including significant expense (approximately $2.8 billion) due to medical complications (both expenses and medical complications are only exacerbated as people with impaired bladder function age) and admissions to skilled nursing facilities. The 2021 MedPAC report to Congress noted that UTIs were one of the top five reasons for referral to a facility.

Individuals with Neurogenic Lower Urinary Tract Dysfunction (impaired bladder function) are often dependent on managing their bladders with clean intermittent catheterization (CIC), done 4-6 hours every day. Even with careful technique, CIC can lead to false passage, bladder infections and pain especially with uncoated catheters. Advancements in hydrophilic (coated/lubricated) catheter technology can make catheterization easier, but more importantly, safer, by reducing trauma to the urethra and allowing individuals to catheterize with less pain and discomfort increasing patient adherence to follow their catheterization schedule. Decreased friction leads to less damage to the urethra over time. Ready-to-use hydrophilic catheters, for example, are often medically necessary for individuals with limited functional capabilities, specifically for individuals with limited to no hand function and/or anatomical considerations.

In a recently published guideline on adult Neurogenic Lower Urinary Tract Dysfunction (NLUTD), the American Urological Association and the Society of Urodynamics, Female Pelvic Medicine & Urogenital Reconstruction stated:
"The clinician treating patients with NLUTD needs to balance a variety of factors when making treatment decisions. In addition to the patient's urologic symptoms and urodynamic findings, other issues that may influence management options of the lower urinary tract include, cognition, hand function, type of neurologic disease, mobility, bowel function/management, and social and caregiver support.”

REQUEST TO MEMBERS OF CONGRESS
Ensure that the Centers for Medicare and Medicaid Services work with United Spinal Association’s Access and Care Coalition to support coding reform that provides access to catheters that serve the needs of intermittent catheter users. The uniqueness of different catheters and their varying costs and features warrant consideration of codes that adequately describe these diverse products.

Take Back Our Air Travel Rights

BACKGROUND
In 1986, over 35 years ago, President Ronald Reagan signed the Air Carrier Access Act (ACAA) into law. The ACAA prohibits discrimination based on disability in air travel. Despite some progress, too many travelers with disabilities still encounter significant barriers, such as personal injuries, damaged assistive devices, delayed and uninformed assistance and limited or unsafe seating accommodations. Thousands of United Spinal members have experienced difficulties with air travel. Recently, United Spinal President & CEO Vincenzo Piscopo was not only dropped on the airport floor by an airline personnel, but the employee also asked a complete stranger, a random air passenger, to help pick him up. And in a separate incident the back of his wheelchair was so damaged, it was unusable. Access for people with disabilities in air travel must move into the 21st century with equitable and inclusive standards. Otherwise, people with disabilities will be left further behind, unable to compete in today’s job market and denied the opportunities available to other Americans.

To address disability-related complaints under the ACAA, passengers with disabilities must file a complaint with their airline AND the U.S. Department of Transportation (DOT). As of 2018, new reporting requirements that United Spinal fought for were put in place so that airlines must report detailed numbers about mishandled wheelchairs and scooters separately from mishandled baggage. Just from December 2018 to March 24, 2022, the DOT announced the number of “lost, damaged or completely destroyed” wheelchairs at 20,000 and after this announcement the number of mishandled wheelchairs and scooters continues to grow averaging over 1000 a month. This January, the “mishandling” rate for wheelchairs and scooters was more than double the rate for luggage (1.81% to 0.81%) as reported by DOT.

Many of the difficulties that travelers with disabilities still encounter in air travel are not sufficiently addressed by the ACAA and its implementing regulations. Inadequate training for airline and contractor personnel and inaccessible airplanes result in injuries, damaged devices and delays that lead not only to lost time and missed flights but to missed opportunities for people with disabilities. Enforcement of ACAA protections is limited to administrative action and civil fines. Unlike most other civil rights laws, the ACAA lacks a guaranteed private right of action; that is the ability to sue in court. Consequently, people with disabilities typically receive little if any compensation for personal injury or damaged property.

