Disability Law Center

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Executive Office of Health and Human Services
c/o D. Briggs
100 Hancock Street, 6th Floor
Quincy, MA 02171

Re: Disability Law Center Comments on Proposed Regulations – 130 CMR 438 and 101 CMR 361

To the Executive Office of Health and Human Services:

The Disability Law Center (DLC) appreciates the opportunity to comment on the proposed Continuous Skilled Nursing (CSN) Agency regulations, 130 CMR 438, and Rates for Continuous Skilled Nursing Agency and Independent Nursing Services regulations, 101 CMR 361. DLC is the Commonwealth's Protection and Advocacy system, representing the rights of people with disabilities in Massachusetts. This includes the federal mandate of the Protection and Advocacy for Persons with Developmental Disabilities Act, 42 U.S.C. § 15041 *et seq*. One aspect of this role is the authority to engage with policymakers on issues of concern to our constituents with developmental disabilities. *See* 42 U.S.C. § 15043(a)(2)(L).

As the Executive Office of Health and Human Services (EOHHS) is aware, the current CSN program has significant access and operation issues that put members and families at serious risk. DLC appreciates that EOHHS has been working on solutions to some of these issues, including obtaining community input, researching improvements, and drafting the proposed regulations. While we are hopeful that aspects of the proposed regulations will improve the CSN program, we would like to note the following concerns with the proposed revisions:

I. COMPLEX CARE ASSISTANT (CCA) – 130 CMR 438.415(C)

The addition of a CCA position in the proposed regulations has the potential to be a useful option when contending with nursing shortages in home care. CCAs could bring vital support for members and some income to families working around the clock providing nursing services due to unfilled CSN hours. DLC appreciates the addition of this option, but has broad concerns about its implementation as well as pointed concerns related to the language of the proposed regulations, as explained below:

a. CCA Impact on Approved Nursing Hours

DLC is deeply concerned that members and families who utilize CCAs as a stopgap measure will risk losing previously approved nursing hours. The CCA option is only beneficial to CSN recipients and their families if it supplements, rather than supplants, nursing hours. We urge EOHHS to provide clarification as to whether the number of hours assessed and allotted for CCA is a separate determination from the number of hours assessed and allotted for nursing. If there is a separate assessment and authorization, there appears to be a very real possibility that members will lose nursing hours.

To guard against the loss of CSN hours, the regulations should be revised to include explicit language that utilization of a CCA cannot be considered as grounds to reduce the number of nursing hours for which the member qualifies.

b. Determination of Appropriateness of CCA Services (130 CMR 438.415(C)(3))

We request clarification regarding how the determination is made as to whether or not services may be safely performed by a CCA. Based on the proposed regulations, a high acuity member may have needs/services for which a determination is made that it is not safe for a CCA to perform. High acuity members and their families often struggle the most to secure nursing coverage, leaving the families to provide a significant amount of the care. If the determination is that no services can safely be performed by a CCA, a parent providing the bulk of the care due to lack of nursing cannot receive compensation as a CCA. Based on the proposed regulations, such a parent caregiver could only be compensated as a Home Health Aide (HHA), a significantly lower pay rate than a CCA and fewer eligible hours for pay since the HHA program is for ADLs. The possible disparate impact on high acuity members and their families is concerning, and we strongly recommend that EOHHS engage with stakeholders to create flexible solutions to avoid this impact.

At the same time, it is important to recognize that, due to training received in the hospital on various interventions and providing nursing care day in and day out, families have a level of expertise in the medical care provision to their loved ones. The same is not necessarily true of a non-family member, non-nurse CCA. We are aware of particular family member community concerns, and support those concerns, about some of the services the proposed regulations allow non-family member, third-party CCAs to perform. If problems arose while a third-party CCA performed one of the listed nursing interventions, there are potentially serious ramifications for the member. Without the on-site back up of a licensed nurse, this could be a potentially dangerous situation, and leaves some families wondering if they would have to remain in the home at all times to essentially supervise the CCA.

