



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)
September 19, 2023, 12:30 p.m.–4:30 p.m. ET

Welcome Remarks

Alison Barkoff, Senior official performing duties of the ACL Administrator and Assistant Secretary for Aging

Alison Barkoff welcomed the incoming members of the RAISE Family Caregiving Advisory Council (FCAC) and the Advisory Council to Support Grandparents Raising Grandchildren (SGRG). Barkoff introduced U.S. Department of Health and Human Services (HHS) Secretary Xavier Becerra and noted he is a true believer in the work of the advisory councils, joining the advisory councils for events on three separate occasions, including the release of the 2022 National Strategy to Support Family Caregivers (the Strategy).

Xavier Becerra, Secretary, U.S. Department of Health and Human Services

Secretary Becerra thanked Barkoff and the team at ACL. Caregiving is a priority for the Biden Administration. The members of the two advisory councils deserve kudos because their work is the cornerstone for the next generation of caregiving. Secretary Becerra acknowledged the need for more progress. New laws give caregivers and grandparents more attention, and they are critical. However, it takes work to put laws into action.

Overview and Analysis of the Public Comments

Greg Link, Director, Office of Supportive and Caregiver Services

The RAISE Family Caregivers Act requires that the public be given an opportunity to provide input on the Strategy. ACL placed a notice in the Federal Register, and the comment period closed on November 30, 2022. A team from the LeadingAge LTSS Center at UMass Boston analyzed the public comments.

Pamela Nadash, UMass Boston

A total of 580 responses were received from the public. Respondents were asked to identify the three most important topics or issues for the advisory councils to consider. Respondents were also asked to note what was missing from the Strategy. They were also allowed to add any other further comments.

The breakdown of respondents by category: family caregivers, 44%; researchers, 13%; and advocates, nearly half. Some were employed by government programs or other organizations

serving family caregivers. Many respondents said they belonged to more than one category. For example, many advocates were also family caregivers.

Goal 3 of the Strategy (“Strengthen Services and Supports”) attracted the most comments. Findings for this goal:

- Improved training, supply, and wages for the direct care workforce, with a particular focus on ensuring quality of care.
- Increased attention to caregiver training and support, including respite care.
- Increased supply and affordability of long-term services and supports (LTSS).

Goal 4 (“Ensure Financial and Workplace Security”) received the second-most comments. Findings for this goal:

- Pay for family caregivers.
- Expanded access to health care services.
- Caregiver-friendly workplaces.

Some respondents said that it was hard to be open about the need to provide care to someone you love. There were many comments about the financial harm people experience when they must leave work to provide care.

There were also comments about kinship families and grandfamilies. People noted that family caregivers simply are not treated the same way as foster parents or caregivers of young children, even though kinship caregivers need many of the same services and supports. Yet, there are different issues associated with this role, many of them having to do with supporting children in schools. Kinship caregivers need:

- Training and respite care.
- Legal help and guidance.

The interrelated aspects of caregiving create challenges when trying to prioritize issues of focus.

There was a widespread endorsement for supporting diversity, equity, and inclusion goals and accessibility. Many comments concerned the need to make different types of provisions or make an extra effort to serve different populations of caregivers and care recipients equally.

Other priorities identified:

- Raising awareness about the importance of caregiving.
- Including caregivers as partners in health care and LTSS.
- Need for data and research on family caregiving.
- Need for evidence-based practices.
- Need to develop an accountability structure for the Strategy (dashboard on ACL).
- Need for strong partnerships across sectors.

Answers to the question about what is missing from the Strategy overlapped significantly with comments about top priorities. Answers included:

- More focus on long-term services and supports.
- More awareness raising.
- Development of the direct care workforce.
- Respite opportunities.
- Caregiver training and support.

- Paying family caregivers.
- Diversity, equity, and inclusion.
- Financial impact of caregiving.
- Workplace reform.
- More attention to the needs of people with intellectual and developmental disabilities (I/DD), spousal caregivers, and people with mental illness.
- Transitions from home to hospital and vice versa.
- Research that evaluates the return on investment for caregiver support programs.
- Ways to share best practices.
- Financial support for family caregivers.
- Concrete mechanisms for ensuring effective collaboration, i.e., an infrastructure across federal agencies to ensure collaboration on addressing family caregiving topics.
- Coordinated data collection across all levels of government.

