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

Hosted by the Administration for Community Living
Wednesday, April 29, 2026 | 12:00 - 4:00 PM ET

Call to Order and Welcome Remarks

Jonathan Westin, Aging Services Program Specialist with Health and Human Services' Administration for Community Living (ACL) and lead staffer for the Recognize, Assist, Include, Support, and Engage (RAISE) Council, called the meeting to order, thanked participants, and introduced Mary Lazare, Principal Deputy Administrator serving as the senior official performing the duties of the ACL Administrator and Assistant Secretary for Aging.

Mary Lazare expressed appreciation for participants' continued engagement and recognized the essential role of family caregivers, kinship caregivers, direct care workers, and support personnel. She emphasized that caregiving is both a necessity and an act of love, and thanked attendees for their commitment to advancing the 2022 National Strategy to Support Family Caregivers (National Strategy). Mary highlighted the three focus areas of the meeting: state implementation, kinship care, and care coordination; noting the importance of learning from state efforts and identifying scalable and replicable models. She underscored the complexity of implementing the National Strategy across federal, state, local, and community levels, and stressed the importance of collaboration across public, private, and nonprofit sectors. She also acknowledged the ongoing contributions of national and community-based partners in strengthening the caregiving ecosystem and emphasized the shared responsibility of supporting caregivers nationwide. The session was framed as an opportunity to review progress, share innovations, and identify opportunities to further advance and expand support for family caregivers.

A roll call of the RAISE and SGRG council members followed.

A View from the States: Implementation of the National Strategy to Support Family Caregivers

Jonathan Cottor opened the session, emphasizing the importance of learning from complex caregiving systems and advancing innovation and collaboration. He highlighted the National Strategy as a key roadmap supported by ACL's funding of innovative initiatives and introduced moderators Nikaela Frederick and Bernice Hutchinson from ACL.

Bernice Hutchinson introduced the inaugural cohort of states (California, Maryland, Massachusetts, and Wisconsin), who have been advancing the 2022 National Strategy since September 2024 through policy development, infrastructure building, partnerships, caregiver engagement, and impact measurement.

Each state is working across at least three of the National Strategy's five goals in coordination with disability agencies, Title III aging programs, and Title VI tribal organizations. The session will focus on progress, lessons learned, and replicable models. Nikaela Frederick then invited panelists to introduce themselves and describe their projects and alignment with the National Strategy goals.

State Introductions and Project Overviews

- **CA:** Sarah Steenhausen (California Department of Aging) described California's "CalCARES" initiative, which aligns with Goals 1, 2, and 3 of the National Strategy and supports the state's Master Plan for Aging, particularly its "Caregiving that Works" goal. The initiative partners with the Department of Developmental Services, disability organizations, AAAs in rural and suburban areas, media, and academic partners, and is closely connected to the CalGrows caregiver training effort. Its three core focuses are: increasing caregiver awareness through media engagement, understanding how caregivers access information and services, and building a statewide inventory of training and resource materials for both paid and unpaid caregivers.
- **MD: Molly** Wisniewski (Maryland Department of Aging) outlined Maryland's ACL State Implementation Grant work advancing Goals 2, 3, and 5. Maryland's 1.15 million caregivers provide over 1 million hours of care valued at approximately $24M, while navigating fragmented systems. Efforts include strengthening cross-agency partnerships and caregiver voice through the Maryland Commission on Caregiving, expanding centralized resources and peer support, and using BRFSS data, surveys, and focus groups to guide policy under the Longevity Ready Maryland framework, with a focus on building caregiving infrastructure.
- **MA:** Molly Evans (Massachusetts Executive Office of Aging and Independence) shared that Massachusetts designed its grant project around four core objectives. First, the state established a cross-agency working group involving health and human service agencies to develop a more holistic caregiver support strategy. Second, strengthening economic security of family caregivers through innovative interventions funded by five mini grants awarded to AAAs. Third, the state worked to improve caregivers' access to information through the development of an accessible statewide resource guide. Finally, Massachusetts expanded efforts to collect additional caregiving data to better understand the needs of caregivers.
- **WI:** Lynn Gall (Wisconsin Department of Health Services) highlighted the use of Goals 1-4, building on the Wisconsin Family and Caregiver Support Alliance, established in 2017, as a key partnership bringing together stakeholders across government, aging services, academia, developmental disability organizations, and respite providers to advance caregiving solutions. Wisconsin's efforts include employer engagement, respite expansion, navigation, and outreach, along with website updates, training platforms, social media outreach, and recognition of caregiver-supportive employers.

