Joint Meeting of the RAISE Family Caregiving and Supporting Grandparents Raising Grandchildren Advisory Councils

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Joint Meeting of the RAISE Family Caregiving and Supporting Grandparents Raising Grandchildren Advisory Councils

January 25, 2022
Call to Order

Alison Barkoff
Principal Deputy Administrator
Administration for Community Living
Council Business Announcements & Next Steps

Greg Link, Director
Office of Supportive and Caregiver Services
Administration for Community Living
Council Business Announcements & Next Steps

• Agenda Overview
• Anticipated work plan through August 2022
• Formation of new working groups
• Call for nominations
• Discussion
Today’s Agenda

• Welcome remarks
• Council member introductions
• Presentations
  – Findings from Stakeholder Listening Sessions
  – Panel: Caregiver Employment and Financial Preparedness
• National Family Caregiving Strategy: Update and Next Steps
Anticipated Work Plan Through August 2022

• Completing the National Family Caregiving Strategy
  – Monthly subcommittee meetings: February, March, April 2022
  – Federal partner convenings – Feb (and/or March) 2022
  – Two-phased or single dissemination - TBD
  – Joint full council meetings (tentative)
    ▪ May 2022
    ▪ July/August 2022
Formation of New Subcommittees

• **Primary task**: Finalize non-federal actions for the Strategy
• **Monthly meetings**: February, March, April (and TBD)
• **New subcommittees** (organized by goal):
  – Awareness and Outreach
  – Engagement and Partnership
  – Strengthening Services and Supports
  – Financial & Workplace Security
  – Data, Research and Evidence-Based Practice
• Comprised of federal and non-federal members of the RAISE and SGRG Councils
• Doodle Poll sign-up following today’s meeting
Call for Nominations

• Current non-federal member terms end in August 2022
• ACL will be seating new RAISE and SGRG Councils
• Federal Register Notice – “Call for Nominations”
  – Mid-February 2022
  – Open for 30 days
• Multi-agency review and selection process
• Invitations emailed: early June 2022
• New council members sworn in: September 2022
Opening Remarks

Honorable Xavier Becerra
Secretary of Health and Human Services
Council Member Introductions

When introducing yourself please tell us your:

Name
Affiliation

and…

Complete the sentence: “Once the National Family Caregiving Strategy is completed, family and kinship caregivers will be able to ________________.”
Findings from Stakeholder Listening Sessions

Pamela Nadash, Ph.D.
Associate Professor
Department of Gerontology| McCormack Graduate School
University of Massachusetts

Eileen Tell
CEO, ET Consulting
Fellow, LTSS LeadingAge Center at UMass Boston

Siena Ruggeri
Program and Policy Coordinator
Center for Consumer Engagement in Health Innovation
Community Catalyst
Building a National Strategy to Support Family Caregivers

Report to the ACL RAISE Family Caregiver Advisory Council: Findings From Key Informant Interviews and Stakeholder Listening Sessions

January 25, 2022
Report Outline

• Research Design and Methods
• List of Stakeholder Organizations
• Findings: Recommendations for Implementation
  • Organized by RAISE GOALS
    • Actions for Federal Entities
    • Actions for State, Local and Private Sector Entities
  • Quotes from Stakeholder Sessions
• Appendix
Research Design and Methods

Objectives and Methodology
Research Objectives

• Help inform a roadmap for the National Strategy, focusing on priority topics that emerged from the Phase I consumer listening sessions

• Identify implementation logistics around cost, timing, challenges and ownership for:
  • Raising awareness and self-identification among family caregivers
  • Addressing the needs of culturally and ethnically diverse caregivers
  • Workplace and financial accommodations for working caregivers
  • Expanding respite care supply and demand
  • Caregiver training, needs assessment and other supports
  • Including caregivers in the care planning, hospital discharge and care experience
Data Collection Activities

• **Phase I:** Stakeholder Strategy Sessions
  • Organized by Goal

• **Phase II:** Key Informant Interviews and Stakeholder Listening Sessions
  • Organized by topic and constituency group
Phase I Stakeholder Sessions

• Identified relevant stakeholders and key thought leaders at both the national and state levels

• Aimed to reach a range of organizations working on caregiver issues, from aging and disability groups to providers, researchers and other advocates, representing the many faces of caregiving

• 60 organizations were invited. Of these, 42 sent a representative to participate in six two-hour sessions.

