July 25, 2022

Daniel Tsai
Deputy Administrator and Director of the Center for Medicaid and CHIP Services
Centers for Medicare & Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Deputy Administrator Tsai:

I am writing to you on behalf of the Coalition to Transform Advanced (C-TAC). C-TAC is a national non-partisan, not-for-profit coalition dedicated to ensuring that all people living with serious illness receive comprehensive, high-quality, person- and family-centered care, consistent with their goals and values. C-TAC is made up of over 190 national and regional organizations who share a common vision of improving care for people with serious illness in the United States.

We commend you and your leadership team for advancing a new strategic vision for the Center for Medicaid and CHIP Services (CMCS). We believe a more equitable system of care for those with serious illness within the Medicaid program, particularly given Medicaid's role as the largest payer for long term services and supports, is key to meeting many of the goals outlined in the vision. Unfortunately, individuals with serious illnesses frequently experience barriers to care or suboptimal care; additionally, people of color with serious illnesses suffer disproportionately, experiencing high unmet needs, poor quality of life, and excessive caregiver burden.

To support CMCS' proactive policy agenda, we have shared input on the areas outlined in the strategic vision. We understand the unique role that CMCS plays with regard to Medicaid policies and programs, given the nature of the state and federal partnership driving the program. C-TAC is actively working with state Medicaid partners as well. *As noted in the attached, we believe guidance and technical assistance from CMCS would also be tremendously impactful and create a conducive policy context that will better support individuals with serious illnesses in Medicaid programs nationally.* We see an opportunity to accelerate CMCS's strategic vision and are happy to facilitate discussions with our membership and individuals living with serious illnesses to inform this implementation.

We appreciate your leadership and attention to these important issues and look forward to further discussion.

Sincerely,

Jon Broyles
Chief Executive Officer

Improving Care for Populations with Serious Illness: Considerations for Medicaid and CHIP

Serious illness is defined by the National Academy of Medicine as "a health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life, or excessively strains their caregivers."[1] Medicaid, as the predominant payer of long-term services and supports in the United States,[2] plays a critical role in facilitating access to serious illness care.

Unfortunately, individuals with serious illness often experience unnecessary suffering and receive services contrary to their individual care preferences,[3] while needed community services remain underfunded and utilization of palliative care and hospice is low.[4] Evidence demonstrates that people of color suffer disproportionately in the face of serious illness, experiencing high unmet needs, poor quality of life, and excessive family caregiver burden.[5]

CMCS has a unique opportunity to improve how individuals with serious illness are served within Medicaid. This document offers background on serious illnesses among Medicaid beneficiaries and potential supports CMCS could offer to the field based upon our work with providers, payers, patients, and caregivers across the country.

I. Background

Population

The Commonwealth Fund estimates that 12 million individuals aged 18 and older living in communities nationwide have high healthcare needs, defined as "people who have three or more chronic diseases and a functional limitation in their ability to care for themselves (such as bathing or dressing) or perform routine daily tasks";[6] this population includes a large portion of individuals with serious illness, many of whom rely upon Medicaid for coverage and access. While precise estimates of serious illness among Medicaid beneficiaries are difficult to ascertain because of differing state programs, spending indicates a tremendous need as Medicaid programs spent:

- **$12.2 billion** on Chronic Obstructive Pulmonary Disease (COPD) and
- **$11 billion** on cancer-related treatments in 2020;[7]

[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5756466/
[2] https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/
[3] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6145747/
[4] https://hospicenews.com/2021/01/19/sociodemographic-barriers-to-hospice-and-palliative-care/
[5] https://www.capc.org/health-care-for-black-patients-with-serious-illness-a-literature-review/
[6] https://www.commonwealthfund.org/publications/issue-briefs/2016/aug/high-need-high-cost-patients-who-are-they-and-how-do-they-use
[7] https://www.nashp.org/supporting-the-continuum-of-care-for-serious-illness-in-medicaid-managed-care/

Additionally nearly every state in the nation covers hospice services under Medicaid.[8]

Equity

We stand in support and close alignment with CMS' whole-government equity agenda and commend CMCS for committing to bold investments in equity, recognizing that **Medicaid covers one in three people of color** and that significant healthcare disparities remain. Ensuring consistent and high-quality access to serious illness care is itself an equity issue and must be a part of these bold investments.

