

January 15, 2021

The Honorable Joseph R. Biden  
President-Elect of the United States  
1717 Pennsylvania Avenue N.W.  
Washington, D.C. 20006

Dear President-Elect Biden:

Congratulations on your election and thank you for your decades of service to our nation. The Coalition to Transform Advanced Care (C-TAC) looks forward to working with you and your Administration to ensure that all individuals living with serious illness, especially the sickest and most vulnerable, receive comprehensive, high-quality, person- and family-centered care that is consistent with their goals and values and honors their dignity.

We are pleased to share with you and your team our policy priorities for 2021 to improve the care of those living with serious illness. In collaboration with our members and partners, our policy and advocacy activities are inspired by and in service of our goal to improve the quality of life for 12 million people with serious illness by 2030. As part of these efforts, C-TAC's policy work focuses on a broad range of clinical services such as palliative care, hospice care, and community-based social and spiritual supports. As your presidential transition team moves forward, your nominees are approved, and other critical positions are filled, we ask that you keep the needs of those with serious illness as a priority.

### **C-TAC Background**

Since its launch in 2011, the non-profit, non-partisan Coalition to Transform Advanced Care has convened as an alliance of patient and consumer advocacy groups, health care professionals and providers, private sector stakeholders, faith-based organizations, and health care payors. We collaborate with others to change the care system and the larger environment by sharing best practices and proven solutions in care delivery, promoting professional education, empowering consumers, enhancing provider capacity, and improving public and private policies.

<https://www.thectac.org/>

### **Current Environment**

The two overarching issues in the current environment that C-TAC considers to be a part of each of our priority issue areas are the ongoing COVID-19 pandemic response, as well as efforts to address systemic health equity challenges. We applaud you and your team's commitment to addressing both.

The **COVID-19 pandemic** has exacerbated problems facing individuals with serious illness and has changed the way much of our health care system provides services to and supports this population. C-TAC supports a number of policy changes to help ensure they receive the care they need and prefer in a safe environment throughout

the public health emergency. In order to continue protecting and supporting this most vulnerable population, we encourage you in the short-term to advance policies that will achieve the following:

- Ensure that providers of home-and-community-based medical and social care are included in prioritized categories for the distribution of vaccines, personal protective equipment (PPE), and testing materials. This is in addition to the currently Tier 1 priority category of providers that work in inpatient settings like hospitals and skilled nursing facilities.
- Ensure that essential family members and caregivers are able to have safe in-person visits with their seriously-ill or quarantined loved ones in care settings like hospitals and skilled nursing facilities, as well as other types of congregate living settings such as assisted living communities. We were encouraged by HHS Secretary-Designate Becerra's recent remarks that "*No one should ever have to die alone in a hospital bed, loved ones forced to stay away. That seems so contrary to the values of a great nation.*"<sup>1</sup>
- Ensure that coverage and access barriers to Medicare advance care planning (ACP) counseling services are removed, especially for those most at risk for bad outcomes and death from COVID-19, such as seriously-ill long-term care residents.

**Health care equity** and the racism found throughout the health care system is finally being openly acknowledged. At the core of our policy agenda is a commitment to advancing equity and dismantling systemic barriers to high quality serious illness care for traditionally underserved communities. C-TAC is developing a strategy focused on utilizing public policy levers (state and federal) to address inequity issues that impact those with serious illness and their loved ones. This includes:

- Removing financial obstacles to quality serious illness care for low-income minority individuals, such as cost-sharing and deductibles.
- Providing better access to preventive care and chronic care management in appropriate settings.
- Increasing access to culturally and linguistically appropriate (CLAS) translation services.
- Increasing diversity among care providers of all kinds, as well as investing in solidifying the community-based workforce, to include shoring up and better supporting community health workers, direct care aides, and personal care attendants.
- Institutionalizing pathways that allow community members to play a larger role in designing and having decision-making influence over the health and social care infrastructure in their own geographies.

C-TAC looks forward to working with the Biden-Harris Administration and Congress to ensure that those with serious illness, especially the sickest and most vulnerable, have high quality of life. Implementation of the following additional longer-term policy priorities will move us steadily in that direction.

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<sup>1</sup> <https://buildbackbetter.gov/speeches/health-team-nominees-appointees-remarks-as-prepared-for-delivery/>

## **2021 Priority Issues**

### **Advance Care Planning**

*Goal:* Ensuring accessibility and use of advance care planning counseling, advance directives, and other advance care planning documents. C-TAC supports:

- Improving Medicare's coverage of advance care planning (ACP) services through mechanisms including 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 get paid for these services under Medicare, including properly trained clinical social workers, case managers, chaplains, and others; and removing portability barriers to ensure people's medical preferences are honored across state lines. Further, we support measures that will help facilitate access to ACP for all individuals with serious illness.
- Standards for including ACP documents within an individual's electronic medical record, and related research and evaluation of such standards.
- Funding for on-line consumer and provider information and resources on ACP, as well as a culturally and linguistically appropriate national public and provider educational campaigns.
- Focus on policies that improve gaps in ACP for minority communities, including advocating for a permanent expansion of the pandemic-related flexibility under Medicare to allow for reimbursement of phone-based, audio-only ACP services.

