

December 20, 2019

To: All Presidential Campaigns

Re: Disability Community Principles Regarding Long Term Services and Supports in Healthcare Proposals

The undersigned co-chairs of the Consortium for Citizens with Disabilities (CCD) Long Term Supports and Services (LTSS) Task Force are writing to offer you the enclosed Disability Principles for Inclusion of Long Term Service and Supports (LTSS) in Universal Health Care. These principles were developed by the disability community and should inform any policy proposals aimed at expanding access to health care. While the principles were developed in the context of the discussion regarding strategies to achieve a universal or "For All" health care system in the United States, we stress that they are relevant to all types of healthcare proposals, from increasing access to private markets to expansion of the Affordable Care Act (ACA) to single payer.

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. CCD's work is accomplished through Task Forces; the Task Force on Long Term Services and Supports focuses on issues concerning the delivery of services, including personal care, non-acute health care, employment supports and other day services, residential services, and other supports that enable individuals with disabilities of all ages to live, fully participate and be productive members of their communities.

Access to healthcare is, of course, a key issue in the 2020 presidential campaign, and a number of candidates have offered proposals for improving the US health care system. Addressing LTSS is crucial to the success of any of health reform proposal. For too long, our nation has ignored the urgent need to address the emerging LTSS crisis facing older adults, people with disabilities, and family caregivers. In 2018, 14 million adults in the United States needed long-term services and supports. Of that population, 7.9 million (56 percent) were over age 65 and 6.1 million (44 percent) were ages 18 to 64. Total Medicaid LTSS expenditures, which represent the largest share of spending on these important services, grow year after year and were approximately \$167 billion in FY 2016.

These vital services have a profound effect on the health and quality of life of the individuals with disabilities and older adults who need them. LTSS directly address many of the social determinants of health that impact health outcomes and costs. Health care proposals that do not take these services into account are excluding the millions of individuals who need them from equitable access to the health care system.

Furthermore, proposals to address access to LTSS--whether or not they are embedded within a larger health reform package--must include people with disabilities under the age of 65. Policies that advance improvements to the nation's LTSS system for older adults without including people with disabilities create a bifurcated system that leads to added expense and leaves people behind. People with disabilities, like older adults, rely on LTSS to ensure their functioning, independence, and ability to fully engage in the life of their communities. Their needs are no less important.

We recognize that some candidates have also put forward specific stand-alone proposals on LTSS, prior or in addition to a larger health reform package. The attached principles also apply to these plans. Increasing the independence, community integration, and quality of life of people with disabilities, older adults, and family caregivers is crucial to the overall health, strength, and fiscal outlook of our nation, and we welcome any proposal which shines a spotlight on this critical issue.

The CCD LTSS Task Force is composed of organizations with deep expertise and experience with LTSS issues. We represent people with disabilities who rely on LTSS, family caregivers, service providers, disability rights advocates, and other key stakeholders. We are available as a resource to any campaign, or other entity, exploring policy proposals to expand access to health care.

Sincerely,

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Attachment

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