

Coalition to Transform Advanced Care Policy Priorities: Improving the Quality of Life for Those with Serious Illness

INTRODUCTION

Community-based organizations (CBOs) offer aid like spiritual care, housing support, transportation, and healthy meals that ensure that medical care is most effective. However, CBOs often lack the infrastructure--sustainable financing models, IT and workforce- to support this population in their community.

In collaboration with our members and partners, C-TAC works to ensure that all individuals living with serious illness, especially those who are under-served and under-resourced, have a high quality of life – on their own terms. Our [Core Principles for Care Models](#) serve as the guidance in our policy work. Included in our Principles is our commitment to advancing equity and dismantling systemic barriers to high quality serious illness care, which we have integrated into our three Policy Priorities:

I. ADVANCE CARE PLANNING (ACP) AND SHARED DECISION-MAKING (SDM)

Objective: By 2023, care planning and decision-making will be more accessible and equitable. ACP is an ongoing process done within health systems or trusted community networks that helps align care with what matters most to patients and family caregivers. We support:

- Improving Medicare's coverage of ACP through several mechanisms, including:
 - Eliminating the patient cost sharing for these services that serve as a financial barrier to their greater use (particularly for low-income individuals)
 - Advocating for a permanent expansion of the pandemic-related flexibility under Medicare to allow for reimbursement of phone-based, audio-only ACP services and with the home as an originating site.
- Funding for consumer and provider information and policies that improve accessibility to ACP for communities of color, including Standards for including ACP documents within an individual's electronic medical record, and related research and evaluation of such standards.
- Advocating for patient quality measures such as "feeling heard and understood" to be endorsed by the National Quality Forum (NQF) and used across Medicare and other programs.

II. COMMUNITY-BASED SUPPORTS AND SERVICES

Objective: By 2025, ensure that Medicare and Medicaid provide expanded funding for a package of community-based services, especially for those most in need. We support:

- Center for Medicare and Medicaid Innovation (CMMI) funding of providers of medically related and non-medical social services that have an impact on health outcomes; as well as spending or legislation that will do so.
- Expanding alternative payment models to include non-medical social supports and services, including palliative care services.
- Funding for the nation's Area Agencies on Aging (AAAs), others in the Aging Network, and other community-based organizations (CBOs), and 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.
- 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, and for State Health Insurance Programs (SHIP).
- Additional American Rescue Plan Act (ARPA) funding to expand and improve access to Home and Community-Based Services.
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III. STATE INNOVATION ON PALLIATIVE CARE

Objective: By 2025 three states will expand Medicaid benefits for social services and supports, including palliative care, for patients and family caregivers living with serious illness. We support:

- Medicaid waivers, state plan amendments, legislation, and other avenues that align community social supports with medical services to improve health outcomes
- Definitions and standards that ensure an equitable approach to care, including need-based assessments and referral requirements
- State benefits and care models, that include public engagement strategies, expanded workforce training, and increased infrastructure support to CBOs to fill the need and develop competencies
- Measurement and reporting efforts that ensure state leaders understand the current need of people and families with serious illness and the workforce capacity to deliver services

MONITORING

Issues that we monitor and support our Coalition partners who champion these issues include:

- **Family Caregiving**

- Creating 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 caregivers.
- Supporting research on caregiver out-of-pocket costs, caregiver burden, and caregiver experience of care so that the caregiver voice can be included in surveys and model evaluations

- **Pediatric Palliative Care**

- Efforts to expand the definition of children covered under concurrent care services to ensure comprehensive palliative care services are available to children who are not terminally ill and for children covered by Medicare and private insurance.

- **Workforce**

- Strengthening and expanding the workforce to better care for people with serious illness through programs for career development
- Policies 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 with a special focus on home or community-based care.
- Use of Nurse Practitioners and Physician Assistants to provide initial certification of patients for hospice care.
- 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.
- Paid leave policies, especially for essential and direct care workers and a living wage and career development for direct care workforce.

WHO WE ARE

The Coalition to Transform Advanced Care (C-TAC) is dedicated to improving the lives of underserved and under-resourced people impacted by serious illness. We work with regulators, legislators, advocates, and funders to craft policies that ensure more equitable, comprehensive, accessible care and support for patients, families and unpaid caregivers. Nonprofit and nonpartisan, we are recognized as an unbiased source of expertise on serious illness and a respected convener of more than 190 organizations that share our vision of a healthcare system that serves patient needs and honors their dignity. For more information on our policy work and members, please contact jblemur@thectac.org.