### **Community-Based Supports and Services**

*Goal:* Bridging the traditionally siloed fields of medical care and social services by developing and advocating for new policy, flexible delivery and payment approaches, and programmatic channels that will integrate aging and disability network services into models of care serving the serious illness population. C-TAC supports:

- Funding for 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 illness and their families.
- Expanding Medicare Advantage (MA) supplemental benefit flexibility and funding sources to support more investment from MA organizations in non-medical social and functional service delivery for seriously ill members.
- Full implementation of 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*.
- New funding opportunities to provide long-term supports and services for those with serious illness in minority communities.
- Data collection and program evaluation for quality improvement in all programs.
- Increased funding for the Racial and Ethnic Approaches to Community Health (REACH), the only CDC program that funds communities working to reduce racial and ethnic health disparities.

- Increased funding for State Health Insurance Programs (SHIP) to help seriously ill people and their family caregivers navigate the financial challenges associated with living with a life-limiting condition.
- Ensuring visitation rights to the loved ones of individuals with serious illness in long-term care facilities and providing the necessary personal protective equipment (PPE) and supports for safe visits.
- Increased funding for the Long-Term Care Ombudsman Program authorized under the Older Americans Act and Elder Justice Act to help ensure quality care and that patient care preferences are respected.

### **Care and Payment Models**

Goal: Encouraging development of new value-based care and payment models focused on those with serious illness, as well as the successful implementation of current promising models such as the Center for Medicare and Medicaid Innovation's (CMMI) *Primary Care First-Seriously Ill Population (SIP) Model*. Supporting additional models that incorporate home-and community based serious illness management and non-medical social supports and services, including palliative care, in a systematic and sustainable way is a critical step to increasing access to high-quality care for the most vulnerable. C-TAC supports:

- Alternative Payment Models for serious illness care, including models that include key roles and defined support for family caregivers and home-and-community-based palliative care providers.
- Requiring that all models providing care for individuals with serious illness include a quality measure of the use of advance care planning.
- Efforts to encourage CMMI to implement models that directly fund providers of non-medical social services that have an impact on health outcomes and spending.
- Requiring providers participating in CMMI demonstrations to explicitly report on the impact their efforts have on reducing health disparities, with an eventual shift to linking progress on this reduction to payment.
- Ensuring that new value-based payment and care delivery models include publicly reportable quality metrics specifically relevant to the serious illness population and adopted across Medicare, Medicaid, and private payer programs.
- Assessment and risk adjustment payment that accounts for the social determinant of health (SDOH) characteristics of patients.
- Collecting and disaggregating data to track and address social determinants of health, disparities in COVID-19 related testing, hospitalization, death, and recovery among different racial and ethnic groups.
- Flexibility in providing care, treatment, training, and assessment through technology, including expansion of broadband, use of telehealth in serious illness care programs, including fair reimbursement for telephonic/virtual care coordination across hospital, post-acute care, outpatient, and home settings, particularly in rural and underserved areas. We encourage the permanent removal of the geographic and originating site requirements for Medicare telehealth services that were waived as part of the COVID-19 response.
- Expanding the CAHPS survey and other measurement tools to incorporate questions relevant to people living with serious illness and their families.

## **Workforce, Education, and Engagement**

*Goal:* Strengthening the workforce to better care for people with serious illness. C-TAC supports:

- Strengthening and expanding the workforce to better care for people with serious illness through programs for career development in primary, palliative, and hospice care and geriatrics and to train the next generation of clinicians, the direct care workforce, community health workers, and others. This includes increased funding for programs such as the *Geriatric Workforce Enhancement Program* (GWEP), the *Geriatrics Academic Career Award Program* (GACA), and the *Community Health Worker Health Disparities Initiative*.
- Policies that will enhance continuing education to increase the capabilities of the workforce to care for those with serious illness, including Administration support for the passage of the *Palliative Care and Hospice Education and Training Act*.
- Grants to medical schools and teaching hospitals for career development awards, workforce development and fellowships for palliative care and hospice doctors, nurses, social workers, and others.
- Inclusion of palliative care medicine as an eligible primary care service in the National Health Service Corps, as called for in the *Provider Training in Palliative Care Act*.
- Use of advanced practice nurses and physician assistants to provide initial certification of patients for hospice care.
- Policies for community-based palliative care that require it be delivered by trained/certified professionals.
- Training on serious illness in medical and health education schools, and development of new curricula on advance care planning and end-of-life care for continuing education, as called for in the *Compassionate Care Act*.
- Paid leave policies, especially for essential and direct care workers and a living wage and career development for the direct and personal care workforce.

## **Family Caregiver Support**

*Goal:* Supporting family caregivers of individuals with serious illness. Many families caring for someone with serious illness struggle with significant financial, emotional, and health burdens due to their caregiving responsibilities. C-TAC supports President-elect Biden's announced caregiving plan and recommends the following additions:

- 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.
- Policies that recognize family caregivers as key members of the care team, and that support all of the dimensions of their caregiving experience.
- Increased funding for respite care and adult day care services for temporary relief from the work and stress of being a family caregiver.

- Recommendations developed by the RAISE Family Caregiver Advisory Council, which is overseen by the Administration for Community Living (ACL).
- 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.

We look forward to working with your Administration to implement the solutions outlined in this document. C-TAC would appreciate the opportunity to meet with your transition staff and members of your Administration to discuss policies and recommendations at their convenience. If you have any questions about our policy work or the recommendations in this letter, please reach out to Davis Baird, C-TAC Policy and Advocacy Manager, at [dbaird@thectac.org](mailto:dbaird@thectac.org)

Sincerely,



Jon Broyles  
Executive Director, Coalition to Transform Advanced Care (C-TAC)