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**Comments regarding the Renewal of the 1115 Waiver**

Dignity Alliance Massachusetts, a grass-roots coalition of aging and disability service and advocacy organizations and supporters, is dedicated to securing fundamental changes in the provision of long-term services, support, and care. We, the undersigned organizations and individuals, all members of Dignity Alliance Massachusetts, appreciate the opportunity to comment on the Commonwealth’s 1115 Waiver Renewal.

The negative consequences of providing treatment in nursing facilities were exposed and exacerbated by the COVID pandemic.  In the first six months of the pandemic, 66% of all COVID-19 related deaths in Massachusetts involved persons in nursing facilities. Moreover, residents of Massachusetts who are people of color have been disproportionately represented in the number of deaths across the state; similar health disparities have been found for residents with limited English proficiency. Despite this tragedy, the Commonwealth’s current 1115 Waiver Renewal application fails to include any major programs or services, and particularly residential programs with supports, to help individuals transition from nursing facilities to their homes and communities or to prevent unnecessary admission to nursing facilities.

The importance and urgency of taking action to reduce the state’s dependence on nursing facilities is indisputable. The Commonwealth must take the opportunity with the 1115 Waiver Renewal to address the long-standing problem of the unnecessary segregation in nursing facilities of adults with disabilities and older adults. Such action would align with the goals laid out in the Commonwealth’s Nursing Facility Task Force report of January 31, 2020. The report concluded that funding spent on empty nursing beds should be redirected to support the expansion of community services. Additionally, the Task Force proposed that, in order to reduce the excess bed capacity in the nursing facility system, the State should provide incentives to allow for the conversion of nursing facilities to “alternative services,” such as affordable senior housing or assisted living units. The 1115 Waiver Renewal should include a primary goal of downsizing the current nursing facility system and creating more robust home and community based services. It should describe strategies and provide substantial incentives for expanding transition and diversion services and residential programs and supports, in order to permit older adults and individuals with disabilities to live in integrated settings in their homes and communities.

This goal and these strategies would support the long-delayed implementation of the Commonwealth’s Olmstead Plan and realize the State’s commitment to shifting the focus of long-term care resources from institutions to the community. A program directed at a cross-disability population that provides greater choices for people to remain home and in the community addresses the goal of advancing health equity, as laid out in the 1115 Waiver Renewal Application.

Despite the fact that the current 1115 Renewal application does not include such an initiative, the Commonwealth need not invent a new strategy or design a new program in order to address the immediate, pressing need to transition individuals from nursing facilities to the community, as well as to support older adults and individuals with disabilities to avoid unnecessary admission to nursing facilities. The Community First 1115 Waiver Proposal, created in 2008, provides a well-designed initiative that should be included, almost as is, in the 1115 Waiver Renewal Application to address this essential issue. The process to develop the Community First Waiver involved a wide-range of stakeholder engagement, including the older adult and individuals with disabilities communities, long-term care providers, families and caregivers, and other health care and interest groups who worked together to design key components of programs. The workgroup developed the eligibility determination process and the case management and waiver system infrastructures. The result of the Commonwealth’s significant efforts was an ambitious and comprehensive proposal that rebalanced the State’s long term care system and ensured a full continuum of care for people in the community, while maintaining necessary nursing facility capacity. The product was the effort of a broad, inclusive workgroup composed of various stakeholders who reached a unanimous recommendation that is as valid today as it was thirteen years ago.

This thorough, development process led to the creation of a proposal that was ambitious in scope and impact, while also achieving budget neutrality. The Community First 1115 Demonstration identified three cross-disability target populations for expanded services: (1) persons at imminent risk of entering nursing facilities (diversion group); (2) persons in nursing facilities (transition group); and (3) persons whose future admission could be avoided (prevention group). A service package was created for each cross-disability population, and an expansion of financial and other eligibility requirements for Medicaid waiver services was included to ensure maximum access to services.