Many comments about the government's role in supporting family caregivers. They included:

- A public-facing dashboard for checking the status of actions across federal agencies.
- A cross-agency task force for implementation of the Strategy with public meetings and progress reports.
- Guidance to states focused on supporting caregivers and caregiving for veterans, children with disabilities, and federal employees.
- Reduced administrative burden for ACL grants.
- Federal actions
 - Expand eligibility and flexibility for Medicaid benefits, especially for home and community-based services (HCBS) and “Money follows the person.”
 - Expand the ability to pay family caregivers.
 - Add respite as a mandatory Medicare or Medicaid benefit.
 - Improve access to mental health services.
 - Expand the use of Medicare Special Supplemental Benefit for Chronically Ill.
 - Prioritize equity to address caregiver health and economic disparities.
- Congressional actions
 - Tax credits and mechanisms for relieving financial pressures on family caregivers.
 - Consider immigration reform to help expand the direct care workforce.
 - Expand benefits for working caregivers, including paid family medical leave.
 - Act as a model employer by creating a supportive federal work environment.
 - Expand funding for implementation, for federal grants to states to implement the Strategy on a state level, and to support LTSS more generally.
 - Ensure that tribal entities have support.
 - Establish a new office of caregiver health at HHS.
- State actions
 - Payment for family caregivers.
 - Paid family and medical leave.
 - Encourage the medical system to collaborate with family caregivers, including them in hospital discharge processes.
 - Include family caregivers and community-based organizations in state planning.
 - Improved coordination of funding to ensure collaboration among organizations.

- Improved data collection on caregiver-related services and outcomes.

Comments and Discussion of New Goals

Council members and members of the public contributed ideas around possible new goals.

- Kinship caregivers are getting younger, and a lot of funding comes from Older Americans Act money, which is restricted by age.
- Some sociodemographic characteristics make caregivers — especially grandparents raising grandchildren — more vulnerable and may predict worse outcomes, adding that male caregivers are especially vulnerable.
- The needs of specific caregivers, such as men and caregiving youths.
- Would like the advisory councils to work more closely with residential care facilities and family day care centers to create support groups where caregivers can gather while their loved ones have their own activities.
- Combining respite and support services could represent a new type of support.
- Churches and other faith-based groups offer “inclusive respite”— providing services for the caregiver and the care recipient at the same time. This leads back to Goal 3 and expands the idea of respite as a dual need, not an individual need.
- Referring to payment for caregivers as “financial assistance for caregivers,” especially when referring to kinship families, framing the assistance as to meet children's needs.
- Some caregivers feel that receiving compensation for their care carries a stigma, but others feel that payment represents respect and value for the work and time they put in.
- Medical and nursing schools should incentivize students to teach caregivers how to provide care to family members.
- There is a need for information about support services, including what they are eligible for and how to access them, especially for people who suddenly find themselves in a caregiving role. A program like one for grandparent caregivers via Zoom during the pandemic could be expanded, especially for people who can't leave the house.
- For parents of children with disabilities, caregiving is a lifetime role. These parents need ways to connect with others at various stages in life. For families of young people with disabilities, it is incredibly important to learn from other families. Who is the best barber in town to give my autistic child a haircut? Families also need help to challenge their communities to include their children with disabilities in the mainstream of life.
- Develop practical tools to help organizations figure out whether an agency has the authority to make a change, for example, in respite policies, without federal legislation.

Overview of Federal Actions

Pamela Nadash

The goal getting the most attention is Goal 1, which is about raising awareness. The second area that gets quite a bit of attention is Goal 3, which involves services and supports for family caregivers and what the federal government can do to support LTSS. Actions to promote partnerships with family caregivers, or Goal 2, came next. There is also emphasis being placed on research, which is under Goal 5. Goal 4, which addresses financial security, received the fewest federal actions, most likely because it has to do, in large part, with private sector actions and with supporting and encouraging private sector action. There are things that only employers can do and things that need to be employer-led.

Some actions are around huge programs, and some are smaller, specific actions. Some actions are focused on specific caregiver groups. The majority of actions relate to all family caregivers, but a number are related specifically to kinship families. The groups mentioned most often in these federal actions are people living with dementia and their caregivers.

Progress on Federal Actions

Greg Link

ACL is working with its federal partners to implement the actions in the Strategy and track their activities. Link acknowledged the calls for accountability in the public comments on the Strategy, pointing out that council members can discuss the cadence of any progress reports as well as any new actions to add to the Strategy.

