

MEMORANDUM
S.323 (Stewart-Cousins)

AN ACT to amend the public health law, in relation to aiding in the transition to adulthood for children with medical fragility living in pediatric nursing homes and other settings

LeadingAge New York supports this legislation, which would permanently authorize a current demonstration program aimed at providing continuity of appropriate care to medically fragile children as they transition to being young adults with medical fragility. Public Health Law Section 2808-e was enacted in 2021 and authorized the Commissioner to approve two residential health care units for medically fragile children transitioning to young adulthood on a demonstration basis. Legislative authorization for this two-year demonstration program expires Aug. 17, 2023.

Advances in medical technology have led to an increasing number of children residing in pediatric nursing homes surviving past infancy and early childhood, into adolescence and even adulthood. These individuals have a wide range of complex medical conditions which, as these children survive and transition into adulthood, has resulted in a growing number of young adults who need complex and specialized nursing home care.

Section 2808-e defines “children with medical fragility” as individuals up to the age of 21 who have a chronic debilitating condition or conditions, are at risk of hospitalization, are technology dependent for life or health-sustaining functions, require complex medication regimens or medical interventions to maintain or to improve their health status, and/or require ongoing assessment or intervention to prevent serious deterioration of their health status or medical complications that place their life, health or development at risk. “Young adults with medical fragility” are defined as individuals who meet the definition of children with medical fragility, but who are between 18 and 35 years old.

Once these individuals reach the age of 21, most medically fragile children need to be discharged from the pediatric facilities they may have resided in for years and moved to "adult" nursing homes. This transition can be traumatic for these vulnerable young adults who are sometimes placed with elderly residents and often in settings that are significantly different than the pediatric nursing homes that they have lived in, often for many years. Adult nursing homes may be unwilling to care for these fragile young adults as they may have limited experience in providing nursing, medical, psychological, and counseling support services appropriate to the needs of young adults with medical fragility. Sadly, an estimated 30 percent or more of these highly complex young adults die within the first 12 months of discharge from their pediatric facility. Continuity of specialty care is vitally important to these individuals.

Importantly, this legislation would ensure continued access to this needed specialty care by permanently authorizing the program that was created by the demonstration under Public Health Law § 2808-e. The bill would also make it possible to expand the number of facilities and beds available on a statewide basis to care for these extremely medically fragile young adults.

For these reasons, LeadingAge NY supports S.323 (Stewart-Cousins) and urges that it be adopted.

Contact: Sarah Daly at sdaly@leadingageny.org

LeadingAge New York

13 British American Blvd., Suite 2 | Latham, New York 12110-1431 | P 518.867.8383 | F 518.867.8384 | www.leadingageny.org