Nikaela Frederick and Bernice Hutchinson then asked the panelists the following questions.

Question 1: Since the release of the 2022 National Strategy and your work on the State Implementation grant, have there been any key changes or emerging trends in caregiving, caregiver needs, state systems, and strategic planning that offer opportunities to inform the 2026 National Strategy Update?

- **CA:** Sarah Steenhausen highlighted emerging caregiving challenges including more childless adults, more people living alone, and remote caregiving, all requiring new support approaches. She emphasized peer caregivers as trusted sources of information, especially in rural areas, and the need for training and resources to support safe home care and reduce institutionalization. She noted fragmented systems and the need for a "no wrong door" approach through a statewide resource hub, better data sharing, and warm handoffs. California is also prioritizing multiple communication channels, ethnic media partnerships, and support for the "overlooked middle" who do not qualify for Medicaid or Medi-Cal but cannot afford long-term care, while developing peer-based models that train caregivers as community support specialists, particularly in rural areas.

Question 2: Are there systemic or structural aspects of caregiver support that are proving to be more complex, interconnected, or difficult to initiate, develop, and sustain?

- **MA**: Molly Evans identified three key caregiving barriers. First, system fragmentation across health, behavioral health, housing, transportation, labor, and education, making navigation difficult and reinforcing the need to treat access as infrastructure. Second, a direct care workforce shortage increases strain on families who fill care gaps and underscores the need to align caregiver and workforce policy. Finally, financial strain, with many caregivers working full time while providing care, leading to burnout, reduced productivity, and long-term economic impacts, including retirement security, with about 40 percent reporting negative financial effects. She also noted that supportive workplace policies improve retention and productivity, and shared early Massachusetts survey findings showing caregiver employees report equal or higher satisfaction in teamwork and collaboration when caregiving is recognized.
- **WI**: Lynn Gall highlighted persistent challenges in securing public financing for caregiver support and in-home care despite broad agreement on its importance, emphasizing the need for clearer messaging on return on investment, including public cost savings and workforce benefits. She noted ongoing caregiver and respite shortages, especially in rural areas, alongside competing political priorities and the need for bipartisan support. Referencing a 2019 state task force with 16 recommendations, she noted limited implementation to date and emphasized that while some progress has been made through the state alliance, more legislative action is needed. She concluded by calling for stronger evidence-based return on investment arguments and hoped future updates to the National Strategy will address this gap.

Question 3: How are changes in the paid direct care workforce affecting family caregiver roles, stress levels, or decision making and what do the dynamics in your state suggest about efforts to align the needs of caregivers and the workforce?

- **MD:** Molly Wisniewski explained that Maryland's direct care workforce shortage is increasing pressure on family caregivers, who are stepping in to provide more intensive and often unplanned care when paid support is unavailable, contributing to burnout and affecting decisions such as hospital discharge timing and care planning due to uncertainty about services. She emphasized that the direct care workforce and family caregivers are interdependent and must be addressed together. Maryland is responding by aligning health, labor, education, aging, and Medicaid systems and reframing caregiving as both a workforce and systems issue. Through initiatives like "Together in Care" and the ACL caregiver implementation grant, the state is advancing shared training, improved referral pathways, and consistent messaging, with a goal of building an integrated model that strengthens both the workforce and family caregiver supports.

Question 4: Are there approaches, partnerships, or collaborations that have shown stronger promise or broader relevance than originally anticipated within or outside of the State Implementation grant? What seems to be driving these accomplishments?