While data on race, ethnicity, language, disability status, and sexual orientation and gender identity can undoubtedly be improved, the evidence that is available paints a troubling picture. For example, Black patients with serious illness are less likely to be asked about care preferences than white counterparts, less likely to have their pain adequately managed, and less likely to access care in a home setting.[9] Additionally, functional impairment, cognitive impairment, and isolation (lack of caregiver support) are often also experienced at disproportionately high rates among individuals with serious illnesses.

Addressing these disparities requires multiple strategies, but **access to affordable serious illness care is foundational to any approach.** It is in this spirit that we offer feedback on how the federal Medicaid program might play a role in clarifying how states design programs that maximize access to serious illness care.

II. Services

C-TAC approaches the concept of serious illness care broadly and holistically. We see this type of care as a continuum of services, in part because of the underlying heterogeneity of serious illnesses and also because the advancement of such illnesses mean that beneficiaries have different needs over time. Unfortunately, in part due to their historical development and evolution, regulatory and policy frameworks often artificially separate different components of serious illness care from hospice to advance care planning to palliative care.[10] **C-TAC strongly encourages federal partners to support policies, programs, and guidance that tether these programs and concepts together, to create a supportive system of care for individuals with serious illness.**

III. Requested CMCS Support

[8] https://www.kff.org/medicaid/state-indicator/hospice-care/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

[9] https://www.capc.org/blog/acknowledging-barriers-and-implementing-strategies-to-reach-black-people-with-serious-illness/

[10] https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care and https://www.nia.nih.gov/health/advance-care-planning-health-care-directives#:~:text=family%20and%20friends.-,What%20Is%20Advance%20Care%20Planning%3F,care%20providers%E2%80%94about%20your%20preferences.

Guidance

In recent years, C-TAC members have increasingly raised questions about allowable Medicaid coverage of serious illness care. C-TAC is currently partnering with a number of states developing community-based palliative care programs for their Medicaid beneficiaries. We surfaced many of these concepts at a recent event co-hosted with the Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School, *Emerging Policy Opportunities for Community-Based Serious Illness Care*.

C-TAC appreciates that some of this implementation work may fall outside of CMCS' direct purview. However, within its statutory authority, we believe there is an urgent and important role **for CMCS to play in clarifying payment, reimbursement, and other technical policy questions related to serious illness care**. We have not seen prior guidance from CMCS related to palliative care and observe that guidance related to hospice care was issued over 10 years ago.[11]

Now is an ideal time to issue guidance to the field: nearly a dozen states are actively pursuing new Medicaid programs focused on serious illness care, furthered through American Rescue Plan Act resources related to home and community-based services;[12] states and communities are expanding community alternatives to institutional care given the ongoing COVID-19 pandemic; and the continued increase in chronic illnesses.[13] We believe there is a confluence of interest and need among state stakeholders that commends a proactive federal strategy related to serious illness and Medicaid, and there is a unique opportunity to provide guideposts and remove barriers to this state-led work by exploring the following areas:

- Comprehensive palliative care services across settings, and associated waiver or state plan amendment authorities
- Concurrent curative and hospice care for adults and for children, including removing the 6-month requirement for children[14]
- Components of serious illness care, in addition to hospice and advance care planning, that can be supported through a continuum of care
- The extent to which existing Medicaid programs, such as health homes or home-and-community-based waivers, can be used to identify needs and coordinate serious illness care
- The extent to which "in- lieu- of" services or other Medicaid authorities that enable community-based supports might permissibly be used to support serious illness care (e.g. medically-tailored nutrition models)
- The extent to which 1115 or other waivers can be used to test any components of serious illness care (e.g. use of non-traditional care providers on care-teams, such as spiritual supports)

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[11] https://www.medicaid.gov/federal-policy-guidance/downloads/Info-Bulletin-5-27-11.pdf

