



Joint Meeting of the RAISE Family Caregiving Advisory Council and Advisory Council to Support Grandparents Raising Grandchildren

Hosted by the Administration for Community Living (ACL)
July 27, 2023, 2:00 p.m.–4:30 p.m. ET

Call to Order and Welcome Remarks

Alison Barkoff, Acting Administrator and Assistant Secretary for Aging, ACL

Alison Barkoff welcomed the incoming members of the RAISE Family Caregiving Advisory Council (FCAC) and the Advisory Council to Support Grandparents Raising Grandchildren (SGRG). She noted that the mandate for the new advisory councils is to pick up where the first councils left off to ensure implementation of the 2022 National Strategy to Support Family Caregivers, the first national strategy to support family caregivers.

The 2022 National Strategy is the result of an unprecedented public-private partnership, Barkoff explained. After more than three years of work, the first advisory councils produced a strategy to ensure that family caregivers are included in policy, program design, and service delivery. Federal agencies are partners in this work and accountable for moving the ball forward. Together they have made 300-plus commitments to supporting the 2022 National Strategy.

However, Barkoff emphasized that government cannot do this alone. States, philanthropic organizations, businesses, and others must join the effort.

Issues of caregiving have never been more visible, she said, and there has never been more momentum for change. Supporting the care infrastructure is a top priority of the Biden administration and was featured in the State of the Union address in February 2023 and in an executive order in April 2023. U.S. Department of Health and Human Services (HHS) Secretary Xavier Becerra also strongly supports these efforts.

The charge to the new advisory councils is to build on the work of the previous councils and update and improve the 2022 National Strategy to solve existing problems and address new ones.

Advisory council members have received an orientation document that gives an overview of the work of the previous councils and outlines the diversity of caregivers and those receiving support, who should be at the center of caregiving efforts.

The orientation document also addresses the interconnections between family caregivers and the paid workforce. A lack of paid caregivers means that the family must take on more. Therefore, initiatives to stabilize and strengthen the direct care workforce are vital to supporting family caregivers.

Finally, Barkoff noted that the advisory councils' work is essential to ACL's mission to support living in the community—which is a civil right.

- Barkoff thanked ACL's Office of Supportive and Caregiver Services with special thanks to its director, Greg Link, and Program and Management Analyst, Lori Stalbaum.
- She also thanked partners from the private sector, the John A. Hartford Foundation for funding the establishment of the RAISE Resource Technical Assistance and Dissemination Center, and the National Academy for State Health Policy (NASHP), which manages the Dissemination Center, for their work to support the RAISE FCAC in its work.
- She then acknowledged the work of Generations United, which — through an American Rescue Plan-funded grant from ACL — established the first national technical assistance (TA) center for kinship and grandfamilies. The TA center helps state, tribal, and territorial government agencies, nonprofit organizations, and kinship navigator programs work across systemic and geographic boundaries to better support kin and grandparent caregivers.

HHS Leadership Remarks

Meg Sullivan, Counselor to the Secretary, HHS

Meg Sullivan started by saying how honored she was to work with Barkoff and her team at ACL.

Developing the first National Strategy to Support Family Caregivers was a historic accomplishment, Sullivan said, expressing excitement to be present to swear in new council members, whose goal will be to ensure that the strategy remains up to date.

She said the COVID-19 pandemic reinforced the need for a coordinated approach to caregiving, and the Biden administration responded with the April 2023 executive order supporting family caregivers' calls for improving support to family caregivers and making long-term services and supports more affordable for families, including military families.

She pointed out that as many as 53 million people — including grandparents — care for relatives, adding that caregiving has physical, emotional, and financial consequences that can impact wellness. The 2022 National Strategy provides a roadmap for finding solutions and working together for a shared vision for a more robust caregiver response.

Swearing in of New Council Members

Performed by Alison Barkoff

Barkoff swore in the 14 members of the FCAC and the 9 members of the SGRG Advisory Council.

RAISE FCAC Members

Jesse Bracisco
Jonathan Cottor, MBA, MPH
Lynn Gall
Felicia Gibson
J. Neil Henderson, M.S., Ph.D.
Sharon L. McDaniel, Ph.D., Ed.D., MPA
Daniel Murphy, PMP

Denise Myler
Nancy C. Richey, B.A.
Gloria J. Sanchez
Kezia Scales, Ph.D.
Deborah Stone-Walls, M.A.
Jennifer L. Wolff, Ph.D.
Carol Zernial, M.A.

SGRG Advisory Council Members

Donna M. Aguiniga, Ph.D., MSW
Ana Beltran, J.D.
Anntesha Chesterton
Carole Cox, MSW, Ph.D.
Megan Dolbin-MacNab, Ph.D., LMFT

Bert Hayslip Jr., Ph.D.
Rainie B. Jueschke, CFRE
Keith Lowhorne
Cheryl Miller, M.A.

White House Remarks

Jessica Schubel, Special Assistant to the President for Health Care at the Domestic Policy Council

After the swearing-in, Jessica Schubel congratulated the new members and thanked them for all their work on behalf of the nation's families.

She explained that the Biden administration is committed to increasing access to community-based services to support family caregivers and their families. These family caregivers are why millions of older adults and people with disabilities can live in the community.

Family caregivers need greater recognition and support, she said, including a robust home care system that supports Medicaid and Medicare beneficiaries and additional Medicaid and Medicare funding to expand access to vital services. She said that investing in care is an investment in the nation's families and the country, and President Biden's administration is using all available tools to support caregivers.

