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Committee Members
Review of Federal Policy that Contribute to Racial and Ethnic
Health Inequities
National Academy of Science, Engineering, and Medicine
HealthEquityPolicies@nas.edu

Re: **Federal Policies Contributing to Racial Disparities during Serious Illness**

Dear Committee Members:

Thank you for the opportunity to submit comments on federal policies that create racial and ethnic health disparities.

The Center to Advance Palliative Care (CAPC) is a national organization dedicated to ensuring that all persons living with serious illness have access to high-quality care that addresses their symptoms and stresses, including access to specialty palliative care services. We offer our insights and recommendations from a recently completed scan of disparities during serious illness, focused on Black patients and families. Our investigations revealed racial disparities across multiple aspects of serious illness care, including the quality of clinician-patient communication, pain management, the burdens on caregivers, and utilization of hospice services, to name a few. These findings lead us to highlight several federal policies contributing to disparities during serious illness, detailed below.

Barrier #1: The Medicare hospice benefit requires termination of curative care in order to receive hospice services.

When compared with white patients, Black patients have greater preference for and use more life-sustaining treatments like breathing support, artificial nutrition, dialysis, and cardiopulmonary resuscitation. Several studies also show that Black patients may have a greater desire to spend their last days in the hospital, compared to their white counterparts. The reasons for this are not well-studied, but key informants speculate that these preferences may reflect personal or spiritual beliefs, or a fear of not receiving valuable treatment due to structural racism and sustained health inequities. The data may also indicate greater pressures on Black caregivers that make care at home difficult or impossible.

This difference in racial preferences does not align with the current Medicare hospice benefit, which requires beneficiaries to discontinue curative treatment of the terminal illness in order to receive hospice benefits. As a result, fewer than 41% of Black Medicare decedents used hospice care, compared to 54% of white decedents. CMS could revise the benefit to address variation in care preferences by piloting concurrent curative care benefits with hospice benefits, as is currently allowed for all Medicaid and Children's Health Insurance Program beneficiaries under 21 years. Moreover, early tests of a concurrent hospice benefit, via the Medicare Care Choices Model, have shown a reduction in Medicare spending simultaneous with quality of life improvements. We recommend expanded tests of concurrent hospice and treatment under Medicare.

Barrier #2: A lack of standardized symptom and caregiver burden assessment in Medicare programs, including in Medicare Advantage.

Current Medicare requirements leave the assessment of symptom distress and caregiver burden solely at the discretion of the individual clinician, yet we know that this results in significant disparities in both screening and assistance. For example, physicians are twice as likely to underestimate pain in Black patients compared to white patients, and indeed compared to all other ethnicities combined. As recently as 2016, half of white medical students and residents held false beliefs about biological differences between white and Black patients, and these beliefs lead to perceptions that Black patients experience less pain than do white patients.

At the same time, research confirms that non-white family caregivers face greater harm to their own physical and financial health than do white caregivers.

Existing laws and regulations require specific assessments across Medicare programs. For example, all new admissions to Medicare home health care or Medicare skilled nursing require completion of a standardized assessment. With nearly half of Black beneficiaries now enrolled in Medicare Advantage, there are new opportunities for regulations to impact large numbers of the undertreated population. Therefore, we recommend the following regulatory changes to mitigate clinician bias and address racial disparities in symptom management and caregiver support:

- Create a standardized annual assessment for Medicare Advantage beneficiaries that includes both symptom burden and caregiver burden.
    - There are several brief and validated symptom assessment tools, including the Revised Edmonton Symptom Assessment System or the Condensed Memorial Symptom Assessment Scale.
- Add a validated caregiver burden assessment tool (such as the Zarit Burden Interview), to all existing Medicare program assessments.
- As with other required assessments, findings should result in a care plan to address any issues identified.

Barrier #3: Federal oversight of hospitals does not require access to specialty palliative care services.

Specialty palliative care services relieve suffering and improve quality of life in precisely the domains where Black patients receive lower quality care – symptom management, communication, and caregiver support. Numerous studies have shown that palliative care is a high-value service that both improves quality of life for patients and caregivers, and in so doing, reduces the total costs of patient care. Yet, palliative care is not reliably available to all patients in need. In particular, patients utilizing hospitals in the South and for-profit hospitals, often used by non-white patients, are less likely to report having access to palliative care services. Other studies have found that those hospitals which serve a higher proportion of minority patients are less likely to provide palliative care services (as measured by billing codes) when compared to hospitals serving a greater proportion of white patients.

Inequitable access to palliative care services across geographies and populations is possible only because acute care hospitals are not required to provide this service. The absence of palliative care requirements and standardization contributes to the racial disparities during serious illness. Moreover, if palliative care were required in all hospitals, the hospitals will most likely benefit from improvements in their financial performance, potentially mitigating the concern regarding an "unfunded mandate."

Barrier #4: Insufficient federal programs to increase health care provider diversity and the number of minority-owned agencies.

One of the strongest findings in our investigations was the potential for improvement in patient experience when the patient and the provider are racially concordant (likely due in large part to implicit improvements in communication). The same holds true for patients using hospice agencies owned by people of their own race and/or ethnicity. For example, in Nashville Tennessee Black patients and families referred to Black-owned Heart and Soul's hospice agency were more likely to enroll.

How to diversify the professional workforce and home care agency ownership is a complex problem, which is only exacerbated by the health worker burnout crisis. It requires policy solutions that go well beyond the health care space, ranging from education, pipeline programs, and economic development. For instance, while the Small Business Administration has valuable programs to support entrepreneurs and small businesses, and operates some specialized programs and contracting opportunities for non-white small business owners, no program is yet targeted to health care small businesses. Given the urgency for racially concordant health care provider organizations, we suggest that this committee explore policy options to catalyze racial diversity among health care providers.

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We hope that these comments – and the perspective of patients and families facing serious illness – are helpful as you develop your report. Please note that CAPC can provide resources, additional literature, and guidance on mitigating disparities in the care of people with serious illness, and we would be pleased to provide further assistance. You may contact me at Allison.Silvers@mssm.edu or Stacie Sinclair, Associate Director of Policy (Stacie.Sinclair@mssm.edu) if you have any questions or need additional information.

Sincerely,

Allison Silvers
Chief, Health Care Transformation

Cc: Stacie Sinclair, Associate Director Policy and Care Transformation