



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)
June 13, 2024, 12:30 p.m.–4:45 p.m. ET

The RAISE Family Caregiving Advisory Council (RAISE) and Advisory Council to Support Grandparents Raising Grandchildren (SGRG) convened for their fifth joint meeting to present an overview of the 2024 Progress Report: Federal Implementation of the 2022 National Strategy to Support Family Caregivers. During the meeting, a vote was taken to advance the report into U.S. Department of Health and Human Services (HHS) clearance. The meeting was hosted by the Administration for Community Living (ACL).

Call to Order and Welcome Remarks

The meeting was called to order by Alison Barkoff, the senior official performing the duties of the ACL Administrator and Assistant Secretary for Aging. She thanked everyone for their participation and dedication to supporting America's family caregivers. She introduced the council chairs: Jonathan Cottor, RAISE Co-chair; Carol Zernial, RAISE Co-chair; and Keith Lowhorne, SGRG Chair.

Following a roll call of the RAISE and SGRG council members, Greg Link, Director of ACL's Office of Supportive and Caregiver Services, provided an overview of the meeting's agenda.

Presentation of the RAISE/SGRG Council 2024 Progress Report: Federal Implementation of the 2022 National Strategy to Support Family Caregivers

Carol Zernial, RAISE Co-chair, gave a brief overview of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act, highlighting its three key components: the formation of the council, the comprehensive report to Congress, and the [2022 National Strategy to Support Family Caregivers](#). She also shared the history and activities behind the Supporting Grandparents Raising Grandchildren (SGRG) Act.

Jonathan Cottor, RAISE Co-chair, elaborated on the four components of the 2022 National Strategy, including the background narrative on the breadth of family caregiving, the first principles that describe the 4 cross-cutting considerations that must be reflected in all efforts to improve support to family caregivers, and the two final components, which lay out the nearly 350 federal actions as well as at least 50 recommended actions for state, local, and community organizations.

Keith Lowhorne, SGRG Chair, discussed the significant public feedback received— over 1,000 comments in three months. He emphasized the top priorities for future iterations of the strategy based on this feedback, including:

- The need to address the affordability, quality, and supply of direct care professionals.
- The demand for long-term services and supports, caregiver training, and respite access.
- The improvement of mechanisms to mitigate the financial and workplace impacts of caregiving.

Following these presentations, Link invited comments from the attendees. Several participants noted the strategy has effectively increased capacity and inspired the community, and they recognized the substantial progress made thus far.

Federal Agency Progress and Looking Ahead

Jonathan Westin, Aging Services Programs Specialist at ACL's Office of Supportive and Caregiver Services, focused on updates from the federal agencies contained in the 2024 Progress Report. He highlighted the significant progress made in nearly 350 federal actions outlined in the Strategy. Specifically, federal agencies started work on 270 actions across all five goals, with 84 actions completed by HHS and 157 still in progress. ACL completed 36 actions, with an additional 50 actions ongoing. Furthermore, since the release of the Strategy, federal agencies have proposed forty new actions. A federal partner noted that some actions are not one-off events but ongoing efforts that are never "complete."

Following the 2024 Progress Report overview, Westin asked the federal partners to share their insights and responses to discussion questions.

Discussion question #1: As we prepare to begin working on an update to the Strategy, where do you see the biggest challenges and greatest surprises? Moreover, where are the opportunity areas for new actions or emerging policy areas the advisory councils could consider as they update their strategy?

- More representative data is needed to design policy and services appropriately for caregivers. This is both a challenge and an opportunity.
- State-level data is available from the Behavioral Risk Factor Surveillance System (BRFSS) survey. However, we need to explore innovative approaches to gathering national-level data. The Centers for Disease Control and Prevention (CDC) has proposed a caregiving question for the 2025 National Health Interview Survey, which will move us in this direction.
- Workforce development is needed to address the shortage of direct care workers, especially certified nursing assistants and community health workers. More caregiver education and training are needed for both paid and family caregivers, especially in caring for older adults, people with serious illness or multiple chronic conditions, and on the intergenerational aspects of caregiving and distinguishing the caregiving needs of older people versus the younger people.
- The definition and use of the term "caregiver" need to be consistent. It should be specified that relatives, even without pay, can be caregivers.
- State and local programs, such as area agencies on aging (AAAs), that support caregivers should be involved in developing and implementing the strategy.