The following reports from the federal agencies look at progress between 10/1/2022 and 3/22/2023. It was noted that priority shifts can alter schedules and policy environment and funding structures. At several agencies, new opportunities have arisen since the Strategy came out. Some of the steps taken by agencies were not even in the Strategy.

The Strategy is a document that will always be changing, growing, and refocusing as broader policy and program environments change. He thanked the federal partners for their enthusiasm for and commitment to the Strategy, which reflects the importance of caregiving issues to this administration and to the agencies represented on the advisory councils. Caregiving is a deeply personal issue to many of the federal members on the councils.

Goal Summary

Goal 1: 65 of 117 actions in process; 13 complete; 8 modified; 31 had not been started.

Goal 2: 33 of 55 actions in process; 8 complete; 3 modified; 11 had not been started.

Goal 3: 67 of 103 actions in process; 12 complete; 5 modified; 19 had not been started.

Goal 4: 16 of 22 actions in process; 4 complete; 2 had not been started.

Goal 5: 31 of 52 actions in process; 8 complete; 1 modified; 12 had not been started.

Administration for Community Living (ACL)

Greg Link

Of ACL's 93 actions, six had been completed by March, and 41 were in process.

Under Goal 1 of the Strategy, ACL's Administration on Disabilities began work to establish a community of practice across the 10 states currently funded to develop consensus on the scope of needs and challenges facing individuals with developmental disabilities and their families.

For Goal 1, ACL's Center for Regional Operations (CRO) completed more than five hours of education and training on family caregiving with a total of five caregiving workshops at this year's Title VI conference. (Title VI of the Older Americans Act addresses Native American, Native Alaskan, and Hawaii Native populations.) The goal had been to present one workshop.

The CRO also provided specific information and guidance to states required to submit new state plans on aging on how to incorporate and address the Strategy in their state plan.

Also under Goal 1, ACL's Office of Elder Justice and Adult Protective Services identified grandfamilies as a priority population for the next round of Legal Assistance Enhancement Program Grants.

Funded by ACL's National Institute on Disability, Independent Living, and Rehabilitation Research, the National Rehabilitation Research & Training Center on Family Support at the University of Pittsburgh began implementing its goal-setting procedures for family caregivers of older adults enrolled in the Community Aging in Place, Advancing Better Living for Elders (CAPABLE) program.

Under Goal 5, ACL's Office of Performance and Evaluation will pilot a new question in the 2023 National Survey of Older Americans Act Participants. The question will ask whether recipients of services (such as home-delivered meals or transportation services) are caregivers.

Link also announced a new ACL initiative for caregivers that wasn't part of the Strategy. Later this month, they will launch five demonstration grants with money from the new demonstration authority that was restored in the 2020 reauthorization of the Older Americans Act, specifically under Title III-E. Four demonstration grants will address Goals 1, 2, 3, and 5 and the fifth grant will be a technical assistance center.

Centers for Medicare & Medicaid Services (CMS)

Jodie Sumeracki

CMS took on 28 actions; six had been completed, and 20 were in progress as of March.

Under Goal 1.4, CMS pledged to conduct by July of 2023 a national training on the Home and Community-Based Services (HCBS) funded through Medicaid that could benefit and support caregivers. In February 2023, the Medicaid Benefits and Health Programs Group conducted a [presentation during a national all-state call](#) that provided information on methods states can use to operationalize payment for family caregivers in their Medicaid programs.

At the national HCBS conference, CMS presented strategies for supporting individuals with intellectual disabilities as well as their aging caregivers.

In light of the ongoing direct care workforce crisis, in June 2023, CMS released four [action briefs](#) designed primarily to support agencies that play critical roles in the design and delivery of services and supports for adults with I/DD and their aging parents and caregivers.

A state spotlight resource highlights innovative strategies that states are using to support adults with I/DD and aging caregivers in four areas of focus including building interagency partnerships and relationships, providing navigation supports, implementing person- and family-centered systems, and planning for the future.

U.S. Department of Veterans Affairs (VA)

Meg Kabat

The VA has 21 actions across all goals. Several actions are within Goal 1. The VA raises awareness and reaches out to caregivers in several ways, including a newsletter called Vet Resources that goes out weekly to the listserv of over 13 million people. Occasionally, it covers resources available to caregivers. They also have listservs specifically for caregivers.

