



## **RAISE Family Caregiving Advisory Council: September 2021 Meeting Summary**

On September 21, 2021, the RAISE Family Caregiving Advisory Council (FCAC) convened to discuss the release and dissemination of its Initial Report to Congress. The Council watched video presentations of the report overview recorded by the Council Co-Chairs, and listened to two caregivers who were invited to the meeting to share personal stories of their caregiving experiences. Attendees also heard presentations on key priorities of the Biden-Harris Administration, as well as other emerging legislative initiatives that impact family caregiving in the US, and explored ways for shifting focus to the development of a National Family Caregiving Strategy.

### **Call to Order and Welcome Remarks**

The meeting was called to order by Alison Barkoff, Acting Administrator and Assistant Secretary for Aging at the Administration for Community Living (ACL). Administrator Barkoff welcomed members and other participants to this important event. She expressed special gratitude to members personally and collectively for their hard work and commitment in achieving this important milestone of producing an Initial Report that will be submitted to Congress the following day on **Wednesday, September 22**. She shared how important and timely the recommendations are as they will pave the way for the development of a National Family Caregiving Strategy that is long overdue. She acknowledged and conveyed special appreciation to ACL's collaboration with partner organizations such as the John A. Hartford Foundation (JAHF) who supported the Council's work with a grant to the National Academy for State Health Policy (NASHP) which funded the RAISE Family Caregiver Resource and Dissemination Center, and others like the National Alliance for Caregiving (NAC), UMass-Boston, Community Catalyst and others who have contributed in so many ways to make today's accomplishment possible.

Administrator Barkoff explained that there are 53 million caregivers in the US and that at any given time, one in seven of us serves as a caregiver. She shared how the COVID-19 pandemic has exposed the real importance of family caregiving in the last 18 months, and how the work and contributions of caregivers have also been exacerbated during the pandemic. She elaborated by stating that is why the President has made caregiving a center piece of his *Build Back Better Plan* which Congress is currently focused on. She spoke about key provisions in the Administration's reconciliation bill now in Congress to support family caregivers such as *Better Care Better Jobs Act*, and the expansion of paid family leave. She explained that the Administration is already making use of certain provisions of the American Rescue Plan of 2021 as a down

payment to pay caregivers who step in to provide care for their loved ones. She commended the ACL team for completing this report at this particular point in time and extended special thank you to Greg Link, Director, Office of Supportive and Caregiver Services who spearheaded the Council's work especially, through a ravaging pandemic to a finished initial report that is ready for submission to Congress tomorrow.

## **Overview of Report**

The Council's attention was drawn to the recorded video presentations of the report overview by the three Council Co-Chairs: Nancy Murray, MS, Alan Stevens, Ph.D., and Casey Shillam, Ph.D. Below are some of the important issues the Council tried to address in the now completed initial report to Congress:

- The economic value of family caregiving in the US is estimated at \$470 billion annually.
- Family caregivers are the backbone of care in the US but not adequately supported by policies at all levels of government.
- The report will result in the development of the first ever National Family Caregiving Strategy in the US to ensure that there is adequate support for family caregivers.
- There is a significant personal relationship between family caregivers and the people receiving support.
- Due to lack of consistent supports, the caregiving experience usually leave caregivers to be financially, emotionally, and physically depleted and socially isolated.
- Caregiving has become more complex than is usually the case as most caregivers now perform medical, administrative, care coordination duties, etc.
- Caregiver voices were the driving force behind the work the Council has done.
- The 25 videos of caregivers who told their stories is the unique part of the report and informed the 26 recommendations.
- The report is the first step to implementing the RAISE Act.
- The Strategy when completed, will form the roadmap for change and truly supporting our nation's caregivers.
- The report reflects concerns of caregivers nationwide as gathered through the more than 1600 RFI responses, caregiver focus groups, stakeholder listening sessions, 25 caregiver narratives and videos.

The Council also watched a special video, titled, [Faces of Caregiving](#), which was created by the National Alliance for Caregiving (NAC). Two of the caregivers, Debbi and Sarah, featured in this video were present at the meeting. Administrator Barkoff spoke with Debbi and Sarah, asking each of them questions about their lived experiences. Their stories were so powerful and personal that they put a human face to the real lives of family caregivers, as well as the sacrifices and often lonely terrain they have to navigate on a daily basis with little or no support in place to help them.

At the conclusion of her remarks, Administrator Barkoff handed the meeting over to Greg Link who asked for a roll call of the attending Council members to acknowledge

their contributions, and to thank them for what they have accomplished. He expressed special appreciation to Rani Snyder and Scott Bane of the John A. Hartford Foundation (JAHF) for their grant to the National Academy for State Health Policy (NASHP) as well as to Wendy Fox-Grage and her team at NASHP for their support. He reminded the Council of the need to continue to stay informed of what is going on in Congress, the federal government, and across the country especially, now that its focus has shifted to developing a National Family Caregiving Strategy.