- CA: Sarah Steenhausen emphasized that system change in caregiving depends on strong partnerships. She described California's Cal Grows initiative, an ARPA-funded workforce program that trained about 34,000 direct care workers and family caregivers using multiple approaches across the state. She noted that the program helped participants gain skills, feel more valued, and receive incentives, and that California built on this work through CalCARES by creating an inventory of trainings. A key new development has been formal partnerships through a memorandum of understanding with the California Labor and Workforce Development Agency and the Community College Chancellor's Office. These partners are exploring how community colleges can support caregiver training, provide pathways into healthcare careers, and offer credit for prior learning and caregiving experience. She explained that the community college system may also serve as a hub for free training resources, creating continuity and expanding opportunities for both paid direct care workers and the state's 7 million family caregivers.
- MA: Molly Evans emphasized the importance of cross-sector and non-traditional partnerships, describing a cross-agency workgroup of 11 health and human service agencies, including behavioral health, public health, and Medicaid, working together to address shared caregiver challenges and reinforce that caregiving spans every system. She noted that caregiver innovation grants intentionally fund "unlikely partnerships" between aging services and sectors such as banks, legal organizations, financial professionals, graduate schools, and hospitals to reach caregivers earlier in community settings, and she highlighted the Massachusetts Caregiver Coalition, as an example of caregiving being recognized as a workplace issue and strengthened through employer engagement. She explained that Massachusetts uses a "high-low" approach, combining statewide systems' work with small community-based mini grants that test promising practices at the local level, supporting organizations already working closely with caregivers to develop innovative models focused on economic security and reducing social isolation. She added that these ground-up efforts have been especially valuable for learning what works in practice and will inform future next steps and scaling of caregiver supports.
- MD: Molly Wisniewski emphasized that partnerships are the foundation of their caregiving work and that system change depends on shared ownership rather than isolated efforts. She highlighted the Maryland Commission on Caregiving as a key cross-agency structure that brings caregivers and state agencies together to ensure alignment and accountability across aging, health, human services, disabilities, and Veterans Affairs. She also described a collaboration with Johns Hopkins University School of Nursing and the Maryland Information Network that developed a practical memory care checklist, helping caregivers identify needs, receive recommendations, and connect to Maryland Access Point services. National partners like ACL and Advancing States supported efforts such as the respite care ambassador model, strengthening best practices and sustainability, while local partners ensured services reach caregivers in their communities. She concluded that partnerships are the system itself and should remain central in future national strategy efforts to build lasting caregiver support.
- WI: Lynn Gall shared that framing caregiver support as workplace wellness has been especially effective in engaging employers and building new partnerships. This approach led to strong interest at the Wisconsin Wellness Council conference and connections with the technical college system, the Department of Administration, and public health partners to better integrate caregiver support into

workplace and community health planning, including efforts to prioritize caregivers in local and tribal public health plans. She also described a partnership with Summit Credit Union that created a free caregiver financial resource portal, offering tools for budgeting, planning, and advance directives. In addition, a caregiver training adapted from the University of Alberta unexpectedly expanded through the University of Wisconsin–Madison, where it is now being used to support a pilot caregiver clinic that helps identify and support family caregivers directly in clinical settings.

Question 5: Through your efforts on this project, what emerging outcomes are anticipated to have the greatest impact on assisting caregivers? How are you planning to record these results?

- **CA**: Sarah Steenhausen explained that the state's biggest impact will come from expanding access to statewide caregiver trainings through its partnership with the Community College Chancellor's Office, which can help reach caregivers across California. She noted that this effort will be strengthened by lessons learned from the awareness campaign and from understanding caregiver referral pathways, which will inform how the state conducts outreach and engagement through community college partners.
- **MD**: Molly Wisniewski shared that success would be measured by whether caregiving becomes easier to navigate and less overwhelming for families, with caregivers able to find help faster, face fewer dead ends, and feel more supported. She emphasized that the goal is not just to count services, but to understand whether the system is truly working for caregivers. She added that data should reflect both the reach of programs and the real-life experiences of caregivers, noting that both are necessary for meaningful reform moving forward.
- **MA:** Molly Evans shared that one of the most promising innovations is the caregiver innovation grants testing new service delivery models, including a care-based respite model that combines technology with local networks to support peer respite and reduce social isolation while potentially expanding capacity without proportional cost increases. She also highlighted the development of a volunteer workforce model in which trained caregiver specialists serve as "champion teachers" who then train both volunteers and other caregivers, creating a multiplier effect that extends beyond what Title III staffing dollars alone can achieve and strengthens social connection and support.
- **WI:** Lynn Gall shared that improving outreach efforts and technology-based platforms, including an education system for family caregivers, will likely have the greatest impact. She noted that these improvements are relatively easy to track through usage data, which helps measure reach and engagement. She added that grant funding has been instrumental in strengthening and sustaining these tools and described that support as very beneficial.

Question 6: What is your biggest lesson learned from this grant? What is your biggest lesson learned about increasing awareness and outreach to family caregivers? What does your state need to continue its work overall?

- **WI**: Lynn Gall emphasized that funding and leadership support are critical. She noted that while initial efforts began with very limited resources, federal support and prioritization from ACL have been very important. However, she explained that most Older Americans Act funding is currently directed toward direct services, leaving little available for innovation, special projects, or implementing the National Strategy. She concluded that additional state and federal funding would be essential to sustain and expand innovative caregiving initiatives.

