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The Honorable Cindy F. Friedman, Chair

Massachusetts State Senate Committee on Health Care Financing
24 Beacon Street, Room 313-B
Boston, MA 02133

Position Letter: S.866 (An Act to Protect Medically Fragile Children) – Support if Amended

Dear Chairwoman Friedman and Members of the Massachusetts Senate Committee on Health Care Financing,

Students for Patient Advocacy Nationwide supports the intent of S.866, which aims to strengthen care delivery for medically fragile children in the Commonwealth by increasing access to continuous skilled nursing (CSN) under MassHealth. We recognize the importance of this legislation in addressing the profound challenges faced by families caring for children with complex medical needs. However, after careful review of the bill's language, we respectfully request a focused amendment to improve data transparency and long-term care planning, ensuring that S.866 is both effective and sustainable in practice.

Specifically, S.866 sets a goal of fulfilling at least 85% of approved CSN hours by 2024 and calls for a biennial review of CSN delivery. Yet, the bill does not define how "fulfilled" or "unfulfilled" hours will be measured, nor does it include a mechanism to formally capture caregiver and family experiences with barriers to care. Without standardized reporting criteria or patient-level feedback, fulfillment data may obscure root causes, such as staffing shortages, administrative delays, or care refusals, and ultimately fail to guide responsive policy interventions.

This is more than a technical issue. A 2023 report by the Home Care Alliance of Massachusetts found that nearly one in four approved CSN hours statewide were going unfilled, and many families reported waiting months before any care began. Additionally, a significant number of respondents cited inconsistent scheduling, provider unavailability, or inadequate communication as primary reasons for gaps in coverage. Without codified caregiver feedback or clear metrics, these real-world challenges are unlikely to be captured in state reporting, making future legislative or regulatory response difficult to justify or target.

To address this concern, we provide the following Amendment Proposal:

Amend Section 3 of S.866 to add the following provisions:

“MassHealth and the Center for Health Information and Analysis (CHIA) shall jointly establish standardized definitions for the terms 'fulfilled hours' and 'unfulfilled hours' as used in reporting CSN delivery. These definitions shall include, but not be limited to: (i) hours unfilled due to staffing shortages, (ii) hours declined by the family, and (iii) hours lost to hospitalization or administrative issues. This information shall be included in the biennial CSN delivery report.

Additionally, MassHealth shall conduct an annual caregiver and patient satisfaction survey to identify barriers to receiving authorized CSN hours, including care coordination challenges, service denials, and provider access limitations. A summary of the survey findings shall be published as an appendix to the biennial report.”

This amendment will ensure that the reporting infrastructure created by S.866 produces actionable insights, while giving voice to the families directly impacted by service gaps. It requires no new regulatory body and minimal administrative overhead, yet offers meaningful benefits to patients, providers, and policymakers alike. In codifying definitions and feedback mechanisms, Massachusetts can ensure that this well-intended legislation results in real-world impact.

SPAN is proud to Support S.866 If Amended to include this clarification. We respectfully urge the committee to adopt this amendment to strengthen the bill's effectiveness and long-term accountability. We are available to provide additional data, testimony, or technical input upon request.

Sincerely,



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Collegiate Ambassador, SPAN



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