For example, if the third party CCA is performing a Gastrostomy tube or Jejunostomy tube feeding or care of the same and the G- or J-tube comes out, it is not appropriate for the CCA to try to reinsert the tube or insert a new tube. This is a nursing service that requires specific training and is not a listed service for a CCA in the proposed

regulations. Removing or inserting such tubes incorrectly can cause severe damage. If the CCA is performing oral suctioning or using a suction toothbrush and an issue occurs resulting in significant aspiration, the CCA cannot assess the aspiration and next steps as a licensed nurse is trained and licensed to do. The same is true for oxygen related services resulting in a respiratory issue, such as oxygen desaturations. From a logistical standpoint, it is unclear how a CCA performs, for instance, overnight continuous oxygen therapy when a member requires other interventions during the night that, per the proposed regulations, only a nurse can perform, such as tracheal suctioning.

We strongly recommend that EOHHS engage with family stakeholders regarding the CCA role, training and allowed services to perform.

c. CCA Assessment Requirement

The proposed regulations are not clear about whether CCA services are an opt-in service or whether all members must be assessed for receipt of CCA services. We urge you to revise the proposed regulations to clarify that CCA is an opt-in service that is among the services that care coordinators must provide information about and access to but that assessment for and acceptance CCA services members are not requirements.

d. Flexibility with CSN/CCA Hours Based on Nurse Availability

The proposed regulations provide no clarity as to whether a CSN member will be able to shift back and forth between CSN hours deemed to be medically necessary and CCA hours depending on the availability of providers. This flexibility is critical to the success of this program.

e. CCA Training, Employment, and Oversight Requirements (130 CMR 438.415(C)(3), (5))

While the CCA program is being promoted as compensation for family caregivers who have been providing services due to lack of nursing coverage, the proposed regulations do not differentiate between training requirements for a family member CCA and for a non-family member CCA. Requiring families already doing the work of a nurse, never mind the work of the proposed CCA, to undergo the same lengthy training as a third party CCA is burdensome and impractical. In many cases, families must be trained and demonstrate competency with required medical interventions or equipment usage as a requirement for hospital discharge (or rehabilitation center, such as the Franciscan). We request that EOHHS amend the proposed regulations to reflect two training tracks – one for families already doing this work and one for third party CCAs.

The proposed supervision requirements for the agency RN supervisor in 130 CMR 438.415(C)(5) are overly burdensome on members and families. It is unclear why the RN supervisor has to go into the member's home every 14 days or less to assess the CCA, but the CCA need not be there. If such a check-in must occur, it seems it could occur through a phone or video call and at a less frequent interval. It is also unclear why this on-site visit every 14 days or less must occur when the CCA is the family member. Families

already provide skilled nursing care due to lack of nursing coverage. Adding this layer of supposed supervision because they may now receive payment for all their work seems to be an unnecessary administrative expense. Like our recommendations regarding CCA training, we recommend that separate tracks for supervision exist for family member CCAs and non-family member CCAs.

f. Permissible Percentage for Agency Administration Costs (130 CMR 438.15(C)(2)(a))

DLC is concerned that allowing CSN agencies to take up to 35% of the CCA rate for administrative costs will lessen the rate of pay too much to attract appropriate candidates for the job. Individuals and families across the state already struggle to fill PCA hours due to low pay. The typical rate for a basic babysitter is usually $20-$25 per hour. The CCA position, if meant to attract candidates other than family members already responsible for providing the care, must provide compensation significantly above the PCA rate and rate of an untrained babysitter.

We recommend that EOHHS provide stakeholders with the methodology it used to determine the percentage for CSN agency administrative costs. It is difficult to understand the high percentage of up to 35% for administrative costs when the CSN agency role should be quite small with a parent CCA who has been doing the CCA job, and more, all along.

Further clarity as to the high percentage is also needed to ensure community buy-in. Ongoing issues already exist with the amount of uncompensated training the member or family must provide nurses new to their case often due to insufficient hands-on training the nursing agency provides.

II. BACKUP STAFF RESPONSIBILITIES (130 CMR 438.415(A)(1)(C))

We have concerns regarding the regulatory responsibility of CSN agencies to provide backup staff when coverage is required due to illness, vacation, or other reasons. The provision of backup staff is infrequent, and, instead, the responsibility to provide the medically necessary nursing care falls to families. The regulations require further clarity as to the consequences to the CSN agency when the member or their family has requested backup staff and the agency fails to provide it. The required administrative policies and procedures that each CSN agency must develop and follow to provide backup staff are not consistently provided to members or their families. We recommend that EOHHS ensure families receive all required policies so that they can advocate for compliance with the same or pursue complaint mechanism for noncompliance.