- **MA:** Molly Evans said that the key lesson from the Massachusetts grant is that caregiver support is not a single program or policy, but a system-wide challenge. She emphasized that the most effective solutions treat caregiving as shared infrastructure that connects across sectors and partners, making it easier for caregivers to find and sustain support over time.
- **MD**: Molly Wisniewski echoed colleagues in emphasizing that innovation in caregiving only works when paired with flexibility and sustainable funding. She noted that the ACL caregiver implementation grant allowed Maryland to build infrastructure and improve statewide coordination in ways traditional service funding could not. She also highlighted that caregivers often must first recognize themselves as caregivers before seeking help, so outreach should focus on helping individuals identify their role and connect to supports like respite. She concluded that continued progress requires stronger alignment between grant-funded innovations, Older Americans Act services, and long-term system sustainability.
- **CA**: Sarah Steenhausen stated the key lesson is the importance of meeting caregivers where they are, recognizing that different populations require different approaches and using data to better target outreach to harder-to-reach groups. She stressed the need to continue building statewide infrastructure, including web platforms supported by data sharing, to create more seamless access to information and handoffs across systems.

Nikaela Frederick and Bernice Hutchinson then introduced Wendy Fox-Grage, Senior Director at The National Academy for State Health Policy (NASHP) who gave remarks as the discussant of the panel.

Discussant Summary:

Wendy Fox-Grage reflected on her experience working with the RAISE Family Caregiving Advisory Councils, ACL, The John A. Hartford Foundation (JAHF), and the National Academy for State Health Policy (NASHP), as well as a 13-state learning collaborative, noting that she has seen the National Strategy move from concept to implementation across states. She emphasized four key takeaways. First, states and their partners have been strong innovators, using the National Strategy to develop awareness campaigns, resource guides, training programs, referral systems, data and ROI tools, and web-based navigation platforms supported by cross-sector partners such as universities, workforce boards, community colleges, and employers. Second, the direct care workforce and family caregivers must be treated as one interconnected system, and effective caregiver policy must include workforce considerations. Third, care coordination and navigation are central challenges, requiring culture change and better caregiver assessments to identify needs and ensure follow-up support. Lastly, the work is still in an early but strong phase, with growing momentum across multiple states and learning collaboratives that create opportunities to scale promising practices into standard systems of care. She concluded by highlighting a shared resource platform designed to support implementation of the National Strategy across states, employers, caregivers, and community organizations.

Closing Thoughts

Bernice Hutchinson concluded by expressing hope that the discussion provided actionable insights to advance implementation of the National Strategy and reflected on how the participating states' progress can inform and strengthen future efforts. They concluded by announcing the expansion of state cohorts, with California, Massachusetts, Maryland, and Wisconsin joined by Alabama, Minnesota, Montana, Pennsylvania, and South Carolina, and noted that a third cohort is planned with FY2026 federal funding.

Goal 3: Kinship Care

Jonathan Westin welcomed participants back from the 15-minute break and introduced Keith Lowhorne, Chair of the Supporting Grandparents Raising Grandchildren (SGRG) Council and Moderator for the Goal 3: Kinship Care Panel. Keith Lowhorne introduced the SGRG mission, which focuses on coordinating and sharing resources and best practices to support kinship caregivers in meeting children's needs while maintaining their own well-being. He described the scope and challenges of kinship care in the United States and then introduced the panelists Dr. Ali Caliendo of Foster Kinship, Dr. Moses Dixon of Senior Connection, Inc., and Lisa Grodsky of Oakland Livingston Human Services Agency. Keith Lowhorne then asked the panelists the following questions.

Question 1: In the original Strategy, Goal 3, Outcome 3.10, listed indicators of success in which family, kin, and grandparent caregivers feel more confident in their ability to provide care. Which areas have you witnessed the most progress in since 2022?

- **Dr. Ali Caliendo** explained that kinship navigator programs are gaining increased attention as an essential infrastructure to help caregivers navigate complex systems like child welfare, education, healthcare, and legal guardianship. By providing timely, accurate information and guidance on issues such as guardianship, licensing, and Medicaid access, these programs help kinship caregivers build stability and confidence so they can focus on meeting children's needs and supporting their well-being.
- **Dr. Moses Dixon** described launching a Grandparents Raising Grandkids Resource Center in 2023, supported by a congressional earmark and technical assistance from Generations United, to create a "one-stop shop" model for kinship families. Legal barriers are often the first challenge caregivers face, and the program addresses this through partnerships with legal aid and guided support to help families secure custody and then access services such as food assistance, respite care, and school enrollment.
- **Lisa Grodsky** highlighted how kinship caregivers showed strong resilience during and after the COVID-19 pandemic, particularly in adapting to virtual tools like Zoom, while also facing significant barriers such as limited internet access, lack of devices, and financial constraints. She described community-driven responses in Michigan, including partnerships with faith-based groups repairing laptops and a university supporting device distribution, as well as ongoing challenges like transportation barriers for caregivers managing children's needs without adequate service support.

