January 30,2020

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 as a follow-up to the presentation at the Nursing Facility Task Force’s January 10 meeting by Paul Spooner of MWCIL, Millie Hernandez of BCIL, and Dennis Heaphy of the DPC. We wish to offer comments on overriding concerns we hope can be considered for the final report and any resulting next steps.

First, however, we wish to emphasize that while there are positive stories sometimes emanating from facilities, oftentimes the quality of life is desperate. Paul and Dennis expressed fear, as persons with significant disabilities, about needing to go in a facility. Millie, also with significant disabilities, detailed how her stay in a nursing home was marked by filth, neglect, harassment and inattentiveness to health.

 Moving forward, points we believe must be considered include these:

* There’s a need to review complaint and oversight mechanisms for facilities.
* The predominant model for nursing facilities must be seriously reconsidered. As able, people choose to remain at home or, if unable to remain at home for health reasons, to at least go to more homelike settings as exists in assisted living residences or in places exemplified by the Greenhouse model. Simply addressing the financial problems plaguing nursing homes by providing more resources but otherwise preserving the status quo is unacceptable.
* Quality measures built around what people would want if unable to stay at home—not shaped by what exists—are needed, as are risk adjustment policies supporting higher levels of care as needed.
* Any financial package must include support for the workforce directly caring for residents. We also strongly support an audit of MassHealth nursing home cost reports, as recommended by Massachusetts Advocates for Nursing Home Reform, to verify the amount of any MassHealth shortfall and to ensure MassHealth funds are being utilized in the best interests of nursing home residents.
* Commensurate examination of steps that can enhance alternatives to nursing facility placement are essential. These include support for LTSS and affordable, integrated and accessible housing; and a revamping of regulations and support for assisted living residences to allow them to serve people with a broader range of health needs and insurance coverage, including MassHealth.

As we have noted, 20% of those in nursing homes are under age 65. The future of facilities is very much a concern for the disability rights community and we look forward to future engagement.

Thank you for the opportunity to convey our concerns.

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

Millie Hernandez, Boston Center for Independent Living

Arlene Germain, Massachusetts Advocates for Nursing Home Reform

Lisa Orgettas, Disability Resource Center (Salem)

Steve Higgins, Independence Associates (E. Bridgewater)

Lisa Pita, Southeast Center for Independent Living (Fall River)

Coreen Brinckerhoff, Cape Organization for Rights of the Disabled

Dennis Heaphy, DAAHR

Meg Coffin, Center for Living and Working (Worcester)

Joe Castellani, Ad Lib Center for Independent Living (Pittsfield)

June Savageau, Northeast Independent Living Program (Lawrence/Lowell)