The Community First 1115 Demonstration was designed to transition at least 1,000 people from nursing facilities (half older adults and half adults with disabilities); to divert 10,600 individuals in the imminent risk group; and to target 4,000 in the prevention group. The service packages proposed in the Community First Demonstration – some new and some broadened offerings of existing services – would be available across disability and age groups and directly addressed the Commonwealth’s obligation under the Americans with Disabilities Act (ADA) that individuals with disabilities be placed in the most integrated setting. Since this obligation remains largely outstanding with respect to thousands of individuals in or at risk of entering nursing facilities, the 1115 Waiver Renewal presents a critical opportunity to implement the Commonwealth’s Olmstead Plan, to improve compliance with the ADA, and, most importantly, to provide thousands of older adults and persons with disabilities meaningful choices to remain in their homes and home communities – a choice made ever more urgent by the pandemic.

The 1115 Waiver Renewal’s goal of advancing health equity could be addressed by adopting most of the elements of the 2008 Community First Waiver Demonstration. The renewal application should be amended and expanded to include the following services, as described in the service definitions for the Community First Waiver Demonstration:

1. Clinical assessments – provided to all individuals at imminent risk of placement in a nursing facility and those in the prevention group in order to determine the needs of the individuals;
2. Care plan development – provided to all Demonstration participants to determine appropriate programs and services based on the assessed need for services;
3. Case management – provided to all Demonstration participants to enable access to Demonstration services; and
4. Residential and non-residential support services – provided to persons with a range of disabilities, regardless of age, in nursing facilities (transition population) and at risk of being placed in a facility (diversion population).

A few modifications to the Community First Waiver Demonstration are probably necessary. In light of CMS’s concern in 2008 about the lack of data to support budget neutrality projections for the diversion population, it may be prudent to reduce the number of persons in the diversion population, unless MassHealth has more current and reliable data on the utilization of diversion services. Concomitantly, it is necessary to significantly expand the number of persons in the transition population – from 1,000 to 5,000 – to reflect both the actual number of persons in nursing facilities who could safely transition to the community, the demand for the MFP waivers, and the lessons learned from the pandemic.

There are approximately 35,000 persons in nursing facilities in Massachusetts, approximately two-thirds of whom are eligible for the State’s Medicaid program, at least once they have exhausted private insurance or Medicare benefits. Only two of the Commonwealth’s ten Medicaid HCBS waivers provide residential and community living (non-residential) services to persons of any age and any disability in nursing facilities, rehabilitation facilities, and some other institutions. The Community First Waiver Proposal expanded eligibility and provided substantially more opportunities and supports to avoid unnecessary institutionalization in nursing facilities, so that more people have the chance to return to, or remain in, their homes and communities. Using the knowledge, experience, and scaffolding the Commonwealth has acquired through some of its current HCBS waiver programs, the State could significantly reduce the number of MassHealth-funded nursing facility residents, avoid the unnecessary segregation of older adults and individuals with disabilities in nursing facilities, and expand the State’s capacity to provide needed supports and services in the most integrated settings.

In conclusion, significant modifications should be made to the Commonwealth’s 1155 Waiver Renewal to include the Community First Waiver Proposal expansion of home and community services, in order to transition individuals out of nursing facilities or divert and prevent individuals from unnecessary placement in nursing facilities. An expansion and strengthening of the State’s home and community based service system also aligns with the current Administration’s top priority of expanding access to a broad array of long-term services and supports in local settings. This modification of the 1115 Waiver Renewal will advance its equity goals, rebalance the Commonwealth’s long term care system, facilitate compliance with the ADA, and reflect the lessons learned from the pandemic.

This commentary has been endorsed by twenty-nine participants of Dignity Alliance Massachusetts including the following:

Center for Public Representation

COP Amputee Association, Inc. – COPAA

Disability Resource Center, Inc.

Easterseals Massachusetts

Greater Boston Chapter of the United Spinal Association

MassNAELA

Mystic Valley Elder Services

Betsey Crimmins, Greater Boston Legal Services

Judi Fonsh, MSW

Lachlan Forrow, MD

Pamela Goodwin, Stop Bullying Association

Carolyn Ingles

Paul J. Lanzikos

James A. Lomastro, PhD

Mike Kennedy, Center for Independent Living

Richard T. Moore

Sandra Allyssa Novack, MBA, MSW

Paul Spooner, MetroWest Center for Independent Living