Question 2: What unmet needs are you seeing among kinship and grandparent caregivers at your level?

- **Lisa Grodsky** explained that safe and affordable transportation remains a major unmet need for kinship caregivers in Michigan, especially given reliance on personal vehicles and limited eligibility for state emergency relief funds, which often exclude older adults who are retired or out of the workforce. School transportation cuts have also increased burdens on caregivers, who must now often drive children to school themselves. To address ongoing technolgoy barriers, the program "Gigabytes for Grandfamilies" was developed. This program provides hands-on, intergenerational training to help caregivers and children build digital skills and increase independent access to tools like email and online services.

- **Dr. Moses Dixon** echoed concerns about technology access for older adults raising grandchildren, noting that digital skills are essential for daily tasks like paying bills, communicating with schools, and managing caregiving responsibilities. He also highlighted housing as a major unmet need in Massachusetts, pointing out that most kinship families served are renters facing high costs. Lastly, he described a planned "Grandfamilies Village" in Worcester that would provide housing, a resource center, and on-site community health workers to support families.
- **Dr. Ali Caliendo** shared that one of the biggest practical unmet needs in kinship care is respite care, both to give caregivers a break and to ensure trauma-informed support for children who have experienced abuse, neglect, or separation. A broader structural concern is that kinship care supports are fragmented across multiple eligibility rules and funding streams, forcing families to navigate complex systems based on age, legal status, or location, rather than receiving a coordinated set of supports for both caregivers and children.

Question 3: Are there emerging trends in Kinship Care that the National Strategy needs to address? For example, youth caregivers, older relative caregivers, and men as caregivers.

- **Dr. Moses Dixon** emphasized the need to prioritize kinship care in rural communities, noting that while central Massachusetts includes an urban center, many families served come from rural areas with limited access to healthcare, transportation, and technology. He urged that rural health transformation funding be used over the next several years to strengthen kinship caregiver supports and ensure rural families are not left behind. He also highlighted a growing trend of kinship caregivers raising children with autism or other disabilities that warrants further attention. Finally, he emphasized financial literacy for preteens and teenagers in kinship care, explaining that equipping young people with financial skills is critical so they can eventually support themselves when caregivers are no longer able to provide care.
- **Lisa Grodsky** highlighted several emerging trends in kinship caregiving, including what she described as the "triple-decker" population, i.e. grandparents who are simultaneously raising grandchildren, caring for older adults, and still supporting their own adult or teenage children. She noted that these caregivers face intense demands with limited supports, especially for the children in their care, and emphasized the growing need for respite services and trauma-informed support for children who have experienced adverse childhood experiences (ACEs). Grodsky also discussed challenges faced by kinship caregivers outside the foster care system, including complex guardianship renewal processes, unequal access to benefits compared to foster caregivers, and difficulties navigating legal and service systems. In addition, she pointed to unmet needs related to academic support, tutoring, and therapies for children, as well as the importance of supports tailored to unique family dynamics.
- **Dr. Ali Caliendo** highlighted that beyond conditions such as autism, many children in kinship care are affected by prenatal substance and alcohol exposure, underscoring the need for resources that address their long-term developmental and behavioral needs. She noted a growing number of young adult caregivers, including 18- to 20-year-olds caring for siblings, and emphasized the importance of supporting the emotional and relational strain within kinship families, where caregivers often must navigate complex family dynamics and trauma. She stressed that alongside practical supports like financial assistance, legal services, and respite care, kinship families also need stronger access to

mental health services to help break intergenerational cycles and support healing for both caregivers and children.

Question 4: What are some concrete actions that states, communities, and other sectors can take in the Kinship Care arena for consideration in the National Strategy update?

- **Dr. Ali Caliendo** emphasized that kinship care is a systems challenge that requires shared infrastructure, coordinated navigation, and a "no wrong door" approach so families can more easily access the help they need. Building on themes from the earlier panel, she explained that states and jurisdictions should examine how they define kinship families, including foster kinship, licensed and unlicensed kinship care, informal kinship arrangements, and grandparents with guardianship, because those definitions often determine what resources and support families can access. She stressed that states could improve support for kinship families without immediately changing policies by coordinating existing systems and building infrastructure around current programs to reduce administrative burdens on caregivers and ensure children in different kinship care arrangements receive more consistent levels of support.