### **Looking Ahead to the Development of a National Strategy**

Mr. Link introduced Jessica Schubel, Director of Affordable Care Act and Health Care for the White House Domestic Policy Council (DPC) to provide an overview of some of the Administration's key priorities. Ms. Schubel started by highlighting some of the President's efforts to strengthen Medicaid Home and Community Based Services (HCBS), as well as family caregivers in addition to the following priorities:

- The President believes that healthcare is a right and not a privilege.
- Provide additional funding to States through the American Rescue Plan to help in reducing waitlists, pay caregivers for their work and other ancillary expenses such as upfront transition costs, security deposit and utility bills, telehealth, personal protection equipment (PPE), respite care, vaccine related transportation costs, supplies that are not usually paid for by Medicaid, workforce training, and by allowing caregivers to enroll as Medicaid providers, etc.
- Allow States to use money from the American Rescue Plan to establish or expand HCBS programs by increasing wages or provide paid leave for home care workers, workforce training and workforce quality improvement initiatives. This money can also be used to provide important information caregivers need to perform more complex tasks.
- Two important policies in the Build Back Better Plan that are worth mentioning are 1. *Money Follows the Person Demonstration Program* which allows many families to move back into their homes and communities, bringing with it innovations in long term care delivery. 2. *Expanding Access to Quality HCBS* while creating new employment opportunities, supporting efforts for increased wages, provide health insurance and paid leave, other benefits to caregivers, training and career advancement opportunities, and the establishment of a national paid leave program.
- The president is also calling on Congress to pass the *Healthy Family Act* which will allow workers to accrue 7 days of paid sick leave per year that can be used to attend to their own preventive care needs or that of their family members.
- The President shares what most families already believe – that their loved ones should remain in their homes and communities.
- The President's proposal for the creation of a *National Comprehensive Paid Family and Medical Leave Program* that will ensure employees receive partial wage replacement when they take time to care for a seriously ill loved one, their own illness or take time to deal with the loss of a loved one. When approved, this program will guarantee 12 weeks of annual paid leave for parental, family

and personal illness plus 3 days of bereavement leave starting at first year of implementation.

Members also heard from two speakers from the National Alliance for Caregiving (NAC): Grace Whiting, President and CEO and Mike Wittke, Senior Director, Public Policy and Advocacy. Some of the issues they spoke about included:

- The need for a dynamic, impactful and meaningful strategy.
- Caregivers are partners and high quality care providers.
- Healthy families are core to the nation's public health system.
- Community efforts to estimate the global prevalence of caregiving is important to support a global action plan for Carers, and to build partnerships with the *United Nations* (UN) and the *World Health Organization* (WHO).
- The importance of building awareness and outreach because not all caregivers identify as such and some often resist such labeling. Systems therefore have a responsibility to reach out to individuals instead of the other way around.
- The need to recognize caregivers as partners, the CARE Act is a good starting point but other opportunities exist to engage caregivers like those in the 21<sup>st</sup> Century Cures Act 2.0.
- Caregivers will benefit from paid family and medical leave and wage replacement programs as currently proposed by the Administration to address the need for income security. Additionally, the [Credit for Caring Act](#) and universal family care will help caregivers and recognize the value of their work.
- The need for family centered support to engage caregivers who are often forgotten especially, young caregivers. Some State actions/programs such as the Maryland [Caregiver Services Corps](#) have been deemed helpful during the COVID-19 pandemic.
- Research and data gathering: Actions like expanding the [caregiver module](#) of the Behavioral Risk Factor Surveillance System (BRFSS) and implementing the strategic plan created by the National Institute of Nursing Research will help with gathering robust and consistent data.

Some of the key issues the Council discussed during the Q&A included but not limited to the following:

- Family paid leave for caregivers.
- Lessons learned from the Affordable Care Act (ACA) that could be applied to the National Strategy.
- Why the *Social Security Credit Act* has not received much attention?
- The need to involve families in discussing and defining what respite care means for their particular situation.

## **Closing Remarks**

Administrator Barkoff thanked the speakers for their insightful presentations and expressed her hopes that the report and the 26 recommendations in it will bring about a remarkable change and ultimately translate into an impactful National Family Caregiving Strategy that will set the stage for adequately supporting family caregivers nationwide. She again expressed gratitude to the Council and to the caregivers who may be listening, she thanked them for their participation and urged them to see the report as a recognition for their work. Mr. Link adjourned the meeting.