

2021-22 Policy Priorities for Supporting Caregivers & System Reform

“While caregivers are the backbone of our national health care system, they are often overlooked and alone, and they desperately need our help.”

– Former First Lady
and Institute Founder
Rosalynn Carter

The U.S. lacks an adequate system for supporting the estimated 53 million American caregivers. **Siloed funding, disparate waiver programs, and the lack of state and federal coordination have resulted in an approach that is inefficient, expensive, and difficult to navigate.**

Long-term care is complex and multidisciplinary encompassing a broad spectrum of competencies and skills. Substantial engagement of caregivers is critical to addressing this issue. RCI encourages policymakers to move caregiver needs and preferences from the margins to the center through legislative and regulatory changes that support caregivers in their current role and a redesign of dysfunctional systems that add to caregiver burden. Policies should reflect sound evidence of the experience of caregivers; advance equitable treatment of caregivers regardless of where they live, the health of those they are care for, or the funding source for their healthcare services. Policymakers should focus on the caregiver rather than the caregiving tasks they perform.

Policy Agenda:

Advocate for an unprecedented coordination of support for caregivers across federal research, policy, funding, and programming. Achieving caregiver health, strength, and resilience will require system-level change. RCI encourages the development of policy requiring agency coordination with the ultimate goal of the creation of an Office of the Caregiver at the Department of Health and Human Services to drive inter- and intra-agency coordination and ensure that all federal policies reflect the needs of caregivers.

Support funding for Medicaid Home and Community-Based Services in the current reconciliation bill. The proposed investment in Medicaid is historic and long overdue and must be followed by thoughtful implementation to guarantee meaningful change for the caregiver. RCI will focus on the following policy initiatives to shape regulations and implementation:

- Include caregiver supports for those transitioning out of institutional and hospital settings
- Require that Medicare Advantage plans provide caregiver supports.
- Require standardized collection of caregiver data across Medicaid programs and assess other opportunities to do so.
- Promote guidance and rulemaking that centers caregivers in service and payment delivery design and demonstration projects through the Center for Medicare Services and the Center for Medicare and Medicaid Innovation.

Together, these policy changes represent important reforms that begin to move caregivers from the margins to the center to support their health, well-being, and resiliency. Caregivers are the invisible frontline of healthcare in America. They have been ignored for too long. Now is our moment to support them, change the system, and change lives.

RCI was founded in 1987 on the campus of Georgia Southwestern State University, Mrs. Carter's Alma Mater. RCI continues to be rooted in her belief that there are only four types of people in the world: those who have been caregivers, who are caregivers, who will be caregivers, and who will need caregivers. In 2020, RCI expanded nationally to serve the more than 53 million American caregivers by building cross-sector partnerships, promoting evidence-based programs, and advocating for sound public policy.