



Statement for the Record
U.S. House of Representatives
Committee on Energy and Commerce, Subcommittee on Health
Hearing on “Examining the Financing and Delivery of Long-Term Care in the U.S.”
Tuesday, March 1, 2016

The Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research, and improving the quality of life for people living with paralysis through grants, information and advocacy.

We would like to thank the committee for holding a hearing on this important topic. People with paralysis will need long-term care (also known as long-term services and supports) across the lifespan. And while most long-term care attention focuses on older adults, younger people with disabilities represent a significant demographic of long-term services and supports (LTSS) users.

The story of our namesake – Christopher Reeve – paints a vivid picture: that for anyone, anywhere, and at any time, your life can change in an instant, and with it your need for long term services and supports. According to data collected by the Reeve Foundation, the leading causes of spinal cord injuries are accidents at work, motor vehicle crashes, recreational activities, falls, and acts of violence.¹ These are not events for which a family can plan. People with paralysis often need assistance with basic daily functions, including bathing, dressing, and grooming. LTSS are these fundamental supports and services that people with disabilities rely on for daily life.

LTSS financing is a central concern of the estimated 1.25 million people overall with spinal cord injury, and 5.6 million with all forms of paralysis living in the US right now who will need LTSS for the rest of their lives.² Spinal cord injury affects people across the lifespan, and often occurs in young adulthood. Nearly half of all injuries occurring between age 16 and 30.³ At this age, people are not planning for their long-term care needs or thinking about purchasing long-term care insurance. They are attending high school or college, beginning their careers and starting families. After injury, they are most interested in returning to those lives with as much independence as possible; many will need LTSS to do this. According to the National SCI Statistical Center, 57% of people with SCI were employed at the time of their injury, but only 12% were employed 1 year later. That figure climbs to only 35% 20 years after injury.⁴ While some people have disabilities so significant they cannot return to work, many are hindered by their need for LTSS and a system that would remove their daily supports if they returned to work for a living.

When someone develops a need for LTSS, they find that Medicaid often their only option; few families can afford to privately pay for in home supports. Medicaid is the primary financer of LTSS in the US, and LTSS is a large part of the Medicaid program. In FY 2013, the most recent year for

¹ http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.5184189/k.5587/Paralysis_Facts_Figures.htm

² <http://www.christopherreeve.org/atf/cf/%7B3d83418f-b967-4c18-8ada-adc2e5355071%7D/8112REPTFINAL.PDF>

³ Ibid.

⁴ Ibid.

which data is available, LTSS accounted for 34% of Medicaid spending, down from a high of 40% in the mid 1990's.⁵

While Medicaid is a crucial lifeline for people with disabilities, it has drawbacks. Designed as a safety net program, it has strict income and asset limits for eligibility that limit economic advancement of people with disabilities. Many people are caught in a Catch-22: If they return to work at any substantial level they will lose their Medicaid-funded LTSS, the very services they need to get up in the morning and enable them to go to work in the first place. Faced with this dilemma, people choose to stay on Medicaid, rather than risk being unable to afford their LTSS needs. While smart policymakers have devised several work-arounds over the years, many involve complex financial maneuvering, are limited by age or other rules, and are uneven across states. We need a permanent solution that insures against the risk of life-long LTSS needs, provides people with disabilities supports in their homes and communities, and bases eligibility on functional need, not income or assets.

We encourage the committee, when discussing long-term care financing, to remember the needs of working age people with disabilities – many of whom acquired their disabilities early in life and need LTSS for independence and productivity – and the significant benefits of an LTSS system that encourages economic independence. We recommend the committee consider the approach discussed in the most recent Bipartisan Policy Center report “Initial Recommendations to Improve the Financing of Long-Term Care” that builds on the existing Medicaid program and private LTC insurance systems to insure against the “catastrophic risk” of needing lifetime LTSS.⁶

⁵ <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-fy2013.pdf> (Page 11).

⁶ <http://bipartisanpolicy.org/wp-content/uploads/2016/01/BPC-Health-Long-Term-Care.pdf> (page 22)