[12] See https://kokuamau.org/hawaii-palliative-care-virtual-summit-2021-presenting-medquest-proposed-palliative-care-benefit/ and https://www.nashp.org/palliative-care/

[13] https://www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm

[14] https://www.medicaid.gov/federal-policy-guidance/downloads/Info-Bulletin-5-27-11.pdf

C+TAC

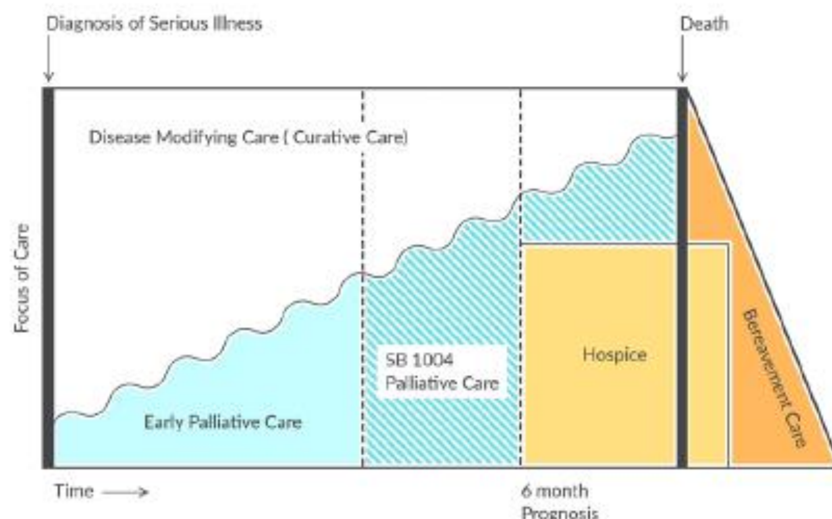
We would welcome the opportunity to work closely with CMCS on any or all of these topics.

Infrastructure and Planning

C-TAC works closely with constituencies across the country to expand serious illness care across payer/provider contexts, including Medicaid. For example, in Arizona, over 40 stakeholders founded The Arizona Coalition to Transform Serious Illness Care (AZ Coalition), focused on topics such as alternative payment models and accountability frameworks/metrics to incent high-quality serious illness care.[15] In Hawaii, philanthropic efforts have supported technical and actuarial planning around a forthcoming palliative care submission to CMCS.[16] In California, the Alameda County Care Alliance was founded by African-American pastors along with congregants, health systems, community groups, and national organizations to offer a faith-based, lay care navigation intervention for individuals with serious illness, now being piloted with Kaiser Permanente.[17]

Also in California, various philanthropies funded the California Advanced Illness Collaborative (CAIC) to develop consensus standards for community-based palliative care within managed care, following on the passage of a state bill (SB1004) that required Medi-Cal Managed Care health plans to ensure beneficiary access to palliative care.[18] At the time, the state Medicaid agency indicated that this work filled a critical void, as there was no state or federal guidance on the topic.

Framework for serious illness care from California State Bill 1004



[15] https://www.azhha.org/az_coalition
[16] https://stupski.org/our-programs/serious-illness-care/
[17] https://www.care-alliance.org/
[18] https://coalitionccc.org/CCCC/Our-Work/Consensus-Standards-for-CBPC-in-CA.aspx

Across these states, a combination of philanthropic support and volunteerism among participants has driven planning, innovation, and implementation; and yet the intent is to generate technical programmatic designs and, at times, to directly inform state Medicaid submissions or Medicaid managed care contracts or policies. To that end, we urge CMCS to play a role in these planning efforts, by issuing guidance or releasing resources such as planning grants to promote consistency and alignment with Medicaid program parameters.

Addressing these concepts globally, partially, or together in new and future guidance efforts or planning grants could dramatically impact both the quality and experience of care for populations with serious illnesses relying on Medicaid. C-TAC welcomes the opportunity to discuss ways to further expand upon any of the concepts defined herein. Additionally, to the extent C-TAC's member network can serve as enrollment partners and supporters to meet CMCS' coverage goals, we are happy to marshal our collective resources to achieve increased enrollment and access to high-quality care.