Disability Law Center

http://www.dlc-ma.org ● mail@dlc-ma.org

Main Office
11 Beacon Street, Suite 925
Boston, MA 02108
617-723-8455 | 800 872-9992 Voice
617-723-9125 Fax

Western Massachusetts Office
32 Industrial Drive East
Northampton, MA 01060
413-584-6337 | 800-222-5619 Voice

August 10, 2023
(via electronic mail to john.lawn@mahouse.gov and cindy.friedman@masenate.gov)

Representative John Lawn, Jr, House Chair
Senator Cindy Friedman, Senate Chair
Joint Committee on Health Care Financing
Room 236
Boston MA 02133

Re: Disability Law Center Comments on Continuous Skilled Nursing (CSN) legislation (H. 1192 and S. 748).

Dear Representative Lawn, Senator Friedman, and Members of the Committee,

We are writing on behalf of the Disability Law Center (DLC) to provide written testimony in support of H.1192 and S.748, An Act to protect medically fragile children.

As you may know, the Disability Law Center (DLC) is the Commonwealth's Protection and Advocacy system, representing the interests of people with developmental disabilities under the federal mandate of the Protection and Advocacy for Persons with Developmental Disabilities Act (42 U.S.C. 15041-15045). *See also,* 42 U.S.C. sec. 10801 (people with mental illness) and 29 U.S.C. sec. 794e (persons with other disabilities). One aspect of this role is the authority to engage with policymakers on issues of concern to our constituents with disabilities, see e.g., 42 U.S.C. sec. 15043 (a)(2)(L).

The Continuous Skilled Nursing (CSN) program serves children and adults with complex medical needs requiring skilled nursing to remain in their homes, with their families, and out of institutional settings. Without medically necessary skilled nursing, these children and adults are **at serious risk of poor health outcomes and institutionalization**. To determine the number of hours that MassHealth will authorize for in-home nursing, the state conducts an assessment to determine the number of hours it deems are medically necessary for the CSN member to remain in the community.

At present, the Continuous Skilled Nursing (CSN) program has significant access and operational issues that put CSN members and families at serious risk of poor health outcomes and institutionalization. As the Committee is aware, many CSN families have large gaps in nursing coverage due to the inability to find nurses to fill their authorized hours. It is commonplace to hear accounts from families only able to fill 15 out of 110 authorized hours, zero out of 65 authorized hours, and other similar scenarios. Many families are resigned to the idea that having 50% of their hours filled is decent coverage.[1] Unfilled authorized nursing hours means the nursing care must be performed by the family, forcing many parents to leave jobs, experience financial instability, and endure extreme stress and trauma caused by the physical and emotional toll of providing of intense care with little or no relief. Significant gaps in nursing hours mean that **families are providing their children with all treatments, assessments, and care related to, for example, central lines, ventilator usage, feeding tubes, respiratory treatments, tracheostomy care, oral and tracheal suctioning, and other life-sustaining interventions**. This is unsafe, unjust, and unsustainable.[2]

DLC supports the provisions in H.1192 and S.748 that set forth expectations that EOHHS will increase the budget for CSN to ensure that 75% to 85% of authorized hours will be filled between 2023 and 2025 and continuing thereafter. We also support

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[1] The 2022 Continuous Skilled Nursing Care Biennial Report prepared by the Massachusetts Center for Health Information and Analysis (CHIA) contains information for 2018 through 2020. Unfortunately, this report does not have more recent data regarding unfilled hours and other key data points. According to this report, over one million authorized nursing hours were not filled (measured by whether MassHealth paid for the CSN service) from 2018 through 2020. Of nearly 2.8 million hours, 1.77 million were filled, or 64%. The percentage filled is even less for pediatric CSN members, hovering around 60%.
https://www.chiamass.gov/assets/docs/r/pubs/2022/Continuous-Skilled-Nursing-Care-Report-2022.pdf

The issue of unfilled nursing hours is not new. In December of 2001 *Sabbag v. Romney,* C.A. 01-12211-WGY was filed in the U.S. District Court for Massachusetts, challenging MassHealth rates that were insufficient to recruit and promptly make available an adequate number and a geographic distribution of private duty nurses. The case resulted in a class action settlement reached in August 2005. See
https://storage.courtlistener.com/recap/gov.uscourts.mad.7596.54.0.pdf