Introduction of Bonnie Knox, Meeting Facilitator

Alison Barkoff

Barkoff introduced Bonnie Knox, Ph.D., who facilitated the council discussions. Knox has a doctorate in workforce development and more than 20 years of experience helping to facilitate government efforts.

Knox emphasized the importance of building connections and getting to know each other as part of working together effectively. Prior to the meeting, incoming non-federal council members were paired with federal members to have a get-to-know-you conversation about their experiences with and relationships to caregiving as well as a few fun facts about their interests or hobbies. The members then introduced each other to the rest of the assembled councils.

Discussion: Setting Our Agenda for the Work Ahead

Facilitated by Bonnie Knox

What is one area of the 2022 National Strategy that we should focus on over the next year?

In response to this question, council members offered the following:

- Improve the use of technology to create connectivity and alleviate challenges for caregivers.
- Disseminate information about using the Family and Medical Leave Act (FMLA) to preserve one's job while caring for loved ones.
- Identify ways to connect caregivers with outside resources for support and financial assistance.
- Communicate the importance of supporting caregivers, particularly to employers.
- Provide resources to help caregivers deal with emergencies, e.g., access to Wi-Fi.
- Establish partnerships to bring the goals of the strategy to reality.

- Connect family caregivers to others who have gone before and know how to navigate systems and overcome hurdles, for example, with schools.
- Educate people about the whole journey of caretaking.
- Address cross-cultural caregiving for dementia and other health issues in American Indian, Alaska Native, rural, and other communities with health disparities.
- Make more public investments in home health care, including paying or subsidizing family members to serve as caregivers.
- Strengthen support for caregivers in the community and make it easier to license and open caregiving programs.
- Reduce barriers to accessing services and educate professionals about the services available to grandparents.
- Develop interventions that can help people gain confidence in how to overcome barriers. Be solution-oriented.
- Address the critical need for formal, paid services that are the counterpart of unpaid family caregivers. Address barriers to reimbursing families for the care they provide.
- Monitor progress in meeting the goals of the strategy to determine whether it is being actualized and where more efforts are needed.
- Focus on strategies to turn the “workforce ship” around.
- Address questions of equity among caregivers and the lack of financial resources among families serving as caregivers.

What information is needed to help your council showcase these areas in the updated National Strategy?

In response to this question, council members offered the following:

- Educate local communities and states about federal mandates and requirements and hold them accountable.
- Socialize and communicate the challenges of caregiving and the current crisis many caregivers face.
- Leverage the fact that everyone across the generations is a caregiver or has a connection to caregiving.
- Identify the work done across all federal agencies.
- Raise awareness and learn more about kinship care roles other than a grandparent.
- Address that many kinship caregivers care for older and younger family members.
- Make valid assumptions when hard data are not available. For example, we know that families are using emergency rooms to get their own respite care, even though it is not documented.
- Identify loopholes that keep people from getting support—i.e., exemptions that allow some employers to avoid federal laws that support caregiving.

How could that information be communicated to the nation?

- Enlist disease organizations to help get the word out directly to impacted families. The muscular dystrophy organization, for example, has conferences that families attend.
- Enlist influencers and celebrities with impact to share their own caregiving stories.
- Use ambassador programs to raise awareness about caregiving, its challenges, and rewards.
- Tap into media and political organizations that have higher credibility with communities facing health disparities (who may be bypassed by prominent media outlets).

- Use a “train-the-trainer” model to increase impact.
- Meet people where they are, for example, in doctors’ offices.
- Find ways to connect with the older generation, given that more and more people will need caregivers.
- Use every modality possible to reach people, especially ambassadors, and think of outreach as a dialog, with opportunities to listen and share information, making sure to ask the right questions and collect—not just dispense—information.
- Engage people who are emotionally involved at the grassroots and who know where the resources are.
- Demystify caregiving so that everyone sees themselves as a caregiver and understands that we will all be caregivers at some point in our lives.
- Involve counties in regional collaboratives such as the Community of Practice in Pennsylvania, which supports families throughout their lifespan with support from the state’s Department of Human Services. Pennsylvania Family Network also uses a train-the-trainer model that identifies ambassadors within communities.
- Raise awareness about the financial hardships facing modern families and the practical impact on caregiving, e.g., identifying what is covered and not covered by Medicare, etc.

Looking Ahead: Tasks and Next Steps

Lori Stalbaum

Stalbaum updated the advisory councils on the next steps.

- Nominations for co-chairs for each council:
 - An email about the roles and responsibilities of advisory council co-chairs will be sent in early August.
 - Council members can self-nominate.
 - ACL leadership will make the decision.
- Resources will be provided to the advisory councils to assist in visioning and goal setting.
- Council member profiles:
 - Council members will be contacted to review their profiles, fill in gaps and ensure that their biographical information is correct before posting them on the ACL FCAC and SGRG Advisory Council web pages.
- Next joint meeting: September 19, 2023.
 - Materials will be sent prior to the meeting.

Looking Ahead: September 19, 2023

Greg Link

Link provided some details about the tentative agenda for the September 19 meeting, which will convene from 12:30-4:30 p.m. ET:

- Announcement of co-chairs.
- Introductory presentations by NASHP, Hartford Foundation, and Generations United.
- Presentations on:
 - Analysis of public comments on the 2022 National Strategy.
 - Analysis of federal actions.
- Updates from federal colleagues.
- Council member discussion.