April 30, 2020

By E-mail
Honorable Ned Lamont
Governor
State of Connecticut
210 Capitol Avenue
Hartford, CT 06106

Re: Need for Support for Home Care and PCA Workers During Crisis
Commensurate to Support for Nursing Home Workers

Dear Governor Lamont:
We are a coalition of groups representing the interests of people with disabilities and older adults in need of long-term care. We appreciate everything you and your commissioners are doing to slow the spread of the coronavirus and provide relief to residents of our state affected by it. One of the most important aspects of this is supporting nursing facilities that house around 22,000 older adults or disabled individuals and their employees, including the recent announcement of substantially increased funding effectively by 15% to these facilities in light of their greatly increased labor costs and the costs of personal protective equipment (PPE). While we wholeheartedly endorse this needed support during the crisis, we are concerned that this appropriate focus on nursing homes may nevertheless inadvertently exacerbate the bias toward institutional care over home and community based care which still persists in the state, and write to urge that you support personal care attendants (PCAs) and home care workers in a manner commensurate with the support you are providing to nursing facilities, as set forth below.

First, we wish to acknowledge that Connecticut has made great strides to address the long-standing bias toward moving individuals into nursing facilities, and to comply with its obligation to serve people with disabilities, including older adults, in the most integrated setting appropriate to their needs as mandated by the decision of the United States Supreme Court in Olmstead v L.C, 527 U.S. 581 (1999). The Department of Social Services, under the leadership of Commissioner Gifford and previous commissioners, and in conjunction with other state agencies, has developed and expanded several home and community based services (HCBS) waivers for both elderly and non-elderly individuals requiring long-term care, as well as the
Community First Choice Medicaid option. In addition, DSS has developed over the years the very successful Money Follows the Person (MFP) program to assist individuals already in facilities at Medicaid expense to transition to the community with appropriate services and supports, both for the transition and thereafter. Unfortunately, those efforts have not been enough to save a large number of individuals from being inappropriately institutionalized when a well-designed care plan could have kept them in the community.

Even without Covid-19, involuntary institutionalization in a nursing facility is costly in multiple ways: Obviously, the vast majority of individuals would prefer to live in the community with appropriate supports rather than be forced into such settings with the loss of privacy and autonomy. In addition, for most individuals, the costs to the state are substantially lower if the person resides in the community than in such a facility, even with extensive daily care plans. However, what we all are painfully aware of right now is that such institutionalization also can be deadly: while over 2,000 have died in Connecticut from the virus, the number of those who are nursing facility residents is a shockingly high percentage: approximately 43% of the deaths.

At the same time, since the virus arrived, many older adults and people with disabilities who are on the community based services waivers administered by DSS and other state agencies or Community First Choice, as well as who pay for home and community based services privately, are being threatened with involuntary institutionalization. This is in part because their workers are terrified of contracting the virus or spreading it unknowingly to the individuals they serve, especially since access to PPE is particularly problematic for such individuals who do not work for a home care agency. These workers are unable to access covid-19 testing, absent significant symptoms, despite being in the category of health care providers. And some of these workers have no health insurance or insurance with very high deductibles such that they are fearful of the high costs of covid-19 treatment should they become infected. Lastly, some of these workers cannot work because they have to care for young children who are out of school due to the pandemic.

As a result of all of these issues, some of these at-risk individuals are already going without services during some shifts, directly threatening their ability to remain at home. Similarly, those individuals who receive services
from home health aides employed by an agency are finding it difficult to continue to receive services, for a lot of the same reasons, with fewer home health aides coming to work for those agencies.

Throughout the crisis, the dedicated social workers and housing coordinators administering the MFP program have continued to work on transition plans to get individuals out of dangerous nursing facilities and have successfully transitioned some such individuals. But the great complexities of trying to do this under pandemic conditions are daunting, requiring additional costly resources to engage in the same planning processes which were already highly labor intensive before the virus. While the money for the MFP program comes from a grant from the federal government, Connecticut can dedicate additional funds to support it during this crisis period, including by using some of the substantial funds Congress has specifically earmarked for HCBS services in the CARES Act.