[2] It is generally accepted that reliance on immediate family as the long-term first line of care provision for any disability population is poor public policy due to its unsustainability. EOHHS recently has devoted substantial resources (staff time and funds) to create positions for parents to be paid care providers for a portion of the medical care they provide. While parents should receive compensation for nursing care they are providing due to the state's inability to ensure sufficient nursing hours coverage, MassHealth and EOHHS must devote resources to addressing the need for skilled nursing to which CSN members are entitled. Moreover, the program that would pay parents for a portion of the total nursing care they are providing requires nurse supervision. This means that a nurse that could be filling authorized nursing hours in a CSN member's home is now being diverted to provide supervision to a parent providing care to their child.

the provisions in this proposed legislation that require detailed annual reporting and reviews of wage payment rates.

However, we are concerned that these provisions, as important as they are, may not go far enough to address the systemic issues with the CSN program. Examples of the individual stories DLC regularly hears makes plain the depth of the current crisis:

- An infant with a trach, g-tube, and other serious medical conditions went home from the hospital/NICU with none of the approximately 85 nursing hours filled. The family had no nursing for three months and no overnight nursing for close to five months.
- A parent providing most of the nursing care to their young adult child, including substantial physical care, has put off their own necessary orthopedic surgery for years because they do not have sufficient nursing hours filled to allow for their surgery and needed recovery time.
- A child was stuck in the ICU for months away from their family and unable to be discharged because none of their nursing hours were filled.
- A young child stopped breathing overnight numerous times over the course of just two months, needing life-saving interventions, all of which were provided by the parents since they had no overnight nursing hours filled.

The impact of unfilled nursing hours on the child or adult goes far beyond their immediate medical needs. Because the CSN program fails to ensure that members get adequate nursing coverage, children and adults, and their families, are losing safe access to their communities and, instead, may experience significant isolation in their home. Without sufficient nursing hours filled either by the school district or through the CSN program, children across the state are missing school and being deprived of their right to a free and appropriate education (FAPE). Adults are unable to access or attend various services to which they may be eligible through the Department of Developmental Services or MassHealth day habilitation.

Rates and Wages for Nurses:

In order to address the crisis of unfilled nursing hours, the Commonwealth must **increase the rates provided for in-home nursing**. The rate increases must be sufficient for CSN agencies to operate, but, most importantly, the wages paid to the nurses must be increased to ensure **they are competitive with similar care and the skills required for working with complex and acute patients.** We acknowledge that the Commonwealth has implemented some rate increases since the start of the pandemic; however, these increases remain insufficient to ensure pay to nurses that is commensurate with the skills required and competitive in the market. For example, a nurse providing in-home services to an individual who has limited, or no mobility and complex medical conditions should not make significantly less per hour than a nurse who administers COVID-19 booster shots.

The acuity of the medical needs of many CSN members cannot be understated. The reality is that many of these children and adults cannot be treated at Urgent Care locations or local, community hospitals. Instead, when they require hospitalization, they are treated in our major medical institutions, and very often in ICU settings within those. However, the wages nurses providing CSN services receive are significantly less than the wages of nurses working in acute care hospitals. A nurse providing CSN services to a child with multiple complex medical needs recently noted that CSN nurses are caring for the same patient, just in a different setting, and doing so with less support. Furthermore, the nurses providing CSN services have a crucial role in cutting down on avoidable, often traumatic, and very costly hospitalizations.

DLC recommends that the Committee consider requiring rate and pay scales that reflect the high acuity/needs of many members. Regular wage reviews, including comprehensive and transparent data tracking, are vital to ensure ongoing competitive wages for nurses providing CSN services. In addition, failure to take high acuity into account when determining pay for CSN services translates to greater difficulty in filling CSN hours for members who require higher levels of care. Therefore, DLC believes that having a **graduated rate scale based on acuity of care** is crucial to ensuring that CSN members with the most critical needs do not have the most difficult time securing nursing coverage. Having a rate add-on can incentivize highly skilled nurses to work on high acuity cases in home settings.

