

December 14, 2023

The Honorable Kathy Hochul
Governor of New York State
New York State Capitol Building
Albany, NY 12224

Re: A.7511 (Burdick)/S.7038 (Harckham)

Dear Governor Hochul,

On behalf of its not-for-profit, mission-driven members, LeadingAge New York urges you to support A.7511 (Burdick)/S.7038 (Harckham), amending the Public Health Law to expand the nursing home demonstration program for medically fragile young adults. 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. This bill would expand the pediatric residential health care facilities eligible to participate in the demonstration program from two to four. In addition to the approval of this bill, LeadingAge New York recommends it be amended to also extend the legislative authorization of the program, as the two-year demonstration expires on Aug. 17, 2025.

Advances in medical technology and improvements in care 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 demand complex and specialized nursing home care.

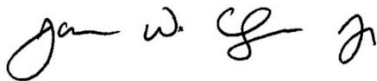
Section 2808-e defines “children with medical fragility” as individuals up to the age of 21 who have a chronic debilitating condition or conditions, are at risk of hospitalization, are technology dependent for life or health-sustaining functions, require complex medication regimens or medical interventions 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 they reach the age of 21, residents of most the pediatric facilities must be discharged from the facilities where they have spent most of their lives and transferred to geriatric nursing homes. This transition can be traumatic, resulting in placements in settings that are significantly different from the pediatric nursing homes. Geriatric nursing homes may be unwilling or unable to care for medically fragile young adults, as they may have limited experience in providing the complex nursing, medical, psychological, and counseling 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.

This legislation would expand access to this needed specialty care for medically fragile young adults. Importantly, the bill should be improved upon by permanently authorizing the demonstration program under Public Health Law § 2808-e, as the needs for this specialty care will only increase as medical capabilities advance.

For these reasons, I strongly urge your approval of bill A.7511 (Burdick)/S.7038 (Harckham) to support the best possible care and quality of life for medically fragile children transitioning to young adulthood.

Sincerely,

A handwritten signature in black ink, appearing to read "James W. Clyne, Jr." in a cursive style.

James W. Clyne, Jr.
President & CEO
LeadingAge New York