

The RESOURCE CENTER FOR ACCESSIBLE LIVING, INC.
Your independence is our mission.

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The Resource Center for Accessible Living, Inc. (RCAL) is the Independent Living Center (ILC) for Ulster County, located in New York's Hudson Valley. RCAL provides advocacy, information, referrals, and other supports to assist individuals with disabilities to live independently in the community.

We support solutions that address health barriers for people with disabilities. Health care barriers can arise from a lack of providers, an inability of providers to meet demand, rulemaking that fails to address needs, cost, or geography. Health barriers may lead to unemployment, underemployment, inability to access a higher education, impaired mobility, involuntary confinement to the home, or institutionalization. We do not see these as acceptable outcomes.

One of the largest health barriers is that of personal care services. These might include services for an individual with paralysis requiring 24 hours of assistance or someone with a Traumatic Brain Injury that requires less hours, but those few hours are vital to living outside of the institutional care system.

A right to Long Term Supports and Services (LTSS) in the New York State Health Act would be the solution from which generations since 1935's Social Security Act have needed. Legislation which protects those of advanced aged or with a disability through social insurance instead of short sighted programs focused on driving individuals and families into poverty, the antithesis of building a great society, due to need of assistance to lead an independent life. While Social Security can cover a limited amount for costs of living and Medicare (added to the SSA in 1965) defrays some medical expense, neither can cover the greatest health barrier to leading a full and independent life, long term care.

Keeping individuals outside of institutions is of the utmost importance because living in the community preserves personal sovereignty that enables one to lead a life of self determination. Determining when to go to bed, wake up, eat, or shower may seem trivial, but they are the monotonous daily events by which we ultimately intersect with the important meaningful events.

For many years advocates for people with disabilities have been actively working to increase service levels, create innovative programs to make more from less, create costs saving programs, and working against short sighted cost reductions. This is ultimately all for the purpose of

preserving personal sovereignty that is paramount to independent living philosophy that enables a full life lead by an individual. We have made progress within a framework of a system that is pieced together through incremental changes. It's time to think boldly about addressing a crisis of a rapidly aging population and the people with disabilities that also exist within the system.

“Among people under the age of 65, less than two percent have LTSS needs, but they represent nearly five million of the 11 million people who need LTSS. Among people now turning age 65, an estimated three in ten will never need any LTSS, while two in ten will need five or more years of LTSS. Most people who need LTSS (over 80 percent of people with LTSS needs living at home) rely solely on family and friends to provide them and do not receive paid services.” - A Comprehensive Approach to Long-Term Services and Supports, Long-Term Care Commission ¹

The financial burden of providing Long Term Supports and Services (LTSS) primarily resides within the Medicaid program which is already funded partially by New York. Medicare for individuals over 65 years of age or covered under SSDI only receive skilled nursing home care for about 3 months if there is a qualifying circumstance or up to 6 months of Hospice (end of life care). Medicare does not cover personal care service at home or what is considered ongoing custodial care which takes responsibility for assisting in activities of daily living.

Many individuals might incorrectly think they are covered as they age through the Medicare program, only to learn they must relinquish their worldly possessions to receive care through the Medicaid program. People that experience traumatic and catastrophic events which result in long term disability also find themselves in a situation where they have to reconstruct their lives around becoming eligible for Medicaid services.

The current system encourages people to strive towards poverty when services are needed because current Long Term Care Insurance (LTCI) market conditions place private long term care plan premiums beyond individuals means and are defined benefit plans which do not guarantee to cover actual costs like a health insurance policy. A defined benefit LTCI policy of \$150/day would equate to only \$6.25/hour for someone requiring 24 hour care. Far below the state minimum wage required.

In the existing Medicaid system there is also an inability to fulfill workforce demand. Cost cuts by failing to adjust wages to market rate through the Medicaid program has resulted in difficulty for people that qualify for hours to fill them. The workforce pool is shrinking as the wages fail to keep pace with other employers and the work can be difficult. In many areas of the state transportation can also be an obstacle just to reach a place of employment, which might be an

¹ <https://www.medicareadvocacy.org/wp-content/uploads/2013/10/LTCCAlternativeReport.pdf>

individual's residence. A significant portion of a day's wages might cover transportation to work.

While personal care services rely on unskilled labor there needs to be a labor pool which is large enough to support choice by employers and facilitate hiring workers suited to the work. There are cases of abuse or theft which put individuals receiving services in the precarious scenario of terminating an assistant, but possibly waiting an uncertain period before service levels return to the needed level.

Regardless of funding streams there needs to be more done to build and encourage the workforce providing personal care assistance. A statewide long term care protection via the New York Health Act presents a great opportunity to create better jobs and build a system designed to handle future services needed to accommodate a rapidly aging population while also filling current needs.

Other states are recognizing the need for long term care services. Economically, the state should not plan to rely on a nursing home system that currently costs about \$150,000 for a semi-private nursing home room in Kingston, NY². While assisted living is becoming more popular it does not deliver the same services while costs are close to that of a home health aide, and until recently assisted living facilities could discriminate on the basis of use of mobility aids like a wheelchair. Thought needs to be put into developing a flexible system to accommodate all needs.

The benefit of statewide healthcare for all will create tremendous opportunities to deliver care in innovative new ways to people with disabilities. It would be a new way to deliver care to people in early stages of a disabling condition or illness without navigating the difficulties of Medicaid eligibility or the health insurance market. A statewide plan can also be an opportunity to ensure specialist care for people with certain complex disabilities is available without a complex appeal process. Procurement, maintenance, and service of durable medical equipment like power wheelchairs could be a simpler process more focused on addressing needs than complicated approvals.

A systemic redesign of healthcare services focused on outcomes, medical needs, improved service delivery, and fair rates could be a solution to climbing costs of care, poverty, currently unmet needs, and suffering. We implore the state to continue efforts in trying to cover properly considered long term care services and other health needs through a New York Health Act.

Respectfully,

²Genworth Cost of Care Survey 2018, conducted by CareScout®, June 2018, <https://www.genworth.com/aging-and-you/finances/cost-of-care.html>

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