• Conducted during the second week of December 2020
Phase I Stakeholder Sessions

• The objectives were broad:
  • Engage key organizations in the work of the Council
  • Start to generate ideas about specific action steps related to recommendations that support the Council’s five major goals
  • Promote continued participation and involvement as the Council develops its national strategy
  • Identify key leaders for the national advocacy work ahead
Phase II: Building Out Strategies

• **Key informant interviews**
  • Explore relevant issues within each of the selected topic areas
  • Help identify suitable participants for listening sessions
  • Aid in the development of the listening session Discussion Guides
  • Convened 17 Key Informant Interviews – 60 minute Zoom sessions
Phase II: Building Out Strategies

- **Stakeholder Listening Sessions**
  - Organized to represent key stakeholder groups
  - Obtain shared and divergent perspectives on how to address specific goals and recommendations
  - Identify specific solutions, timeframes, implementation challenges and other components of proposed strategies
  - Convened 16 Listening Sessions, each 90 minutes, over Zoom
  - Invited 253 individuals/stakeholder organizations*
  - Overall, heard from 103 unique stakeholder organizations

*Includes key informant outreach
## Phase II Workplan*

<table>
<thead>
<tr>
<th>POPULATION/TOPIC</th>
<th>KEY INFORMANT INTERVIEWS</th>
<th>LISTENING SESSIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EMPLOYERS:</strong> Intermediaries, academics, HR reps, and public policy perspectives</td>
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<tr>
<td><strong>RESPITE CARE</strong></td>
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<td><strong>LTSS PROVIDERS/DIRECT CARE WORKFORCE</strong></td>
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<tr>
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<td><strong>COUNTIES</strong></td>
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<tr>
<td><strong>COMMUNITY-BASED ORGANIZATIONS (CBOs) and FAITH-BASED ORGANIZATIONS (FBOs)</strong></td>
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<tr>
<td><strong>GEOGRAPHICALLY-BASED LISTENING SESSIONS:</strong> Rural/Urban/Suburban CBOs</td>
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<tr>
<td><strong>POPULATION-SPECIFIC LISTENING SESSIONS:</strong> Aging, Disability, Indigenous communities, People of Color and Faith-Based Organization</td>
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<tr>
<td>Total</td>
<td>17</td>
<td>16</td>
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*Detailed work plan in Appendices*
Stakeholder Organizations

Who did we hear from?
Broad Outreach To Diverse And Varied Stakeholder Entities

• Input from over representatives of over 162 organizations
• Federal, state, local, private, and public sector
• Over 50 hours of session transcripts
• Grateful to all who participated
Phase I Stakeholder Strategy Session Participants

- AARP
- Access Living
- Alzheimer's Association
- American Bar Association
- American Network of Community Options and Resources (ANCOR)
- Association of Programs for Rural Independent Living (APRIL)
- Autism Society of America
- Benjamin Rose Institute on Aging
- Brookdale Foundation
- California Long-Term Care Education Center
- Caregiver Action Network
- Center for Family Support, University of Pittsburgh
- Center to Advance Palliative Care
- Disability Policy Consortium
- Generations United
- Institute for Healthcare Improvement (The Conversation Project)
- Jewish Federation of North America
- Justice in Aging
- LeadingAge
- Little Lobbyists
- Lucile Packard Foundation for Children’s Health
- Meals on Wheels America
Phase I Stakeholder Strategy Session Participants

- Medicare Rights Center
- Mental Health America
- National Association of Councils on Developmental Disabilities (NACDD)
- National Adult Day Services Association
- National Alliance for the Mentally Ill
- National Asian Pacific Center on Aging
- National Caucus and Center on Black Aging
- National Council on Aging
- National Council on Independent Living (NCIL)
- National Indian Council on Aging
- National PACE Association (NPA)
- National Patient Advocate Foundation
- National Council on Aging (NCOA)
- Scripps Gerontology Center, Miami University
- Services and Advocacy for Gay, Lesbian, Bisexual & Transgender Elders (SAGE)
- Sibling Leadership Network
- Institute on Disability and Human Development, University of Illinois
- Southeast Asia Resource Action Center (SEARAC)
- The Arc
- Well Spouse Association
Phase II Key Informant and Listening Session Participants

