

## **Carolyn Wember**

I am the mother of a 26-year-old young woman with severe physical disabilities, and Medicaid is an issue very close to my heart. My daughter, Athena Savides, was born three months early, weighing just over 2 pounds. She remained in the NICU for around 12 weeks, surviving a number of health scares, until she was finally able to come home at the hefty size of 4 pounds. Athena was eventually diagnosed with cerebral palsy, which affects her whole body. However, it was clear almost from the beginning that she was a smart and sociable little girl. She graduated from Edward R. Murrow High School in Brooklyn with a Regents diploma. In 2014, Athena graduated from Brooklyn College with a Bachelors degree in French. She currently has a part-time job with our local Independent Living Center, and one day would like to become a French teacher.

Through all the years, Medicaid sustained Athena's life in the community, and continues to do so. Shortly after she was born, we enrolled her in the "Care-At-Home" Medicaid Waiver Program in New York. When she turned 18, Athena obtained eligibility for services from the NYS Office for People with Developmental Disabilities (OPWDD), so that she could receive Home and Community Based Medicaid Waiver services from OPWDD. Medicaid has paid for the years of physical and occupational therapy that Athena still needs in order to prevent her condition from deteriorating. Medicaid paid for the custom-made leg braces that Athena needed in order to prevent deformities as her body grew. Medicaid helps pay for the customized power wheelchairs that are Athena's ONLY means of mobility. Finally -- of absolutely critical importance -- Medicaid pays for the personal-care services that Athena needs in order to do ANYTHING, starting with getting out of bed in the morning. She needs "total assistance with all activities of daily living" (as they say in the home-care world): getting in and out of bed, transferring in and out of her wheelchair, bathing, dressing, toileting, eating, and on and on...

Thanks to the generous, Medicaid-funded services that were always available to Athena in New York, she continues to live at home in her Brooklyn community. If the essential, life-sustaining services funded by Medicaid continue to be available, Athena will be able to live in a home of her choice and pursue her chosen career. If those services disappear, Athena – and

thousands of young people just like her -- will be at *extremely* high risk of ending up in nursing homes, or worse.

Without her Medicaid-funded, community-based services, the outlook for Athena's future would be bleak. Athena will *always* need round-the-clock Personal Care Attendants in order to live at home. Personal-care is the one ESSENTIAL service that Athena needs in order to remain at home – and these services can be provided at home, at a relatively low cost. But Medicaid is the ONLY source of funding for long-term, community-based care for people like Athena. If Medicaid funding for home-based personal care is reduced or eliminated, Athena could end up living out her life in a nursing home or similar institution. In the long run, that alternative would cost the government far more -- and would result in the tragic waste of a vibrant young life.