Under Goal 2, the VA has two buckets of training, some directed to the caregiver community specifically and some to the veteran community in general: 1) Help individuals understand their changing role as caregivers, and 2) Practical how-to guides (e.g., “How to change a bandage”). Under Goal 3, the VA is expanding mental health services to caregivers of veterans through telehealth capabilities implemented during the pandemic. This is a better medium for caregivers in many cases. The VA created clinical resource hubs with the technology infrastructure to deliver psychotherapy by licensed professional counselors and psychologists. The VA started out with hubs in three regions of the country and will be moving into several more by the end of this calendar year. So far, the program has provided 500 visits to almost 120 caregivers.

The VA has also partnered with Rosalynn Carter Institute for Caregivers to develop an [emergency preparedness toolkit](#) specifically designed for caregivers.

Just recently, the VA launched a program to provide financial and legal support for family caregivers participating in the VA Program of Comprehensive Assistance for Family Caregivers.

Administration for Children and Families (ACF)

Liliana Chakrabarti

ACF has 14 actions in the Strategy, and seven are complete. Comments focused on the Children’s Bureau’s efforts to educate Americans about the experience of family caregiving.

The Children’s Bureau has created various online resources and videos about the kinship caregivers’ experience. The [“All Relative Guide”](#) talks about the experiences of kinship caregivers, mainly grandparents. ACF has funded kinship navigator programs in all states and for 12 Title IV tribes. The Children’s Bureau has quarterly webinars with the states highlighting best practices. The Children’s Fund Cooperative Agreement Grants developed national training and development curriculum for foster/adoptive parents and kinship families, including a free online resource about building resilience in kinship caregivers.

ACF is hopeful that a notice of proposed rulemaking will change the licensing rules so states will be able to have a distinct set of standards for kinship caregivers than for nonrelatives.

Office of the Assistant Secretary for Planning and Evaluation (ASPE)

Emma Nye

ASPE is the principal advisor to the Secretary of HHS for policy development and policy coordination. Six research projects focused on family caregivers have been completed as of March 2023, and the agency is working on publishing them.

One project under Goal 5 was highlighted — to expand data research and evidence-based practices to support family caregivers. The project, called Supporting Families and Caregivers of Adults with Behavioral Health Disorders, examines the unique needs of family caregivers of adults with behavioral health disorders or substance use disorders. The project included a technical expert panel that hosted researchers, a caregiving support program provider, public health leaders, and people with experience in behavioral health caregiving. The project is complete, and the report will be released later this year or early 2024.

Centers for Disease Control and Prevention (CDC)

John Omura and Greta Kilmer

The CDC took on 41 actions from the Strategy, and all were in process as of March 2023. Eighteen actions were under Goal 1, three under Goal 2, and 10 each under Goals 3, 4, and 5.

Under Goal 1, the CDC committed to updating the Healthy Brain Initiative five-year roadmap by 2024. The roadmap establishes national priorities for public health regarding brain health, including actions around dementia caregivers. The roadmap addresses four domains and is aligned with the Strategy.

- Strengthen partnerships and policy.
- Measure, evaluate, and use data.
- Build a diverse and skilled workforce.
- Engage and educate the public.

A set of 24 actions in the roadmap map to those four domains. These actions are oriented to public health departments and their partners as they consider how to advance brain health among the communities and populations that they serve, including caregivers. So, caregiving is really integrated and represented throughout the road map.

Many of the CDC's actions relate to data and improving current data systems. The data system used most is the Behavioral Receptor Surveillance System (BRSS). CDC reduced the BRSS respondent burden by decreasing the number of questions. The proposed modifications for the caregiver module were developed in conjunction with a process to solicit input, feedback, and ideas from a group of caregiving experts. The revised module has nine questions that align with the CDC's goals around caregiving data and will help serve public health activities. The CDC will begin administration of the new questions in 2024. CDC has also pursued the inclusion of caregiving questions on the National Health and Nutrition Examination Survey.

Health Resources and Services Administration (HRSA)

Joan Weiss

HRSA addressed 15 actions in the Strategy, and all of them are in progress.

Two actions under Goal 1 were described:

- Continue to support its webpage on caregiving.
- Continue to have a caregiver representative on its federal advisory committee.

HRSA also provides [caregiving training](#) for caregivers of persons living with dementia; there are two parts — one for caregivers and one for health care providers.