The Air Carrier Access Amendments Acts of 2021, S. 642 and H.R. 1696, introduced by Senator Tammy Baldwin (D-WI) and Representative Jim Langevin (D-RI-2) respectively, will address the above problems by:
- Strengthening ACAA enforcement by requiring referral of certain passenger-filed complaints to the Department of Justice and establishing a private right of action (the ability to sue for grievances);
- Enforcing new airplanes are designed to accommodate the needs of people with disabilities by requiring airlines to meet defined accessibility standards to address safe and effective boarding and deplaning, visually accessible announcements, seating accommodations, lavatories, and better stowage options for assistive devices;
- Requiring removal of access barriers on existing airplanes to the extent that it is readily achievable, easily accomplishable and may be done without much difficulty or expense;
- Specifying that airport facilities, kiosks and websites must be accessible; and
- Improving the overall safety of air travel for passengers with disabilities.

REQUEST TO MEMBERS OF CONGRESS
Co-sponsor and pass S. 642/H.R. 1696, the Air Carrier Access Amendments Act of 2021, introduced by Senator Tammy Baldwin (D-WI) and Representative Jim Langevin (D-RI-2) to provide consumer protections and assistance in air travel for passengers with disabilities.
Support Disability Community Independence – Wheelchair Coverage

BACKGROUND
In 1965, the Social Security Act clearly defined the difference between the cost and coverage of medical devices in the hospital setting (Medicare Part A) compared to the cost and coverage of mobility devices that are suitable for use in the home (Medicare Part B). This distinction in payment and coverage was a means of determining under which payment model a mobility device would be covered. However, historically, there was no intent to define the benefit to meet the mobility needs of the individual ‘in the home’ only.

The Centers for Medicare and Medicaid Services (CMS) applied the ‘in the home’ rule in the updated 2005 National Coverage Determination for Mobility Assistive Equipment (MAE) by determining that MAE is reasonable and necessary for beneficiaries who have a personal mobility deficit sufficient to impair their participation in mobility-related activities of daily living (MRADLs) such as toileting, eating, dressing, grooming and bathing in customary locations within the home.

Unfortunately, due to the increasingly restrictive interpretation of the ‘in-the-home’ rule and the adoption of the Medicare coverage policy by private insurers, wheelchair users are facing constant insurance denials, resulting in health injuries and secondary health conditions, such as pressure injuries (known as pressure sores) and rotator cuff and carpal tunnel injuries, due to overuse of their upper extremities.

United Spinal would like to work with our colleagues on Capitol Hill to draft legislation for CMS to lift the oppressive “in the home” restriction to allow access to mobility devices that meet a wheelchair user’s needs for both medical necessity and functional mobility in the home and/or in the community in order to be able to fully participate in everyday activities occurring in the home and/or in the community.

- Section 504 of the Rehabilitation Act of 1973 is a national law that protects qualified individuals from discrimination based on their disability and applies to employers and organizations that receive financial assistance from any Federal department or agency, including the U.S. Department of Health and Human Services where the Federal agency, CMS is housed.
- July 1990, Congress enacted the landmark ADA to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities. Title II of the ADA requires public entities to administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.
- June 22, 1999, the United States Supreme Court held in Olmstead v. L.C. that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the ADA. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated.

We would also like to work with our colleagues on Capitol Hill to make sure that CMS holds to its commitment of opening a public comment period for National Coverage Analysis (NCA) of wheelchair standing systems coverage. We thank CMS for opening the NCA for seat elevation in August 15 (deadline September 14) but both seat elevation and standing systems - included in an ITEM Coalition joint request of a National Coverage Determination reconsideration to CMS in September 2020 - are critical wheelchair features to enable wheelchair users to have their medical necessity and functional mobility needs met both in the home and/or in the community. United Spinal Association is a Steering Committee member of the ITEM Coalition. Visit ITEM Coalition’s Rise4Access website.

REQUEST TO MEMBERS OF CONGRESS
Support United Spinal Association and the disability community to: 1) draft legislation to direct CMS to lift the ‘in the home’ restriction in order to allow access to mobility devices that meet wheelchair users’ needs both in the home AND/OR in the community; and, 2) make sure that CMS holds to its commitment of opening the public comment period for wheelchair standing systems coverage expeditiously.