- Alabama Department of Aging
- Alliance of Disability Advocates
- ALU LIKE, Inc.
- Alzheimer’s Orange County
- Apna Ghar Home Care
- Arizona Caregiver Coalition
- ATI Advisory
- Autism Self-Advocacy Network
- Best of Care Inc.
- Cariloop
- Caring Together, Living Better (CTLB), AgeOptions
- Center for Parent Information and Resources
- Chicago Department of Family & Support Services
- Claude Worthington Benedum Foundation
- Coalition to Transform Advanced Care (C-TAC)
- Colorado Cross-Disability Coalition
- Colorado Department of Health Care Policy & Financing
- Continuum of Colorado
- CVS Health
- Dana-Farber Cancer Institute
- Douglas County, NE Board of Commissioners
- Duke-Margolis Center for Health Policy, Duke University
- Easterseals Iowa
- Eastern Idaho Community Action Partnership (EICAP)
- Elizabeth Dole Foundation
- Epilepsy Foundation
- Family & Nursing Care
- Family First
- FamilyMeans
- Federal Reserve Bank of Kansas City/New Mexico Caregivers Coalition
- Five County Area Agency on Aging
- Foster Kinship
- Global Coalition on Aging (GCOA)
- Hā Kūpuna (National Resource Center for Native Hawaiian Elders)
- Harvard Business School
- Health Management Associates
- Helper Bees
- Helping Hands of Vegas Valley
Phase II Key Informant and Listening Session Participants

- Henry Ford Caregiver Assistance Resources and Education Program
- House Works, LLC
- Independent Living Research Utilization (ILRU)
- Integrated Benefits Institute
- Iowa CareGivers
- iRobot
- Jewish Family Service of Saint Paul (JFS)
- J-Sei
- KBH Advocacy
- L'Arche USA
- Learn Care Together LLC
- Little Tokyo Service Center
- L'Orech Yomim/Center for Healthy Living (LOY)
- Lunalilo Home
- MAC, Inc./ Maryland Living Well Center of Excellence
- Massachusetts Lifespan Respite Coalition
- Massachusetts Digital Health Initiative
- Massachusetts Executive Office of Elder Affairs
- MCM CPAs and Advisors, LLP
- Missouri Rural Health Association
- Montana Family to Family Health Information Center
- National Alliance for Direct Support Professionals (NADSP)
- National Association for Home Care & Hospice (NAHC)
- National Association of Counties (NACo)
- National Association of Nutrition and Aging Services Programs (NANASP)
- National Brain Health Center for African Americans, Balm in Gilead
- National Catholic Partnership on Disability
- National Disability Rights Network (NDRN)
- National Rural Health Association (NRHA)
- National Senior Corps Association
- Native American Outreach Program, Banner Alzheimer’s Institute
- National Council on Aging (NCOA)
- Nevada Office of Aging & Disability Services
- New Mexico Caregivers Coalition
- North Dakota Respite Coalition
- Nourish for Caregivers
- Office of Hawaiian Affairs
Phase II Key Informant and Listening Session Participants

- OK Cares
- Paralyzed Veterans of America
- Philadelphia Corporation on Aging
- Rethink First
- Rhode Island Department of Human Services
- Rural Dementia Caregiver Project, University of California San Francisco
- Services and Advocacy for Lesbian, Gay, Bisexual & Transgender Elders (SAGE)
- Silberman Aging, Hartford Center of Excellence in Diverse Aging
- South Carolina Respite Coalition
- Southern Caregiver Resource Center (SCRC)
- The Alzheimer's Project
- The Resource Exchange (TRE)
- Torchlight
- The Renaissance Collaborative (TRC)
- Trellis
- United for Caregivers@Work
- United Methodist Health Ministry Fund
- University of California San Francisco Healthforce Center
- University of Iowa
- University of Minnesota Rural Health Research Center
- The Urban Institute
- United Way of Rhode Island/Family Caregiver Alliance of Rhode Island
- Us Against Alzheimers/Latinos Against Alzheimers
- Vision for Equality
- Warrior Care Network, Wounded Warrior Project
- Washington County Disability, Aging, and Veteran’s Services
- Wellthy
- Working Daughter
- Yale New Haven Health/Geriatric Emergency Department Collaborative
- Zen Caregiving Project
Methodology: Analysis

• Coded data from transcripts
• Analysis conducted with NVivo, a qualitative analysis software program, to assure systematic analysis of data
• Developed common themes across sessions
• Team of 4 researchers developed coding tree organized by goals and by topics/themes
• Each transcript coded/reviewed separately by 2 researchers
Major Findings

Recommendations by Goal
GOAL 1: Family caregivers’ physical, emotional and financial well-being will improve as a result of expanded awareness, outreach and education.