- More data is needed on people with disabilities or who are under 65 and need long-term services and supports (LTSS) and home- and community-based services (HCBS). The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is developing a set of questions for this population that could be fielded on a national survey to get state-level estimates.
- The shortage of direct care workers impacts family caregivers, shifting more of the work to unpaid family members.
- Employers need to support employees who are also family caregivers by investing in supports for them, providing care navigation and sometimes even direct services, and offering flexibility so that those employees can continue working while also caring for their family members.
- States should unify services to better support older adults, people with disabilities, family caregivers, and direct care professionals. For example, 49 states have plans for Alzheimer's Disease, which addresses caregiving, and many states have master plans on aging.
- Research is needed to develop and identify successful and scalable interventions to help address the needs of caregivers.
- The Strategy has created momentum and opportunities to develop strategies and supports for caregivers.

Discussion question #2: On a related note, do you have a sense for (or are you able to talk about) what your agency might be able to put forward as new actions in the first update to the Strategy?

- An increase in funding for ACL's National Family Caregiver Support Program in 2023 has led to the development of a new initiative called The National Caregiver Support Collaborative. This has been added as a new action since the release of the Strategy. The Collaborative will be developing and testing approaches and supporting our aging and tribal service networks to improve services.
- ACL's final budget from Congress included a mandate that appropriated \$2 million to test and evaluate caregiver navigator services. The funding opportunity announcement for this new program went out on June 6, 2024.
- The Centers for Medicare & Medicaid Services (CMS) Innovation Center announced the Guiding an Improved Dementia Experience (GUIDE) model. Medicare also released the Physician Fee Schedule 2024 Final Rule, which includes new policy changes that became effective as of January 1, 2024. The new rule includes reimbursement for certain types of practitioners to train caregivers to support people with specific diseases and illnesses in their treatment plans.
- The Children's Bureau of the Administration for Children and Families (ACF) announced that five kinship navigator programs have met the evidence standards by Title IV-A clearinghouse, and four states will implement these with federal funding. The Children's Bureau also recently created an online national training and development curriculum for foster and adoptive parents and kinship caregivers.
- The new cohort for the Health Resources and Services Administration's (HRSA's) Geriatric Workforce Enhancement Program will focus on the support of the health care and caregiver workforces to maximize patient and family engagement and improve health and health outcomes for older adults by integrating geriatric and primary care. They are also offering funding for training for caregivers for people with dementia.

- The Department of Labor (DOL) plans to continue providing technical assistance and research for the 13 state-paid family and medical leave programs and development for family caregivers who are also employed. DOL will also release research about wages for care professionals later this year.

Discussion question #3: How do you feel we can maximize coordination between agencies for dialogue/learning from one another and synthesizing of communications (not just internal but media releases, etc.)?

- An expectation embedded in the RAISE Family Caregiver and SGRG Acts was to foster greater communication and collaboration among federal agencies. Good groundwork for that has been laid in the past four years, but there's more to be done.
- The coordination of services must go beyond federal agencies, including state and local agencies, nonprofit organizations, etc.
- A regularly scheduled meeting of the federal partners might help encourage more collaboration on caregiving issues and discussion of how to best work together.
- Increased communication and optimized information sharing can help federal agencies properly amplify caregiver programs to their constituents, in particular to families of children with disabilities and grandparents of children with disabilities.
- The CDC plans to release new research and toolkits on caregiver topics and will share them with the federal partners.

Discussion question #4: What are the greatest opportunities to better meet the long-term services and support needs of older adults and people with disabilities and their caregivers in the next decade? Similarly, how can the councils' collaborative work be used to focus more attention on these emerging trends?

