

Reforming Rehabilitation and Improving Lives

BACKGROUND

Given the current U.S. population of 328 million people, the National Spinal Cord Injury Statistical Center estimates there are between 249,000 and 363,000 individuals living with a spinal cord injury (SCI). Each year, there are about 17,730 new cases of SCI.

Current challenges

In large part due to increasingly more stringent Medicare/Medicaid and private insurers reimbursement policies for individuals living with spinal cord injury, average hospital acute care lengths of stay have declined from 24 days in the 1970s to 11 days, and average rehabilitation lengths of stay have declined from 98 days to 31 days. The average life expectancy for persons with SCI has not improved since the 1980s and remains significantly below life expectancies of persons with out SCI. Mortality rates are significantly higher during the first year after injury than during subsequent years, particularly for persons with the most severe neurological impairments.

The average yearly expenses (health care costs and living expenses) and the estimated lifetime costs that are directly attributable to SCI vary greatly based on education, neurological condition, and pre-injury employment history:

- the average expenses for an individual in their first year with a high level SCI quadriplegic (all four limbs affected) is \$1,129,302;
- and, the average life expectancy, after the first year after injury, for a high level SCI quadriplegic who sustained an injury at age 20 is 33.7 additional years

United Spinal's Resource Center has documented a number of current problems with rehabilitation programs and services provided to individuals with SCI/D:

- untimely admission, increased hospital readmissions, admission into inappropriate facility as well as premature discharge from rehab facilities into other facilities such as skilled nursing homes or hospice.
- no SCI-board certified physicians or adequate education/community programs (catheter use and bowel and bladder management, ventilator, adaptive driving or adaptive fitness).
- varied facilities and levels of SCI expertise across the country: [14 SCI Model Systems](#), [Commission on Accreditation of Rehabilitation Facilities \(CARF\)](#), [The Joint Commission](#), [U.S. Department of Veterans Affairs Spinal Cord Injuries and Disorders Systems of Care](#)
- Case B: Insurer: "He will never get any better so we're not paying for rehab." Case C: Intent to discharge quadriplegic on ventilator without SCI rehab.

Request to Policymakers

- **Designating SCI Centers of Excellence** to define standards of care: *average number of people admitted annually to the SCI program? is there a rehabilitation plan (long and/or short-term)? a case manager?* and appropriate SCI rehab program components: *ventilator programs, peer support, counseling services, discharge planning.*
- **Interdisciplinary, SCI specific expertise must be present** in rehabilitation facilities with SCI programs across the country: including physiatry, neurology, urology, rehabilitation nursing, physical therapy, occupational therapy, psychology, speech therapy, recreational therapy, respiratory therapy, and peer mentorship.
- **On-site SCI education (varies widely from facility to facility) needs to be reimbursable:**
 - autonomic dysreflexia; bowel and bladder management programs, skin care programs
- **Rehab continuum for the SCI/D community in out-patient and community programs and services is critical:** access to appropriate durable medical equipment, custom rehabilitative technology, and medical supplies; peer support/networking options; physiatry, psychology services/sexuality education; education on community reintegration (adaptive fitness and wellness and assisted driving, vocational services etc.).
- **Collect rehab outcomes and health economics data to compare outcomes across settings** and review health costs throughout the rehab continuum: Centers for Medicare and Medicaid Services, National Institutes of Health and National Institute on Disability, Independent Living and Rehabilitation Research, Centers for Disease Control and Prevention, National Neurological Conditions Surveillance System (NNCSS) registry.