

UNITED SPINAL^{NOW}

Gaps in Coverage and Care

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When I started at Eastern Paralyzed Veterans Association in 1979 (I had been a disability rights lawyer for two years), the very first client I spoke to was a quadriplegic man from Dutchess County who called and said, “My check didn’t come. My home attendant didn’t come, and there’s hair in my shower drain.” I responded that I knew I could do something about the hair, but the other two issues were much tougher.

He told me that since he’d broken his neck, his wife and children had left, he had no income but Social Security Disability Insurance, and he spent down to Medicaid eligibility every month, so that he could receive homecare. When he was employed, he said, he was a safety engineer for an insurance company. He assessed risk. When I asked him why he didn’t have long-term care insurance or private disability insurance, he said, ironically, “Because I knew the odds.”

Forty-two years later, the situation isn’t much better for most people needing long-term care. Of course, in assessing risk, most people worry about disability even less than they do death. We know because far more people buy life insurance to protect their family than buy disability or long-term care insurance. Nevertheless, the people United Spinal Association represents, and many of you reading this now, rely on personal care assistance to live effectively in the community.

Health insurance – even under the Affordable Care Act (ACA), also called Obamacare – leaves a huge gap in coverage for people needing durable medical equipment (DME) or supplies. Obamacare requires insurers to meet minimum coverage requirements, and of course, eliminates pre-existing conditions, exclusions and waiting periods.

The elimination of pre-existing condition hurdles, when viewed as a policy change could, in fact, be an “Emancipation Proclamation” for some people with disabilities. Those unwilling to risk leaving Medicaid and/or Medicare to go to work, because their pre-existing conditions would not be covered, are no longer plagued by this problem.

However, those who use durable medical equipment, like wheelchairs, and those who need medical supplies (diabetic supplies, catheters, bandages, etc.) are still subject to caps in private insurance policies and in the Obamacare plans that are publicly available. If a motorized wheelchair cost is \$30,000, and an employer’s health plan caps DME at \$2,500 a year, which is perfectly lawful, the wheelchair user is out of luck.

Medicaid would pick up the cost of the chair, but private insurance will not. The need for coverage for medical supplies and DME to be covered by insurers is acute, but unmet and still keeps people with disabilities out of the labor force.

Consider these two issues together, i.e. the difficulty in obtaining adequate home-and community-based services, coupled with the unaffordability, for some of adequate supplies and equipment and the promise of the Americans with Disabilities Act and the Affordable Care Act is somewhat undermined.

To live and work effectively in the community, gaps in care and coverage have to be bridged. Requiring poverty to be a requirement for assistance is not very 21st century, nor does it give people with disabilities equal opportunity to live lives of satisfaction and achievement.

United Spinal Association works hard on these and other government policy issues. If you would like to receive our advocacy e-newsletter or join our organization (you don’t need to have a spinal cord injury or disorder), and receive *New Mobility* magazine free-of-charge, sign up at unitedspinal.org.