- The direct care workforce shortage must be addressed from different angles to build enough capacity to provide care in various settings.
- Assessing the long-term options in this country and the quality of the services provided can help identify what needs to be improved, changed, or added, and explore additional care options.
- Respite care continually comes up as a service need, especially in tribal communities.
- We need to formulate new ways to provide better respite care in a timely manner and to serve the volume of caregivers who need it.
- Caregivers and family members need more and better information on accessing supports and services.
- HRSA requires training program grantees to partner with schools of nursing to develop curricula and teach nurses how to care for older adults in long-term settings. The goal is to encourage students to eventually work in nursing homes.
- Career advancement training can encourage more people to seek work as direct care professionals, CNAs, and community health workers, especially in rural and underserved areas.

Discussion question #5: As currently stated in the Strategy and during the councils' work in subcommittees over the past several months, the idea of developing a centralized federally supported navigation portal/website showcasing services the federal government provides has arisen several times. From your vantage points in your respective agencies, what could such a resource look like?

- A portal would be beneficial but would need to be broken down geographically and by topic and service for it to be effective. It will also be a big commitment for agencies as they would need to continuously feed and update the portal to keep it current. The logistics and potential challenges must be considered beforehand.
- A project of this magnitude would require a large team of people to manage it full-time for it to be truly comprehensive and not direct users to external websites.
- For a caregiving.gov-type website to work, people will first need to realize they are caregivers to know how to search for caregiving-specific resources. We need to ensure they know how to look for resources.
- The portal should include profiles of available and existing services in each state, as well as information on where and how to obtain those services.
- The website should include the capability for patients and caregivers to ask questions and get answers.
- A clearing process should be established to vet any resources added to the portal.
- Part of the challenge is that not all caregivers and care recipients would be eligible for the programs and services that would be on the portal. It would be essential to figure out how to implement something on the portal that educates users on their eligibility for programs.
- Sometimes, a webpage offering resources isn't enough; it may be more helpful for users to have someone who can help them navigate through a page like that and offer 1:1 support.

Council Member Discussion and Vote Report into Clearance

Next, Carol Zernial invited the RAISE and SGRG council members to share their responses to the discussion points presented by the federal partners.

- The National Alzheimer's Project Act has been tremendously successful in bringing together federal stakeholders in the area of Alzheimer's disease and related dementias (AD/ADRD). Are there any lessons learned or best practices we could implement to improve collaboration regarding caregiver issues?
- Council members wondered how best to encourage Congress to increase funding, particularly for reimbursement rates for long-term services.
 - Council members can use the 2024 Progress Report to help educate policymakers and legislators about the importance of caregiving and how they can support it.
- Users may prefer to have somebody knowledgeable about various systems to whom caregivers can speak and explain their situation rather than having to navigate a portal.
- It is vital to keep in mind the value of connection between families and their communities and the lessons learned from people in similar situations.
- Grandparents raising grandchildren and other family and kinship caregivers should be treated the same as foster parents in terms of benefits and services.
- Regarding the caregiving federal portal, it is important to get users as close to the service provider and local resources as possible to avoid the runaround. Navigators would help achieve this.
- To avoid frustration, a screening questionnaire on the federal site can help direct users to the services they're eligible for and exclude resources they don't qualify for.

- It may be more useful for caregivers to start with local resources and then point to federal ones rather than the other way around. The website would also need to include services for caregivers of adults under 65.
- The Children’s Bureau at ACF shared the link to their state and tribal kinship navigator programs. These navigators can help grandparents or other caregivers raising children by providing a list of state contacts so they can learn more about their state’s resources. Some states have websites with resource portals that filter resources based on zip code. ACF would like to see these navigator programs expand by linking to similar programs and partnering with 211 and 311 services to amplify the programs available at the state and local levels.
- Another good example of a similar portal is the HIV.gov website.

The council members unanimously agreed to advance the 2024 Progress Report into clearance.