Part 1 addresses self-care for family caregivers, choosing assisted living/nursing home care, and addressing behaviors in dementia. Part 2 addresses working with family caregivers as allies, including caregivers in shared decision-making and caring for family caregivers.

HRSA is continuing to work on disseminating the training by researching what caregiving organizations could benefit from this type of training.

In the past two years, HRSA has included a caregiver on its Committee on Interdisciplinary Languages, which provides advice and recommendations to the Secretary of HHS and Congress on policy and program development for education and training programs related to primary care, geriatrics, and mental health. HRSA's geriatric programs are required by statute to provide training to family caregivers, and adding a caregiver to the advisory committee was an important step.

Indian Health Service (IHS)

Jolie Crowder

The IHS provides care and services to 2.8 million American Indian and Alaskan people who are members of 574 federally recognized Tribes. The system includes IHS-run facilities, Tribal-run facilities, as well as urban Indian Health Organizations. The bulk of funding goes to care and services provided by Tribes who manage and self-direct their own care. Collectively, the three parts of the IHS system employ tens of thousands of employees, two-thirds of whom are members of the direct care workforce.

The IHS has 12 or so actions in the Strategy and has completed six; the rest are in process.

For Goal 1, IHS conducted a social media campaign for National Family Caregivers Month. IHS has tried to create some specific content to define the term “caregiver” because the term doesn't resonate in their communities, and, therefore, outreach efforts can fall flat. In September, IHS shared posters about National Grandparents Day. They have also incorporated caregiving resources on their webpages.

The IHS has engaged with three CDC Centers of Excellence that are addressing dementia. IHS also funded two new Extension for Community Healthcare Outcomes series this year. These programs expand access to specialty training, are designed for clinical staff, and include case-based learning and some didactic training. A new training led by council member Dr. Neil Henderson is focused on caregiving, with 30-50 participants each month.

Other critical activities include grants that are part of the Alzheimer's Disease and Related Dementias Funding Opportunities. IHS was awarded four grants in 2022 for a total of \$4.2 million, all of which are required to address caregiving in some form. They are currently developing a strategic plan to address cancer and caregiving.

National Institute on Aging (NIA)

Melissa Gerald

NIA completed five action items from the Strategy, and 14 were in process. Several actions have had to be modified along the way. Many of the actions are related to increasing awareness and outreach to family caregivers and advancing and strengthening supports for family caregivers, but the progress presentation focused on Goal 5 and the expansion of evidence-based data.

NIA issued two companion requests for applications to solicit research on methods and measures for family caregiving for people with Alzheimer's. The purpose is to support research that can lead to the development of methods and measures that capture informal caregiving for people living with Alzheimer's disease. The Institute has funded nine new grant awards through these funding announcements — \$4 million in 4-year awards, plus \$1.4 million for 2-year awards.

This research will help capture the growing numbers of adults aging without spouses or biological children — who often provide unpaid care for their family members. In many cases, blended families and families of choice provide informal care. These “kin-like” relationships may play a really important role in caretaking.

Several new initiatives at NIH are related to caregiving and the detection and prevention of abuse and neglect among older adults at risk for cognitive impairment or other dementias.

Substance Abuse and Mental Health Services Administration (SAMHSA)

Liz Sweet

SAMHSA had approximately 12 actions in the Strategy. For Goal 2, it collaborated with ACF on a webinar that focused on substance abuse and child welfare. Two additional webinars focused on issues of caregivers when substance abuse is an issue and providing care for a child with a serious emotional disturbance.

For Goal 3, SAMHSA has increased access to meaningful and culturally relevant information, services, and supports for family caregivers and kinship families.

SAMHSA is partnering with the VA to prevent suicide and address the caregiver crisis and how states and communities can better support military communities and their veteran caregivers. SAMHSA is also developing a curriculum with the Federal Emergency Management Administration to provide peer support for caregivers during emergency situations.

AmeriCorps

Atalaya Sergi

AmeriCorps' Senior Companion Program and RSVP Program are the main programs that support caregivers. The former focuses on independent living and respite services for older adults and their caregivers. RSVP provides a variety of services, and its volunteers do a lot of education in their communities and provide respite and benefits navigation services to caregivers.

AmeriCorps has about 1,100 grantees that engage older adults in volunteerism. The agency works to make sure that grantees understand the needs of caregivers and that organizations working with caregivers know about grant opportunities at AmeriCorps Seniors.