Question 5: What initiative are you most excited about that your organization is working on to further support for Kinship Care? What states or other organizations do you feel are paving the way?

- **Lisa Grodsky** highlighted several ongoing and future initiatives, including the "Gigabytes for Grandfamilies" technology support program and a kinship care respite program launched last year. She shared that her organization received funding from the Michigan Health Endowment Fund to continue expanding respite efforts through mini respite projects and plans to conduct a landscape analysis and community input sessions to better understand the types of respite services kinship caregivers will need in 2026 and 2027.
- **Dr. Moses Dixon** described several mobile outreach initiatives designed to support older adults and kinship families in rural central Massachusetts, including the launch of the 40-foot "Care Express Bus," which provides access to health, dental, vision, and wellness screenings. He also highlighted a newer "Barber Connect Mobile Bus" initiative that offers free haircuts for men alongside wellness and health screenings, noting that these services are intended to improve access to care and have a significant impact on kinship families in underserved rural communities.
- **Dr. Ali Caliendo** expressed optimism about the growing federal attention on kinship care and the increasing recognition of kinship caregiving across policy discussions and funding opportunities. She highlighted upcoming opportunities for states to partner with community organizations to evaluate and expand kinship support programs, including evidence-based models, and encouraged states to explore how federal Title IV-B and IV-E kinship care strategies can align with, and strengthen, their existing Title III-E caregiver support efforts.

Keith Lowhorne then introduced Ana Beltran, Director of the Grandfamilies & Kinship Support Network at Generations United, who gave remarks as the discussant of the panel.

Discussant Summary

Ana Beltran thanked the panel and emphasized that kinship caregiving challenges and solutions span multiple systems, including housing, Temporary Assistance for Needy Families (TANF), child welfare, aging, and education. She highlighted growing federal coordination around kinship care, including the Administration for Children and Families' "A Home for Every Child" initiative, which prioritizes kinship placements, prevention of unnecessary foster care entry, and evidence-based kinship navigator programs. Beltran specifically highlighted the evidence-based kinship navigator model developed by Dr. Ali Caliendo, noting that states including South Carolina, Utah, and Minnesota are replicating the model through Title IV-E funding. She also discussed new federal grant opportunities expected in 2026, kin-specific foster care licensing standards that help relatives access foster care maintenance payments and increasing adoption of these standards by states and tribes. Beltran highlighted additional national efforts supporting kinship families, including free healthcare training modules from University of California San Francisco, action guides from USAging, and research initiatives focused on improving evidence-based kinship services. She emphasized the importance of systems integration, noting that aging, child welfare, and other sectors must work together to create single points of entry and easier navigation for kinship families. Beltran also shared that most Area Agencies on Aging and Title VI Native American aging programs now provide some type of kinship support, while stressing that services must also reach younger caregivers who fall outside traditional eligibility categories. She concluded by encouraging attendees to stay connected with the Grandfamilies & Kinship Support Network and Generations United for resources, updates, and technical assistance, while also recognizing the work of Dr. Moses Dixon and other community partners advancing kinship support.

Closing Thoughts

Keith Lowhorne thanked Ana Beltran for her leadership and encouraged attendees to connect with the Grandfamilies & Kinship Support Network and Generations United, noting that he has learned extensively from their work over the years. He emphasized that while more support is still needed for kinship families, there are existing resources available, including tip sheets developed by the Supporting Grandparents Raising Grandchildren (SGRG) Council on accessing services, working with professionals, and understanding tax credits available to kin caregivers. Lowhorne stressed that kin caregivers are not alone and that support is available to them. He concluded by thanking the audience for the opportunity to participate in the discussion, noting that it had been a valuable and informative conversation before turning the session back over to Jonathan Westin.

Goal 2: Care Coordination

Jonathan Westin introduced Carol Zernial, Co-Chair of the RAISE Council and moderator for the Goal 2: Care Coordination Panel.

Carol Zernial introduced the session focus on advancing partnerships and engagement with family caregivers and ensuring caregivers are recognized as essential members of the care team alongside healthcare professionals. She emphasized that integrating caregivers into care coordination and transitions of care creates better communication, improves health outcomes, reduces disjointed care, and helps caregivers feel recognized and supported. Zernial noted that stronger caregiver integration benefits healthcare providers through more timely information, benefits care recipients through improved coordination and outcomes, and reduces stress for caregivers. She then introduced speakers Robyn Golden, Associate Vice President of Social Work and Community Health, Rush University Medical Center, and Deborah Stone-Walls, Chief of Programs and Services, USAging. She highlighted their extensive leadership experience, caregiving backgrounds, and work advancing caregiver integration and care coordination at the federal, state, and local levels.