Supports and Advocacy for Implementation

Greg Link recognized the [John A. Hartford Foundation](#) (JAHF) for their support and funding of the National Academy for State Health Policy (NASHP). This funding helped establish the RAISE Family Caregiver Implementation and Technical Assistance Center. It has also supported the work of the advisory councils and the implementation of the recommendations and strategies.

Rani Snyder, Vice President of Program at JAHF, thanked Greg Link, ACL, and the RAISE and SGRG councils for their dedicated efforts in developing and advancing the strategy. She provided a brief overview of JAHF’s background and mission, emphasizing its commitment to enhancing the care of older adults across the nation. Through its grantmaking, JAHF aims to bolster caregiver support, increase awareness to drive systemic change, and foster significant, nationwide improvements in collaboration with other national initiatives.

Wendy Fox-Grage, Senior Director at NASHP, shared more about their work with ACL and JAHF. NASHP oversees the [RAISE Family Caregiver Implementation and Technical Assistance Center](#). Wendy encouraged the meeting attendees to help NASHP raise awareness about caregiver issues and support by sharing their Supporting Family Caregivers [video](#), which has garnered over 500,000 views since its release. The Center also offers resource and implementation guides for various audiences and the [RAISE Act State Policy Roadmap for Family Caregivers](#). Lastly, Wendy announced that NASHP will release a progress report in the fall highlighting the state and community actions resulting from the Strategy.

Mike Wittke, Vice President of Policy & Advocacy of the [National Alliance for Caregiving](#) (NAC), spoke about the Act on RAISE campaign, which unites stakeholders across the caregiving spectrum to achieve its key goals and pillars. The campaign aims to promote the implementation of the Strategy’s outlined actions and to enhance federal coordination in support of caregivers through heightened awareness, mobilization, and education. The campaign is advised by a steering committee that includes national organizations representing caregiving, aging, disability, and health care. The committee has reviewed federal actions from the Strategy, prioritizing federal agency goals, and analyzed public feedback received after the Strategy’s release to develop a dashboard that reflects priority activities. Additionally, NAC is creating a “RAISE Policy Playbook” for Congress, which identifies necessary legislative changes to achieve the Strategy’s goals. They are also preparing an overview of further actions to

underscore the work of federal agencies. For more information, Wittke shared the campaign's website, actonraise.org.

Next Steps and Adjourn

The clearance process by the HHS is projected to take approximately six weeks. The forthcoming report package will feature a welcome letter by Alison Barkoff, a narrative detailing the federal-level impacts of the Strategy, an appendix showcasing agency accomplishments, a description of the 40 actions added since 2022, and agency-specific spreadsheets outlining each agency's actions and status. The incorporation of internal and external feedback, as well as final copy and design edits, is expected to require an additional two weeks. ACL anticipates submitting the report package to Congress and publishing it on the councils' websites by mid to late August. In the interim, the Office of Supportive and Caregiver Services will collaborate with the councils to update the Strategy and resume the working group and subcommittee meetings. Greg Link expressed his gratitude to the meeting attendees for their participation and formally adjourned the meeting.

Additional Comments

During the meeting, members of the public asked questions verbally and using the webinar chat function. These comments have been edited for clarity and length.