III. UNUSED NURSING HOURS (130 CMR 438.411(F))

For many members and families struggling to fill nursing hours, unused hours accumulated during a given prior authorization period extend well into the hundreds. 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. It is unclear what happens to all of this money that, at least theoretically, was budgeted for the provision of nursing. DLC strongly encourages EOHHS to engage with stakeholders to address this issue of fundamental fairness and fiscal concern 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.

IV. CARE MANAGEMENT (130 CMR 438.414)

Effective care management is critical to support CSN recipients and their families and keep members living in the community. The regulations should better define care management duties, as the current system provides no meaningful access to care coordination, leaving the burden of filling hours of medically necessary nursing coverage on family caregivers. 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 HHAs; 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 communication and language access needs, income, housing environment, etc. Accordingly, clinical managers must be prepared to fulfill their duties in an accessible, culturally competent manner. We urge EOHHS to continue seeking input from the community of diverse families receiving CSN services.

In addition to our comments above regarding case management, we have specific concerns regarding compliance with current regulatory requirements:

The Needs Assessment "will include input from … LTSS providers, and other treating clinicians." 130 CMR 438.414(A)(2). Clinical managers are, at best, inconsistently seeking input from treating clinicians. It is DLC's understanding that clinical managers typically review treating clinicians' orders; however, orders on file at CCM and/or a nursing agency alone provide an incomplete picture of the member's medical and skilled nursing needs. Realistically, treating clinicians do not put every instruction or intervention in an order. Often, these instructions are communicated through an online patient portal discussion, verbally at an appointment, or over the phone to a family member. Without effective care management, ensuring every instruction given to a member/family from a treating clinician is put into a written order and sent to applicable nursing agencies and/or CCM is extremely onerous and unrealistic for families already stretched thin.

The plain language of the regulation requires more than reviewing orders. Instead, clinical managers should be getting input from important and frequent treating clinicians and specialists, particularly if the member/family has requested it. Often, what a treating clinician's medical opinion is about the amount of nursing hours that should be in place as a medical necessity for their patient to fulfill basic safety needs differs significantly from the actual allotted hours through the Needs Assessment.

Many specialty clinics or hospital programs that members frequently utilize have designated case managers/care coordinators for this exact type of coordination. Per 130 CMR 438.414(A)(6), clinical managers are mandated to work collaboratively with other case managers assisting the member. Based on community report, clinical managers frequently are not complying with this requirement, and members/families typically are not aware of this regulatory requirement for clinical managers.

V. CSN RATES AND ACUITY (101 CMR 361.04)

A major barrier to a properly functioning CSN program that the proposed regulations do not address is a pay scale that reflects the high acuity/needs of some members . Failure to take acuity into account translates to greater difficulty in filling CSN hours for members who require a higher level of care. A graduated rate scale to reflect the acuity of care is necessary for CSN to be competitive with other critical care settings. Having a rate add on can incentivize highly skilled nurses to work on high acuity cases in home settings. As EOHHS considers further rate revisions, DLC urges you to consider industry expertise to develop rates that will help fill the nurse staffing gaps experienced by families.

DLC understands that nursing rates were increased by 20% through the use of one-time American Rescue Plan Act funding. EOHHS/MassHealth has represented that this 20% increase would be permanent. It is unclear from the proposed regulations whether this 20% increase is permanent and incorporated into regulation. Instead, the proposed regulations reflect only the 10% rate increase. Please provide clarification.

The proposed regulations put forth a rate of pay for a "Complex Care Assistant Visit." This language differs from that for nursing, which refers instead to nursing "services." Based on this difference in language, it is unclear if the CCA would provide continuous care or only a task-limited visit. Please provide further clarification through the regulations.

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As discussed during today's hearing, access to CSN services is critical to the ability of families to safely provide care at home for their MassHealth eligible children with complex care needs. We urge EOHHS to take all steps necessary to ensure that all CSN members have access to sufficient CSN services for safe community living and to engage with a diverse array of families receiving CSN services to devise systemic solutions. Should EOHHS have any questions or wish to discuss the above with DLC, please let us know.

Sincerely,

Tatum A. Pritchard
Director of Litigation

Barbara L'Italien
Executive Director