Robyn Golden

Robyn emphasized that although care coordination is well established as improving outcomes and efficiency, care for older adults and family caregivers remains highly fragmented across health care, long-term care, behavioral health, housing, transportation, and community-based services. She noted the system is often reactive and medically focused, making it difficult for caregivers to navigate, especially when managing multiple chronic conditions. Caregivers frequently provide high-intensity medical and nursing tasks but are rarely asked about their own needs, and many do not identify as caregivers. She stressed the importance of simple screening questions such as “Are you caring for anyone?” to better recognize and support them.

She highlighted emerging but underused policy tools and models that could improve integration, including Medicare caregiver training and care management billing codes, the GUIDE dementia care model, CMS age-friendly hospital measures, and the CARE Act. She also described efforts at Rush University to formally identify caregivers in electronic medical records, assess their readiness, and connect them to support and training. Broader system innovations include caregiver journey mapping, community care hubs, and training healthcare teams to treat caregivers as care partners within an age-friendly ecosystem that integrates healthcare, public health, aging services, and community-based organizations. Robyn Golden then turned over to Deborah Stone-Walls.

Deborah Stone-Walls

Deborah emphasized that her perspective is shaped by both her leadership role at USAging and her lived experience as an active caregiver, underscoring how real-time caregiving highlights system gaps. She explained that Area Agencies on Aging (AAAs) and Title VI Native American aging programs are central to implementing the National Strategy but are constrained by Older Americans Act eligibility rules and fragmented systems, including age-based thresholds that can limit access to supports. She noted growing alignment with the National Strategy, with 76% of AAAs implementing related initiatives and 27% supporting caregivers through care transition programs, reflecting increased but still uneven system integration.

She also highlighted measurable growth in caregiver support across the aging network, including increased access assistance (from 66% of AAAs in 2022 to 76% in 2025), expanded healthcare partnerships, and rising use of community care hubs. Deborah pointed to Pennsylvania’s PA CareKit as an example of a comprehensive, multilingual, multi-format caregiver navigation tool. She emphasized the lack of consistent terminology for caregiver navigation, with only 12% of AAAs using that label despite broader activity under other names, and predicted continued expansion of navigation services, greater use of AI, and stronger reliance on data to demonstrate impact. She concluded optimistically, describing this as a “sunrise” moment for advancing more integrated, data-driven, and person-centered caregiver systems.

Carol Zernial then introduced Jennifer Wolff, the Eugene and Mildred Lipitz Professor in the Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, who gave remarks as the discussant of the panel.

Discussant Summary

Jennifer emphasized the significant progress made through the National Strategy, noting its foundation in the 2016 consensus report *Families Caring for an Aging America*, which called for a national strategy. She highlighted key advancements such as new billing codes and payment models, including the GUIDE model for dementia care, and the expansion of community care hubs and cross-sector care coordination efforts, all of which reflect growing recognition of family caregivers across healthcare and community systems.

She underscored the growing complexity and importance of care coordination across fragmented systems, including healthcare, education, workplaces, community supports, and long-term care. While care coordination is strongly linked to improved outcomes, she noted persistent barriers such as system silos, privacy and autonomy requirements in clinical settings, and the lack of family-centered information systems and reimbursement mechanisms that keep caregiver contributions largely invisible. She described three key caregiver roles: providing emotional support and advocacy, serving as hands-on “therapeutic agents” assisting with medical tasks such as medication management and home-based care, and functioning as caregivers who also need supports such as respite and psychosocial services.

She concluded by calling for a shift from reliance on national survey data toward real-time monitoring of caregiver presence, capacity, and needs in care settings and communities. She emphasized integrating caregiver data into quality improvement efforts to better reflect caregivers in practice and strengthen value-based care systems that benefit patients, caregivers themselves, and the broader health system.

Jennifer Wolff and Carol Zernial then asked the panelists questions posed both by themselves and the Q&A participants.

Question 1: What developments in care coordination, particularly in the technology space, can ameliorate the strain on caregivers?

- **Robyn Golden: Improved** interoperability across care coordination systems. This means better connection and data sharing not only between individual healthcare providers, but also across hospitals, AAAs, federally qualified health centers, and other community-based organizations. This would reduce fragmentation in care, thereby reducing administrative and emotional strain.
- **Deborah Stone-Walls:** AI will likely play a growing role in care coordination by improving efficiency and supporting systems, but it must complement, rather than replace, the human touch. Without that human connection, technology alone could increase strain. Practical tools like short training videos and easy-to-use digital resources can empower caregivers by giving them quick, accessible guidance when they need it.

