December 20, 2019

EOHHS Secretary Marylou Sudders Chair, Nursing Facility Task Force One Ashburton Place Boston, MA 02108



Delivered by email to Marylou.sudders@state.ma.us

Dear Secretary Sudders:

We are writing to express serious concern about the Nursing Facility Task Force, most notably because of its exclusion of people with disabilities and what the absence of this critical voice may mean about priorities and the stability of community-based long-term services and supports (LTSS), key components of the state's longstanding commitment to Community First and the Supreme Court's Olmstead decision.

According to MassHealth for FY 2018, 7,593 people, or 20% of those in a nursing facility, were 64-years-old or younger, an age group which would often receive any needed services from disability organizations while likely self-identifying as persons with a disability. In fact, even among seniors, nursing homes are largely institutions for those with disabilities: nationwide, 96% of seniors who are in nursing homes have disabilities, compared to 37% of seniors who are not in nursing homes (West et al, US Census Bureau 2014). Addressing financial concerns around nursing facilities and their place in the elder care continuum, as is the Task Force's charge, will in truth also be a de facto discussion around a care and service system significantly impacting people with disabilities.

We respect that financing and staffing challenges have caused instability in care delivery in nursing homes. But as the committee may understand, addressing a pressing immediate need, including ensuring fair compensation for workers, is distinct from considering the long-term place of nursing facilities in the LTSS picture for people with disabilities. We do not want to see reinforcement of an institutional care model that is inherently unsustainable at its current size and that would have direct ramifications for critical LTSS funding, reducing options to achieve people's primary desire to live in non-institutional settings. As things currently

stand, workforce challenges for community-based programs such as PCA services and the acute shortage of affordable, accessible, and integrated housing undoubtedly contribute to reliance on nursing facilities.

The disability voice should and will be heard on these matters. We look for the opportunity to convey our concerns to the commission in a more extensive manner.

Sincerely,

Bill Henning, Boston Center for Independent Living/DAAHR
Paul Spooner, Metrowest Center for Independent Living
Marlene Sallo, Disability Law Center
Colin Killick, Disability Policy Consortium
Vicky Pulos, Mass Law Reform Institute
Nancy Lorenz, Greater Boston Legal Services
Arlene Germain, Massachusetts Advocates for Nursing Home Reform
Dennis Heaphy, Disability Advocates Advancing our Healthcare Rights/DPC