Coalition to Transform Advanced Care (C-TAC)
2021 Policy Priorities for Improving the Quality of Life
for Those with Serious Illness

Introduction
In collaboration with our members and partners, C-TAC works to ensure that all individuals living with advanced and serious illness receive comprehensive, high-quality, person- and family-centered care that is consistent with their goals and values and honors their dignity. Our policy and advocacy activities are inspired by and in service of our Moonshot goal to improve the quality of life for those facing serious illness. As part of these efforts, C-TAC's policy work focuses on a broad range of clinical services, palliative care, hospice care, and community-based social and spiritual supports.

Current Environment
Given the historical uniqueness of the 2020-2021 state of affairs, C-TAC is committed to absorbing the hard-won lessons-learned of the recent past and ensuring they inform our efforts to improve the quality of life for those with serious illness. To that end, 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.

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.*"[1]
- Ensure that coverage and access barriers to Medicare advance care planning (ACP) counseling services are removed, especially for those most at risk for bad

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[1] https://buildbackbetter.gov/speeches/health-team-nominees-appointees-remarks-as-prepared-for-delivery/

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.

Through engagement with patients, families, consumer advocates, faith-based organizations, health systems, and others, we work to better understand what prevents access to that care and develop policies that address the specific needs of low-income and minority communities and the underlying social determinants of health. We believe in the unique needs of communities and the importance of local characteristics shaping solutions.

2021 Priority Policy Issues
C-TAC will continue to work toward our Moonshot goal of ensuring that 12 million people living with serious illness, especially the sickest and most vulnerable, have high quality of life by 2030. A key component of our work is advocating for federal legislation, regulations, and programmatic innovations that will address the many barriers to personalized care seriously-ill people and their caregivers still face.

We believe that implementation of the following policy priority areas will move us steadily in the direction of a care ecosystem that respects and honors those with serious illness, and builds medical and non-medical supports around their unique needs and values:

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 a number of 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 carry out and get paid for these services under Medicare, to include appropriately trained or experienced clinical social workers, chaplains, and others, and removing portability barriers to ensure wishes 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 public and provider national educational campaign.

➢ 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 disciplines of medical care and social services by developing and advocating for new policy, flexible delivery 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 and advanced illness and their families.

➢ 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.

➢ 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), which is 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 caregivers navigate the financial challenges associated with living with a life-limiting condition.

Care and Payment Models

Goal: Encouraging successful implementation of several existing CMMI models, including the Primary Care First-Seriously Ill Population (SIP) Model, and 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. C-TAC supports:

- ➢ Alternative Payment Models for serious illness care, including models that include caregivers and home-based palliative care.
- ➢ Requiring that all models providing care for individuals with serious illness must include a quality measure of the use of advance care planning.
- ➢ Efforts to encourage the Center for Medicare and Medicaid Innovation (CMMI) to directly fund providers of non-medical social services that have an impact on health outcomes and spending.
- ➢ Requiring providers participating in CMMI demonstration models 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.
- ➢ Organizing care across medical and social boundaries to keep those most vulnerable to COVID-19 - the serious illness population - safer at home.
- ➢ Ensuring that new value-based payment and care delivery models include publicly reportable quality metrics specifically relevant to the advanced and 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.
- ➢ Expanding 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 and to train the next generation of doctors, nurses, pharmacists, social workers, the direct care workforce, community health workers, and others.
- ➢ Polices that will enhance professional education and engagement, increase the size of the workforce, and improve the quality and breadth of clinical training.

- ➢ Grants to medical schools and teaching hospitals for career development awards, workforce development and fellowships for doctors, nurses, social workers, and others.
- ➢ Inclusion of palliative care medicine as an eligible primary care service in the National Health Service Corps.
- ➢ Use of Nurse Practitioners to provide initial certification of patients for hospice care.
- ➢ Policies that would expand coverage for community-based palliative care by trained professionals.
- ➢ Training on serious illness issues in certain medical and health education schools, and development of new curricula on advance care planning and end-of-life care for continuing education.
- ➢ Increased funding for the Racial and Ethnic Approaches to Community Health (REACH), which is the only CDC program that funds communities working to reduce racial and ethnic health disparities.
- ➢ Paid leave policies, especially for essential and direct care workers and a living wage and career development for direct care workforce.

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:

- ➢ 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.
- ➢ 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.

Who we are:
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.

After ten years, C-TAC's policy agenda has evolved, but it has not lost sight of our fundamental goal to improve care for individuals with advanced or serious illness and their families.