Question 2: Are there new training modalities that either of you can point to since the release of the National Strategy in 2022 that have engaged and empowered caregivers in their duties?

- **Deborah Stone-Walls:** Emerging training models are increasingly combining technology with a personal touch, blending self-guided, on-demand learning with opportunities for live virtual or in-person support so caregivers can learn on their own time while still staying connected. This balance is important because caregivers need both flexibility and human connection, including empathy, reflection, and being heard.

- **Robyn Golden: Building** existing workforce training programs rather than creating new ones is important, as many federally funded initiatives already include resources for family caregivers and should be leveraged. While caregivers learn in different ways, peer-to-peer learning is often the most effective, with informal advice, shared experiences, and practical suggestions from others carrying more impact than formal training. Lastly, having a forum for professionals and peers to share valuable real-world experiences.

Question 3: How do we keep from medicalizing social services?

- **Robyn Golden:** While CMS billing codes for caregiver-related services are an important step toward recognizing and reimbursing social care, there is a risk of over-medicalizing caregiving. These codes should be viewed as a way to finally compensate social care within a holistic system that supports both caregivers and care recipients, while still maintaining balance so that caregiving is not reduced solely to a medical framework.

Question 4: What are your thoughts on Lisa Marsh Ryerson, President of the AARP Foundation's, idea of adding caregivers to the electronic health record, ideally allowing them to enter their own data and observations such as blood sugar readings and medication reactions?

- **Robyn Golden:** Caregiver integration into electronic medical records (EMRs) is absolutely critical. Caregivers should be included in the EMR system, ideally with connected records and integrated tools such as MyChart. With current systems remaining highly siloed, there is a need to move beyond fragmented communication and information-sharing practices.
- **Deborah Stone-Walls:** Caregiving is already stressful enough without caregivers having to struggle to access information or communicate updates from home to medical professionals. Allowing caregivers to contribute information and observations directly into records would help create pathways to easier caregiving.

Question 5: What steps could be taken to better train organizations on balancing privacy protections with caregiver inclusion?

- **Jennifer Wolff:** Formalizing the role of caregivers and care partners within healthcare systems is critical to legitimizing their involvement and ensuring they have timely, accurate, and comprehensive information needed to navigate care delivery, interact with clinicians, and provide hands-on support. She highlighted the Coalition for Care Partners, which promotes shared patient portal access so caregivers can be proactively identified, included in communication, complete voluntary assessments, and access tailored referrals, education, and resources, while also allowing multiple care partners to participate in care coordination when appropriate.

Question 6: Do you know of any examples where influencers were used to spread the word about caregiver trainings or resources?

- **Deborah Stone-Walls:** YouTube and Facebook tend to reach older adults, while Instagram and TikTok are more effective for younger caregivers. Communication teams are increasingly tailoring outreach strategies to specific audiences.

Question 7: How do we build infrastructure that allows for monitoring and supporting both the caregiver and the care recipient across settings?

- **Robyn Golden:** Future progress will depend on building a stronger caregiving ecosystem across public health, aging services, and healthcare systems, recognizing that systems cannot function effectively without family caregivers. It is important to not only understand the tasks caregivers perform, but also what matters to them personally, including whether their health and support needs are being met. There is hope that stronger infrastructure and coordination across sites, settings, and providers will emerge through collaborative efforts, with the RAISE initiative playing an important role in advancing systems-level change.

Next Steps and Adjourn

Kari Benson, Deputy Assistant Secretary of Aging at the Administration for Community Living (ACL), closed the meeting by thanking Jonathan Westin and participants for an amazing session, emphasizing that the discussions throughout the meeting reinforced a sense of empowerment, inspiration, and renewed energy around supporting family caregivers and advancing updates to the National Strategy. She recognized the first cohort of funded states implementing the National Strategy, i.e. California, Massachusetts, Maryland, and Wisconsin; as well as the second cohort, i.e. Alabama, Minnesota, Montana, Pennsylvania, and South Carolina. She highlighted discussions on expanding kinship care supports, integrating caregivers into care coordination, and strengthening systems that support caregivers and care recipients. She emphasized that ACL investments are helping build durable, coordinated systems and sustainable infrastructure for current and future caregivers by aligning federal resources with national, state, and local partnerships. She concluded by encouraging attendees to consider their role in advancing the National Strategy’s goals, noting that caregiving support is moving from “best practices” toward becoming “normal practices,” and shared that the next Joint Full Council Meeting would take place on July 29, 2026, 12:00 PM Eastern Time.