Information about caregiving and grant opportunities related to caregiving is shared in monthly newsletters that go out to all the grantees.

Examples of programs using AmeriCorps Senior grants include initiatives using service and volunteering as an onramp to build a respite care workforce through training and certification.

U.S. Department of Labor (DOL)

Sarah Glynn

Comments centered on a few top-level actions at DOL. The first example comes from the Office of Federal Contract Compliance Programs, which oversees contractors and subcontractors to the federal government to make sure they're in compliance with all the laws and regulations, including antidiscrimination measures that combat gender-based stereotypes about caregiving responsibilities.

A new website about paid leave includes information about state programs. DOL's lead center also hosted a think tank and listening session on the shortage in the direct care workforce. The recommendations were shared with 18 different government agencies and compiled into a [report](#).

Issues related to caregiving are an important focus of DOL's Women's Bureau, which recently collaborated with DOL's Wage and Hour Division to look at the lifetime costs of caregiving. Grandparents raising grandchildren are getting attention from the Women's Bureau as well.

The [President's Executive Order](#) on Increasing Access to High-Quality Care and Supporting Caregivers has impacted work and research at DOL, including fostering collaborations with HHS related to home and community-based services providers.

Consumer Financial Protection Bureau (CFPB)

Beverley Yang

CFPB monitors unfair consumer practices that target older Americans and family caregivers, such as attempts by nursing homes to collect payment from family caregivers or have caregivers provide a personal guarantee of payment as a condition of admission. This violates the Nursing Home Reform Act and attempts to collect from caregivers may violate the Direct Collection Practices Act and the Fair Credit Reporting Act, both of which are regulated and enforced by CFPB.

Highlights on actions included a few activities by CFPB to clarify the law surrounding caregiving and financial health, including a [report on medical debt](#), a [joint letter with CMS to debt collectors and nursing homes](#), and a joint blog with ACL for long-term care ombudsmen. CFPB continues to hold webinars for state health insurance counselors and others.

U.S. Department of Education (ED)

Carmen Sanchez

ED partners with ACL and HHS to amplify messages. Most of the work around caregiving at ED is done by the Office of Special Education since it addresses the needs of parents of children with special education or health care needs.

ED funds a series of centers that educate family caregivers about services available for their children. ED has various newsletters that spread the message about what is going on throughout the federal government, and the agency's Office of Communication and Outreach also does a good job of amplifying messages that can be helpful to grandparents who are raising children, to help them find out what is available to them and how they can be supported. These messages go out to parent training information centers as well as direct to consumers.

ED also has family engagement centers in many states, and they focus on helping family members educate their children. The Ohio family engagement center has specific materials for grandfamilies and kinship families. ED also operates community parent resource centers in various states, and the one in Virginia is especially focused on kinship families.

Next Steps

The advisory councils will be meeting in separate subcommittees to think through what to look at next in terms of the Strategy. How do we grow it? How do we expand it? ACL needs to know what types of information will be needed by the councils in the future. Suggestions included:

- How to work with other family caregiving groups, e.g., disabilities, mental health.
- Recognize diverse cultural groups have different views about aging and dementia; no "one size fits all;" also, understand caregiving across health, economic disparities.
- The need to understand how states are tied into the Strategy and the need for partnering with states. What is working for them?
- Information provided at conferences, meetings, etc., around the country.
- Reaching out to a variety of programs to see what's working.

- Best practices and promising practices that may show potential for replication, expansion, and translation.
- Need for more information on the state of the science on caregiving and caregiving interventions. Also, the need to develop electronic health records in a systematic way.

The advisory councils have some cross-cutting themes, such as respite. What are some focus areas for people in both councils to join in on?

- Is there a model that could be built that lists hands-on resources in a digestible way at the time of entry into caregiving?
- Could we put together something like the National Council on Aging's Benefit Checkup.org?
- Ways to increase the number of providers. Can we look at licensing requirements?
- Access to remote programs is key to people who have trouble leaving the house, such as grandparent caregivers.
- Creating a technology or a website that could help caregivers navigate all aspects of caregiving. Some names were suggested, e.g., "Benefit Navigation," "Benefit Access."
- Lifelong caregiving is a topic that may be worth investigating, even though there may be resistance within the disability community to refer to family members of a person with disability as a caregiver, because it could diminish the abilities of the care recipient.