The failure to pay rates that practically allow families to utilize allotted hours and prevent their MassHealth member from institutionalization or risk of it, has legal implications too. This includes the Commonwealth's compliance with the Americans with Disabilities Act (ADA), the U.S. Supreme Court's *Olmstead* decision, and, with respect to CSN members under age 21, the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) provisions of the Medicaid Act. This is well-illustrated by the recent decision, following a bench trial, in *U.S. v. Florida*, a case brought by the U.S. Department of Justice concerning the state's lack of viable community nursing supports. Children are sent to pediatric nursing homes (or are at risk of being sent) when their families cannot fill the nursing hours authorized by the state due to low reimbursement rates.[3] The court's strongly worded decision, detailing and decrying the current system in Florida should motivate Massachusetts not to maintain a CSN program that is similarly flawed.

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[3] *United States v. State of Florida*, 2023 WL 4546188 (S.D. Florida, July 14, 2023), available at https://law.fsu.edu/sites/g/files/upcbnu1581/files/Academics/Clinical%20Programs/Health%20Care/23520565-0--16423.pdf (Finding the state "liable for policies and practices that result in the unjustifiable segregation of institutionalized children with medical complexity, and that place other children at serious risk of similar institutionalization, in violation of Title II of the [ADA]"); See also https://www.miamiherald.com/news/health-care/article277401553.html; https://wusfnews.wusf.usf.edu/courts-law/2023-07-17/federal-judge-rules-against-florida-children-nursing-homes; https://www.justice.gov/opa/pr/court-finds-state-florida-violates-americans-disabilities-act-institutionalizing-children This decision contemplates that the court may consider termination of monitoring and the injunction when 90% of authorized and requested private duty nursing hours are achieved on a rolling 12 month basis. Id at. 64.

Other Areas of Concern:

As noted previously, DLC regularly hears from families in the CSN community regarding the challenges their families are facing with the current CSN program. Below are issues that seriously concern us and warrant the Committee's consideration:

- **Loss of Nurses When Hospitalized**: When a CSN member experiences a lengthy hospitalization, it is common for the family to lose existing nursing coverage. CSN nurses are not paid while the member is hospitalized (even if they were to provide one-to-one care to the member at the hospital). Therefore, hospitalization **often forces the CSN nurse to find employment elsewhere.** Although the individualized nursing for a complex patient that a CSN nurse provides is very often unavailable at the hospital, MassHealth regards it as a duplication of services for the CSN nurse to work with the person while in the hospital.

  A real-life example provides the best illustration of the problem. A parent reported to DLC that her adult child was hospitalized for months and, as a result, the family lost all the nurses and PCAs (Personal Care Attendant) who had been providing care in the home. Since MassHealth deems the presence of the CSN nurse or PCA to work bedside with the CSN member a duplication of services and the member's medical complexity requires constant specialized supervision, assessment and care, a parent had to remain bedside around the clock, sleep deprived, and without pay.

  Each discharge home is incredibly challenging and arguably unsafe without any nursing coverage and parents exhausted from months of bedside care. This loss of services during hospitalization puts the individual at risk of poor health outcomes and institutionalization.

- **Loss of Unused Nursing Hours:** For many families struggling to fill nursing hours, unused hours accumulated during a given prior authorization period extend well into the hundreds, even thousands. At the end of the authorization period, the members/families **lose all of these "banked" hours.** From a fiscal standpoint, these lost "banked" hours constitute millions of dollars that should have been utilized through the CSN program, had nursing coverage been available to members for whom such services are deemed medically necessary. Family members do not understand what happens to all of the funds that, at least theoretically, were budgeted for the provision of nursing. DLC encourages the Committee to consider engagement with stakeholders to address this issue of fundamental fairness and fiscal management and explore solutions such as allowing members to carry over unused hours to a new prior authorization period or using the unused funds to increase nursing wages.

