

Rebuilding the Care Infrastructure to Empower Individuals with Serious Illness

Background:

As the nation embarks on rebuilding its infrastructure, we must not let this once-in-a-generation opportunity pass without addressing the broken and underfunded care infrastructure for individuals with serious illness and their caregivers, both paid and unpaid. We believe that there are programs and ideas in existence that are shovel-ready – primed to be modified, expanded, and targeted to those in the greatest need, particularly to low-income communities and persons of color.

C-TAC is committed to a world where all individuals with a diagnosis of a serious illness have access to quality treatment options, a comprehensive care plan, advance care planning counseling, a coordinated package of community-based supports and services to help them stay at home, transportation to get to appointments, caregiver support, and home care and palliative care, provided by a well-trained and appropriately compensated workforce. To make this care a reality, we need to address several of our inadequate infrastructures.

We support the President’s bold and broad approach to addressing infrastructure, including our long-term supports and services infrastructure, the healthcare workforce education and training infrastructure, and the related transportation and digital infrastructures, both of which are critical to ensuring available services are obtainable by those in need, particularly in low-income communities.

We propose a *Serious Illness Care Equity Act*, a plan that would fund a range of programs and grants to communities in need to better care for those with serious illness and to ensure that they have access to care as well as the right to have their care preferences understood and followed by health care and social service providers. Further, we support a range of policy changes and payment reforms that will address other improvements to access and quality of serious illness care for all Americans.

The following proposals will move us in a positive direction at this unique moment.

Health Care Infrastructure

- Care Payment Models - Fund efforts for the Center for Medicare and Medicaid Innovation (CMMI) to directly fund providers of non-medical social services and palliative care that have an impact on health outcomes and spending or legislation that will do so.
- Quality- Provide funding for all models providing care for individuals with serious illness to include a quality measure of the use of advance care planning.
- SDOH- Fund the assessment and risk adjustment payment that account for the social determinant of health (SDOH) characteristics of patients.

- Public education- Fund on-line consumer and provider information and resources on Advance Care Planning (ACP), as well as a culturally and linguistically appropriate public and provider national educational campaign.
- Medicare Coverage- Improve Medicare’s coverage of advance care planning (ACP) services by:
 - eliminating the patient co-pays for these services that serve as a financial barrier to their greater use (particularly for low-income individuals),
 - expanding the provider types that can carry out and get paid for these services under Medicare, to include appropriately trained or experienced clinical social workers, and
 - removing portability barriers to ensure wishes are honored across state lines.
- MA Supplemental benefits- Expanding Medicare Advantage supplemental benefit flexibility and funding sources to support more investment from Medicare Advantage organizations in non-medical social and functional service delivery for seriously ill members.
- Translation services- Fund access to culturally and linguistically appropriate (CLAS) translation services for HCBS programs, particularly for those with serious illness.

Community-Based Supports and Services Infrastructure

- AAAs- Fund the nation’s Area Agencies on Aging (AAAs) and others in the Aging Network to develop programmatic solutions to strengthen their ability to deliver community-based care and support to those living with serious and advanced illness and their families, with a focus on low-income communities and minority populations.
- Community-Based Non-Profits- Fund non-aging network community organizations to serve low-income individuals with serious illness (e.g., faith-based), including programs to provide transportation, nutrition support, and home modification services to seriously ill people from minority communities.
- OAA provisions- Provide funds to fully implement the Older Americans Act provisions directing the Administration on Aging to disseminate and collect feedback on its *Principles for Person-directed Services and Supports during Serious Illness*.
- REACH- Increase funding for the Racial and Ethnic Approaches to Community Health (REACH).

Health Care Workforce Education and Training Infrastructure

Caregiver Support

- Benefits- Fund a comprehensive suite of benefits and resources that reduce burdens on family caregivers and support the care they provide, including a caregiver tax credit to help with expenses, and programs to assist low-income minority caregivers.

- Respite- Increase funding for respite care and adult day care services for temporary relief from the work and stress of being a family caregiver.
- Payment- Provide payment flexibility to support caregivers, including scaling policies that allow for direct payment to family caregivers in exchange for their efforts to support sick loved ones.

Workforce, Education, and Engagement

- Career development- Strengthen and expand the workforce to better care for people with serious illness through programs for career development and to train the next generation of doctors, nurses, pharmacists, social workers, the direct care workforce, community health workers, and others, including additional funding for the Geriatrics Workforce Enhancement Program (GWEP) and Geriatric Academic Career Award (GACA) program.
- Grants- Fund grants to medical schools and teaching hospitals for career development awards, workforce development and fellowships for doctors, nurses, social workers, and others with a special focus on home or community-based care.
- NHSC- Include palliative care medicine as an eligible primary care service in the National Health Service Corps.
- Paid leave- Fund paid leave policies, especially for essential and direct care workers and a living wage and career development for direct care workforce.

Technology and Digital Infrastructure

- Technology- Fund flexibility in providing care, treatment, training, and assessment through technology, including expansion of broadband, cell phone service.
- Registry- Fund a national electronic registry for advance directives and medical orders and provide seed funding to do so with Medicaid patients across the states.
- Data- Fund data collection and program evaluation for quality improvement in all community-based programs (e.g., OAA).
- HIT support- Fund investment in HIT and interoperability for HCBS and CBO organizations.

Transportation Infrastructure

- Transportation- Provide funds for purchase and use of vans, UBER use, etc. for individuals with serious illness to ensure access to health care and other supports and services, particularly in low-income communities.