**Federal Actions:**
- Interagency awareness campaign
- National website and “help desk”
- Create and disseminate culturally relevant materials to support caregivers
- Fund and support the development of state plans on aging
- Include awareness and education activities specifically focused on employers and healthcare providers

**State, Local and Private Sector Actions:**
- Support Federal awareness campaign with state-based outreach campaigns, working with local stakeholders
- States should fund improvements to state-level “No Wrong Door” systems
- States should support Community- and Faith-based organizations in their work with family caregivers
- States should create community ambassadors reaching excluded groups
- Develop and implement interagency State Master Plans on Aging
Illustrative Quotes – Goal 1

“I’m concerned about the degree of shame that caregivers feel about... accepting support. Any kind of public awareness campaign that is culturally-sensitive and tailored to different communities could help... normalize this experience and reduce the shame... and then enable caregivers to more readily accept the help that’s available.”

[Health policy consulting firm]

“Where we struggle is around supporting caregivers is the identification of caregivers. People in the role of a caregiver don't know they’re caregivers, because they’re a role of, you know, a loved-one or whatever that is.”

[Health systems provider]

“My vote for priorities would be along the lines of a large public education campaign... you can show different types of caregivers, all of us who are somewhat in a caregiver situation.”

[Family caregiver advocacy organization]
Illustrative Quotes – Goal 1

“…I can’t tell you how often I meet with a family and they don't know about resources that are right in their neighborhood. And why is that? Those are the kinds of things that we really need to be examining and understanding and....why....having community-based input...is so important...”

[Aging center for underserved populations]

“We have to do a lot in terms of awareness. And a lot in terms of messaging that's targeted, that's culturally tailored to the audiences that we are trying to speak to. “

[Faith-based organization]
GOAL 2: Family Caregivers are recognized, engaged and supported as key partners with providers of health care and LTSS.

Federal Actions:

• Establish a consensus group to develop strategies for incorporating caregivers into care planning and care teams
• Develop a caregiver identification tool for health and service provider use
• Drive increased use of caregiver assessments
• Create incentives (through the use of reimbursement codes) for providers to engage with family caregivers
• Develop a strategy for medical/health care training to recognize family caregiver roles

State, Local and Private Sector Actions:

• Encourage private payers to create financial incentives for providers to engage with family caregivers
• Health care providers should pilot the use of caregiver assessments to improve identification of caregivers who need support
• Hospitals/Health systems should hire/train family caregiver engagement specialists
• States should adopt/expand the CARE Act
• Hospitals should review/strengthen protocols for incorporating the caregiver into EMR systems
• Hospitals, health systems, state hospital associations and research organizations should identify and promote best practices for family caregiver engagement.
Illustrative Quotes – Goal 2

“I think enabling physicians to be reimbursed for the time they spend providing instruction and support to family members and to make this a [reimbursement] code that just doesn't apply to licensed providers, but would apply to case managers, to be working within primary care or another medical setting.”

[Health policy research entity]

“That goes back to the clinician workforce education where we talk about how do we bring family caregivers into the conversation, being intentional about including them....And listening intently to those caregivers...It's a real culture change... it's a paradigm shift in terms of how we're looking at including caregivers.”

[Health system provider]

“So, as a nurse by training, I never quite formally learned how to assess caregiver needs, family member needs, as well as educating them about their loved-one's chronic illness. And I think that kind of stems up the pipeline in terms of when people are working as clinicians and not having that formal training or even awareness in their clinical rotations in terms of really interacting with the family, having a dedicated time and space for that in their clinical education.”