- **<u>Case Management Services</u>:** Effective care management is critical to support the medically complex CSN population and their families such that CSN members can remain living in the community. **The current system provides no meaningful access to care coordination, leaving the burden of filling hours of medically necessary nursing coverage on family caregivers**.[4] It is essential that care management include, *at a minimum*: (1) securing CSN services through finding, recruiting, training, and scheduling of appropriately-qualified nurses; (2) developing and implementing individualized crisis plans to help ensure back-up nursing coverage during temporary absences and unexpected lapses; (3) assisting with securing other Medicaid-funded in-home services, such as, durable medical equipment, personal care attendants, and home health aides; and (4) supporting discharge planning from acute hospital admissions though coordinating resumption of in-home CSN services. Care management responsibilities must also be responsive to the individualized needs of CSN members and their families, which vary widely based not only on individual medical needs of the member, but also on communication and language access needs, income, housing environment, etc. Accordingly, case managers must be prepared to fulfill their duties in an accessible, culturally competent manner.

- **<u>CSN Assessment Tool</u>**: Based on our individual cases and systemic work, DLC believes **the assessment tool utilized to determine the number of medically necessary skilled nursing hours is flawed** for the following reasons:

    - The assessment determines the duration of medically necessary skilled nursing interventions by minute (not hours). **Calculating and approving nursing coverage per minute is detached from the reality of how nursing coverage is scheduled and provided – in hour long shifts.** Utilizing the current assessment methods, a CSN member who requires medically necessary nursing interventions lasting 5 minutes once per hour every day would be approved for only 14 hours of nursing coverage per week, despite their need for around-the-clock nursing care.[5] In addition,

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[4] EOHHS issued an RFP for a new care coordination program and received no bids. DLC's understanding from CSN community members is that there was a significant amount of community input and concern with aspects of the proposed program that they feel the state did not adequately consider, some of which may have contributed to the failure of the Commonwealth to obtain any bids. Moreover, at the same time as the RFP was issued, MassHealth also noted it would be offering an existing care management program utilized by other MassHealth populations (Cares for Kids) to the CSN community, though only to those under age 21. Our understanding is that there are CSN community members concerned that it is not appropriate for the specific, varied, and acute needs of the CSN community.

[5] DLC is currently representing a young girl, "Deborah" (a pseudonym), who previously lived in Maryland, where she received over 100 hours of skilled nursing through the state's Medicaid program. This allowed her to reside at home with her family for many years. Upon moving to Massachusetts, MassHealth, based strictly on the results of its CSN assessment tool, only

the existing assessment tool does not allot any time for nurses to complete their required charting/documentation; this time comes out of the time that has been determined minute-by-minute per skilled nursing intervention.

- **The assessment tool does not consider the needs of parents to sleep, as a basic matter of health and safety,** if a child requires skilled nursing interventions overnight, as many do, the time allotted is assessed minute-by-minute as well. The tool is **similarly inflexible** in failing to consider the circumstances of family members, including single parents, **to work to provide food and housing for their family.** They are left with the impossible task of working and covering the sometimes-hourly gaps in nursing coverage caused by the unrealistic application of MassHealth's assessment tool.
- Community members report that the assessment tool does not capture time well for **seizures.** The time for task method does a poor job at assessing time for issues or medical emergencies that do not occur on a schedule, or that may not happen every single day but are serious. One parent described to DLC that her child has life-threatening seizures that are "predictably unpredictable" in that it is known the child will have seizures but the specific timing or frequency per day is, of course, unknown.
- Other parents report that the time-for-task tool is not inclusive of every medical need, counts minutes for an intervention based on the assessor's opinion about how long a particular task should take, and does not consider **how long care actually takes** when medical crises happen.

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Thank you very much for the opportunity to comment on this critically important issue. Should the Committee have any questions or wish to discuss the above with DLC, please contact Hillary Stanisz at hstanisz@dlc-ma.org.

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authorized her for about one-third of the skilled nursing hours she received from Maryland, forcing her to be institutionalized in a long-term pediatric care facility, where she remains. MassHealth has agreed that Deborah requires skilled nursing interventions at least every two to three hours, if not more frequently. However, as discussed above, **MassHealth's assessment tool did not account for the high frequency and around-the-clock nature of these interventions.**

Sincerely,

Hillary Stanisz/rmg

Hillary Stanisz
Senior Attorney

Rick Glassman
Director of Advocacy

Barbara L'Italien
Executive Director