April 23, 2021

The Honorable Bob Casey
Chair, Senate Committee on Aging
G31 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Maggie Hassan
United States Senator
324 Hart Senate Office Building
Washington, DC 20510

The Honorable Sherrod Brown
United States Senator
503 Hart Senate Office Building
Washington, DC 20510

The Honorable Debbie Dingell
United States Representative
116 Cannon House Office Building
Washington, DC 20515

RE: Home and Community based Services Access Act Discussion Draft

Dear Chairman Casey, Senator Hassan, Senator Brown, and Representative Dingell,

National Patient Advocate Foundation (NPAF) appreciates your leadership and the opportunity to provide comments to the Home and Community Based Services Access Act (HAA) discussion draft. We support nationalizing home and community-based services (HCBS) in Medicaid which will promote independent living and community engagement among the broader population of eligible beneficiaries with functional impairments and their caregivers.

NPAF elevates patient and caregiver voices by advocating for inclusive policies and practices that put people at the heart of health care. Our direct service counterpart, Patient Advocate Foundation (PAF), provides needs navigation and financial assistance to thousands of primarily low-income families with complex and chronic conditions each year. Since 1996, our organizations have been dedicated to expanding equitable access to affordable quality care, particularly for our nation's most underserved and marginalized populations.

HCBS embody person-centered care which aligns treatment and services with a patient's values and goals – including the desire to receive long-term services and supports in the comfort of their own home and community. Unfortunately, many Medicaid beneficiaries do not have access to HCBS and also face household material hardships due to their health condition, disability, or other extenuating circumstances. The resulting financial distress may worsen underlying health and economic disparities and weigh heavy on patients and their families. In fact, the majority of patients surveyed by PAF rank financial distress as a fate worse than death and characterize their family's financial viability as a critically important goal of care.[1]

Overall, we strongly support HAA and its intent to establish baseline criteria for HCBS. We offer the following recommendation**s** to strengthen equitable access to HCBS while minimizing the financial distress that these populations often face:

[1] Based on a 2019 survey of over 2,800 patients served by Patient Advocate Foundation.

Ensure that the minimum services provided by state HCBS includes those that comprehensively address beneficiaries' unmet financial and social needs. This should include assessment of medical and non-medical costs which may contribute to distressing financial hardship. Few hospitals, health systems, advocacy organizations and communities provide comprehensive financial and social needs support, but those that do have shown to significantly increase treatment adherence, improve outcomes and reduce overall costs for both patients and health systems.[2,3]

We are encouraged by HAA's inclusion of non-emergency medical transportation, person-centered care planning, and caregiver and family support services. To build upon this robust list, consider defining "wraparound services" to include identification of unmet non-medical needs and eligibility for assistance programs related to food, transportation, housing or energy security. Similarly, consider defining "case management" to include the broadest scope of covered services such as financial planning, medical billing assistance, and others deemed necessary by the advisory panel to avoid limitations in support. As our PAF colleagues can attest, case management is a highly personalized service that connects people to a wide array of supports depending on their unique needs.

Specify that the individualized assessment should include screening for financial and social needs which are critical for establishing a person-centered care plan. Financial and social needs screening and service referral are not yet standardized but pose an important opportunity for improving quality care delivery and accountability. Additionally, all beneficiaries coping with complex, chronic and disabling conditions should be asked if they have pressing needs that would warrant HCBS. This inclusive and proactive approach will help identify individuals who are likely to be harmed by lack of HCBS so they can be referred for services and supports before circumstances deteriorate or become dire.

Finally, we support prioritization of consensus and evidence-based practice standards and would be pleased to convene patient, caregiver, and family insights to inform the quality standards developed by the Agency for Healthcare Research and Quality along with State Medicaid Directors.

NPAF appreciates your attention to making HCBS equitably available nationwide and stands ready to support your next steps for the Home and Community-Based Services Access Act. Please contact Nicole Braccio, Policy Director, at Nicole.Braccio@npaf.org, if you have any questions or would like us to elaborate. We welcome the opportunity for a meeting.

Respectfully submitted,

Rebecca A. Kirch
EVP of Policy and Programs

[2] Yezefski T, Steelquist J, Watabayashi K et al. Impact of Trained Oncology Financial Navigators on Patient Out-of-Pocket Spending. Am J Manag Care. 2018;24(5 Suppl):S74-S79

[3] Ell K, Vourlekis B, Xie B et al. Cancer Treatment Adherence among Low-Income Women with Breast or Gynecologic Cancer: A Randomized Controlled Trial of Patient Navigation. Cancer. 2009 October 1; 115(19): 4606–4615.