- Will there be any initiatives to set federal minimum reimbursement for federally funded Medicaid waiver programs that support family caregivers?
- Some language clarification may be needed for the status categories to distinguish the in-progress actions from the continuously ongoing activities.
- The nature and definition of respite are different for caregivers, advocates, and others who receive respite. It is important to take person- and family-centered approaches to address the needs of families and family caregivers and to design services and supports to meet those needs.
- Direct engagement with the 574 tribal governments and leaders presents both challenge and opportunity. As sovereign nations, tribes have a unique government-to-government relationship. There are pathways to connect with tribal communities, e.g., through the health system via IHS or tribal Title IV-B elder programs via ACL. However, these conversations need to elevate to a higher level than those conduits, which would adopt more of a bottom-up approach.
- Is it possible to revise the definition of dependent for receiving Social Security disability benefits? When a grandparent has full legal and physical custody of a grandchild, the grandchild should be able to receive benefits as the dependent of a disabled grandparent. As it stands now, benefits are only available if the grandparent legally adopts the grandchild.
- More discussion is need about terminology in the strategy as well as how and when to convert "unpaid" family caregivers to "paid."
- The Administration for Children and Families, the Children's Bureau (CB) [new funding instructions](#) for state and tribal child welfare agencies in the development, enhancement, or evaluation of federal funding for the Title IV-B, subpart 2 kinship navigator programs are available.
- ACF, through a Children's Bureau grant, created a new free online resource from the National Training and Development Curriculum for foster, adoptive, or kinship caregivers. The [family dynamics curriculum](#) provides an overview of the impact fostering or adopting can have on family dynamics, including the impact on marital relationships, biological children, foster or adoptive children already living in the home, and extended family members.
- On June 26, the Department of Labor's Women's Bureau will host the Paid Leave: Equity in Implementation conference, which will welcome researchers, state paid leave administrators, representatives from the federal government, and others to Washington, D.C., to delve into the latest research findings, policy innovations, and promising practices in implementing equitable paid leave policies. [Register](#) to watch virtually.
- If family caregivers received compensation for caring for a loved one, this may enable them to focus more on their caregiving role, instead of working two jobs and only getting paid for one.
- Caregivers often need education and training from professionals so that they can provide effective support to their family members. Does anyone have any suggestions on where one can find a pool of physical, occupational, and speech therapists and registered dietitians available on an on-call basis to assist with supporting and educating caregiver clients?

- Arizona is considering a pilot program with the COPE Program, in which occupational therapists do home visits to work with individuals living with dementia and their caregivers.
- An easy pathway to paying family caregivers would solve workforce shortages and may save money over other long-term care options. In North Carolina, the policy on Medicaid Community Alternatives Program for Disabled Adults (CAP/DA) deductibles for those who make more than \$1000 a month makes it impossible for other low-income folks to participate. Family caregivers are left unpaid and unable to maintain jobs or obtain unemployment due to this policy.
- Fixing immigration policy can help meet our workforce needs. By 2030, there will be more people 65 years old and older than 18 years old and under.
- It may be better to update the information on [benefits.gov](https://www.benefits.gov) instead of creating a new website.
- The general public is very interested in a [caregiving.gov](https://www.caregiving.gov)-type website. Even professionals have no idea how many federal agencies have programs that can benefit caregivers. This might be an area where artificial intelligence capabilities could help to glean information across agencies.
- A dashboard that directs people to different agencies and allows them to search geographically based on identified needs/interests may be a possibility.
- The demand for long-term care staff would be greatly reduced if the people who can be cared for at home and have somebody to do it are able to stay at home and in their communities. There are so many benefits to living at home in the community and letting the benefits trickle down to every aspect of care.
- The portal could be a valuable tool, but resources, information, and eligibility information need to be in plain language and easily usable by caregivers.
- Synapticure is a virtual medical service that provides services specific to neurological disorders like ALS, including mental health and other therapies. The service is available in all 50 states and accepts most insurance plans, including Medicare.
- Rosemary Payne from SAMSHA invited the attendees to email her at rosemary.payne@samhsa.hhs.gov with any questions on substance, abuse, or mental health.
- The Children's Bureau lists [state kinship care contacts](#) and programs, including navigators for grandparent caregivers.

For more information:

- Read the 2022 National Strategy to Support Family Caregivers here: <https://acl.gov/CaregiverStrategy>.
- This is the [infographic summarizing the National Strategy](#).
- View the video on the [2022 National Strategy to Support Caregivers](#).
- All the action guides from NASHP can be viewed at <https://www.supportcaregiving.org>.
- National Alliance on Caregiving's Act on RAISE webpage: <https://www.actonraise.org/>.