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In July 2020 we made a commitment to advancing health equity, recognizing that it was embedded in our vision as C-TAC, but never fully acted on. We defined equity for our work as the transformation of Care for all Americans living with serious illness, with a particular focus on achieving the highest level of anti-racist care for those who are the sickest, most vulnerable and disadvantaged.

Based on this grounding, we had two objectives: to ensure that those who are racially and economically disadvantaged are supported and that we address systemic injustices in the system of care for those with serious illness.

Nearly 18 months after releasing our action plan, here's what we did, what we learned, and what we're committed to in the future.

In June of 2020 in the wake of the murder of George Floyd, our staff and board felt the urgency to act. Shirley Roberson, a member of our equity taskforce, board member and patient fellow, reminded us that before we took action, we had to ask: who are "we"? How can we act, if we don't have the right people at the table and not only invited to the table but present as equal participants. If we have an instrument out of tune, Shirley

said, you need to find the expert who can tune it. Care for the "sickest and most vulnerable" was in our founding vision statement, but it was out of tune. And the people who could hear where it was out of tune weren't engaged as they should be. Who are the "we" making decisions? Who are the "we" developing solutions for the sickest and most vulnerable?

## Defining the Table

# Lesson #1: Patient Engagement Is an equity issue. They are not the objects of our actions but participants.

Since 2018 we have had an annual Patient / Caregiver Fellowship that provided reimbursement for their time in working with staff on strategic planning, programming or serving as speakers at events. What we learned is that reimbursement for time is not enough. It's just the starting point. To meaningfully include patients/caregivers as partners in developing and refining our work, we needed to incorporate other supports such as: a careful onboarding plan that would include a glossary of terms and acronyms; briefing and debriefing before and after meetings; getting feedback on ideas; and being as concrete as possible about the ultimate benefits to the patient and family caregiver in the work.

#### **Developing the Plan**

#### Lesson #2: We all need concrete actions we can take, especially to get started.

After re-assessing the "we" of C-TAC to include diverse voices and patient perspectives, our next challenge was developing the action plan. Taking on health equity for those with serious illness can seem like an overwhelming task. We outlined four areas for action to help stay focused:

- *Strategic Planning*: Addressing internal and external strategies as we examine culture, policies, practices, attitudes of our board, staff, and members.
- *Data*: Incorporating anecdotes and data from those patients and families who have been disadvantaged by the U.S. healthcare system.
- Advocacy: Naming and unmasking systemic racism and inequities.
- *Models*: Identifying and spreading models of care to address inequities and provide support for those who are living with serious illness, reflecting their goals, and honoring their dignity. This includes the development of our Core Principles for Care Models, which includes equity.

## **Develop Long-Term Relationships**

### Lesson #3: It's going to take time.

We recognized that we needed to recruit more leaders and set a goal of strengthening our board and staff to ensure that at least 30% come from diverse backgrounds. 18 months on, we surpassed this goal and learned a lot on the way.

The response of "we don't know any diverse leaders in [fill in the blank]" was something that we had to grapple with. The problem? We needed to reframe our thinking.

We needed to shift our mindset from finding quick fixes to ensuring long-term change and sustainability; the "bumper sticker" of the approach we sought was an African saying: *it takes a long time to grow a tree.* 

In talking with our members we learned that everyone has something to build on, some seedlings, towards long-term success. For us, we had a terrific leadership core of interfaith leaders for many years, but we recognized that we had to further expand the tent in the Coalition to organizational members that bring missing perspectives and leaders. So we started to develop relationships with new leaders — especially emerging leaders — systematically, with a view toward getting their feedback, engaging them as speakers, consultants, and ultimately as board or staff members.

"I am repeatedly impressed with C-TAC's commitment to concretely addressing racial equity in transforming serious illness care. It's inspiring to see a national organization stand up for what they believe in such an uncompromising way and do the real work of engaging communities and truly sharing the stage."

-Julie Boudreau, Executive Director, The John & Wauna Harman Foundation

	What we did	What we learned	What we will do
Defining the Table	Engaged Staff and Board to define equity in context of 2030 Moonshot	Equity is not "one more thing" we do but instead is rooted in org's vision	Work with outside facilitators to continue refining our approach in strategic plan and help with problem solving

We've summarized our activities below:

		and at the core of work	
	Recruited Board and Staff	Prioritize developing long-term relationships, especially with emerging leaders	Continue to strengthen diversity across org and ensure inclusiveness in decision-making
	Engaged with our Members on their equity plans	There is widespread commitment to equity, with eagerness for specific steps they can take	Share our members' work -Work with leaders in the Coalition to develop shared action plan
Developed the Action Plan	Developed 2025 strategic plan with refined vision/mission	Expand timeline to engage patients and others who have suffered disparities to vet plan	Develop relationships with other patient advocates, incorporate into events, planning and org decision-making
	Hosted JEDI workshops on equity (2020, 2021)	Significant interest from our Members in practical training	Helping JEDI and others with training models connect with Members and Funders

Held two Summits and Policy Forum to hear from members with effective models	C-TAC members are eager for actionable steps they can take on equity with 70% of Summit attendees identifying that they need partners to help them move forward	We will continue to weave these perspectives into our 2022 Summit and all other events and publications
Held listening sessions with patients and unpaid caregivers in developing our policy agenda and strategic plan	Trusted sources of information and support for non-medical needs such as transportatio n and meals were consistent themes	Develop or identify network of patient and caregiver advocates to engage

	Released updated Policy Agenda with recommendations on equity -Sponsored Equity Workshops at Partner Events	Leaders at CMS released their 10 year vision that featured our serious illness population and health equity.	Developing Recommendations for CMS based on their 10 year vision to incorporate equity into care models for those with serious illness
Developing Long-term Partnership s	Promoted faith-based community models at our National Summit as well as helping make connections among members	While effective in reaching the underserved, many faith-based programs need capacity support in model design, sustainability, networking and funding	Sponsoring BIPOC Entrepreneur Accelerator Action Plan and supporting our Interfaith Action Council in promoting models to their networks
	Sponsored two pilot projects in Louisville, KY, and Ward 7, Washington, DC	Community needs are larger than serious illness. Use our connections among the Coalition to find partners who can help with needs	Refining policy agenda based on pilots and helping connect community stakeholders to partners

#### 2022 and Beyond

As we move forward with our 2025 goal we have outlined goals across the four areas of Strategic Planning, Data, Advocacy and Models. In particular, we have increased our budget this year to:

- Support BIPOC entrepreneurs developing in partnership a blueprint of need and a step by step process that needs to take place to help them build capacity.
- Engage with peer leaders to develop an action plan to further change.
- Engage more experts in health equity on our policy agenda.

For more information on C-TAC's health equity efforts, contact Jon Broyles at jbroyles@thectac.org.