Given all of these realities, and our shared desire to prevent the current crisis from exacerbating the bias toward institutional placement at a time when such placement can literally be deadly, we urge you to PCA and home health workers who make it possible for seniors and people with disabilities to remain in the community during the crisis, commensurate with the support you are providing to nursing facility workers, as follows:

1. Increase the hourly rate for PCAs providing services under Medicaid, and through Medicaid waivers administered by DSS and other state agencies (including DDS and DMHAS) by 15%
2. Increase payments to live-in companions by 15%
3. Increase Medicaid rates paid to home care agencies by 10%
4. Directly ensure provision of adequate (meaning sufficient to avoid the need to reuse disposable items) PPE for PCAs and live-in companions providing services under Medicaid or private pay who do not work for an agency by paying for, and coordinating the acquisition and distribution of, all PPE used by such workers
5. Make clear that individual PCA “consumer-employers” are not responsible for providing PPE for their PCA or live-in companion workers, whether they are paid by Medicaid or are private pay
6. Instruct home care agencies that they are proactively responsible for ensuring proper and sufficient PPE for all of their employees doing both live-in and home visits and that the
10% increase is intended in part to cover the cost of this responsibility
7. Ensure that PCAs and home health workers are given priority for covid-19 testing commensurate with the testing available to health care workers in nursing facilities and hospitals, and that direct payment is provided for covid-19 treatment in the event they lack health insurance coverage for this
8. Increase funding for the MFP program

Thank you for all that you have done for older adults and people with disabilities during the crisis. As we seek to address the emergency in nursing homes, we need to also support the alternatives to congregate living in such facilities and prevent the exacerbation of the historical bias toward institutional care. We hope you will continue to move towards meeting the state’s obligations under the Olmstead decision by adopting these additional proposals to protect the thousands of such individuals on home and community based services, or trying to get on such services, and the workers who serve them, and prevent the potentially deadly involuntary placement of such individuals in nursing facilities during this crisis.

Respectfully yours,

Melissa Marshall on behalf of:
CT Cross Disability Lifespan Alliance
Organizations
Connecticut Legal Rights Project
Communitas
Greater New Haven Peace Council
The Arc of Connecticut, Inc.
Greater Hartford Legal Aid
New England Chapter of Paralyzed Veterans of America
CC=A
Moral Monday CT
CT Black Women
Department of Services for Persons with Disabilities, City of New Haven
Independence Northwest
People First of CT
National Association of Social Workers, CT Chapter
Connecticut Legal Services, Inc.
Keep the Promise Coalition
Disability Rights Connecticut
Independence Unlimited
Disabilities Network of Eastern Connecticut
Connecticut Amputee Network
Center for Disability Rights
Access Independence
Agency on Aging of South Central CT
CT State Independent Living Council
New Haven Legal Assistance Association

Individuals
Nancy Alisberg, JD
Ellen Andrews, PhD, CT Health Policy Project
Beverly Jackson
Julie Ball
Mary Ann Langton
Cecilia Lewis
Ellen Hughes
Keith Mullinar
Ruth Grobe
Gary Gross
Debbie Shaffer
Elanah Sherman
Catherine John
Emily Ball
Beverly Kidder
c: Lt. Governor Susan Bysiewicz
   Josh Geballe, Chief Operating Officer
   Paul Mounds, Chief of Staff
   Jonathan Harris, Senior Adviser
   Secretary Melissa McCaw
   Cherie Phoenix-Sharpe, Chief legal Adviser to Lt. Governor Bysiewicz
   Commissioner Deidre Gifford
   Commissioner Amy Porter
   Commissioner Renee Coleman-Mitchell
   Commissioner Jordan A. Scheff
   Commissioner Miriam Delphin-Rittmon