[Health care provider]
“So, it’s about getting the incentives right… what is in it for a health system to collaborate with CBOs to make sure that frail older adults don’t keep coming back to the hospital? … there’s supposed to be an incentive to prevent rehospitalization within 30 days. But it doesn’t seem to really be working. And unless the health systems have that incentive, they’re not going to do it.”

[Economic and social policy research firm]

“There's no one...assigned to monitor the Care Act documentation in the hospitals..... So I think having someone dedicated in terms of a clinician or administrator in these....areas would be essential.”

[Health system provider]
GOAL 3: Family caregivers have access to an array of flexible person- and family-centered programs, supports, goods and services that meet the diverse and dynamic needs of family caregivers and care recipients.

Federal Actions:

• Support funding to create community ambassador programs* to better reach excluded populations and entities that serve them.

• Expand Medicaid access to HCBS

• Advocate for Medicare expansions, including respite, adult day services, and home modifications

• Support family caregiver initiatives through increased funding for the Older Americans and Elder Justice Acts

• Increase funding for the National Family Caregiver Support Program, Lifespan Respite and Alzheimer’s Program Initiative

State, Local and Private Sector Actions

• States should expand access to HCBS through Medicaid expansions and state-funded programs

• States, municipalities, health plans, and health systems should collaborate to enhance the financial viability of community- and faith-based organizations, especially those serving underserved populations.

• These organizations and other provider entities should create or bolster community ambassadors to enhance connections with underserved populations

• In collaboration with other stakeholders, states should create a state master plan for supporting family caregivers.

• States, Medicare Advantage Plans, community- and faith-based organizations should prioritize funding and programing opportunities for respite care.

*Model after Ryan White Act
Goal 3: Continued

Federal Actions:

• Expand access to broadband
• Advocate for the Consumer Financial Protection Board to develop financial planning tools specific to family caregivers
• Publicize the value of direct care work
• Improve direct care work pay (via Medicaid)
• Fund research and demonstration projects to create better understanding of the direct care workforce and ways to improve it
• Create a federal government-led interagency task force to design a Direct Care Workforce development plan
• Increase the availability of programs that pay family caregivers for providing direct care.

State, Local and Private Sector Actions

• States, community- and faith-based organizations, private sector providers and employers should collaborate to create greater awareness/acceptance of respite care including advocacy for additional funding, state registry/directory and awareness campaign
• These entities, along with private philanthropy should expand the capacity of respite programs to serve people supporting care recipients with medically complex or with Intellectual or Developmental Disability care needs.
• States and lenders should provide low-interest loans and startup grants to develop adult day services
• States and municipalities should identify partners to help them be more effective in developing supportive and low-income housing
• States should expand or create opportunities to pay family caregivers
• States should increase wages for direct care workers
• States/home care agencies, and educational institutions should invest in the direct care workforce through enhanced training and job advancement.
“I'm growing....tired of the empty rhetoric about the heroic nature of [direct care] work. It's time to make some fundamental changes here. And that's not a crisis. I mean, a crisis is sudden and temporary and unexpected. We've been having this conversation for 30 years. 30 years! It's not a crisis. It's a systemic failure.”
[Advocate for Direct Care Workers]

“I think we have ambassadors, we have champions, [but] … these need to be empowered paid administrators, managers, directors… that hopefully come from these communities and know what's available… being trained with advanced skills.”
[Faith-based Organization]

“Anything that’s directly related to getting cash and resources into the pockets of caregivers, that should always by our priority.”
[Advocate for LGBTQ Elders]
Illustrative Quotes – Goal 3

“How do you recruit people? Pay them more than Starbucks. It’s not that complicated. In California, there’s signs everywhere because of the workforce shortage. You can work at the smoothie place for $16 bucks an hour. Who’s going [to work for] a minimum wage of $14 an hour. Most IHSS workers in California are at $14 an hour. Why would I do this work that is so hard and so emotional, when I can go make a smoothie?”

[Policy and workforce advocacy organization]

“A comprehensive caregiver assessment is critical. It connects a key caregiver to… a caregiver consultant who can talk to them about all of those things, including respite if that’s what’s appropriate. They need a guide to help them steer that ship.”

[Community-based organization]
GOAL 4: Family caregivers’ lifetime financial and employment security is protected and enhanced

Federal Actions:
- Pass federal paid family leave, expand FMLA to include small employers and a broader definition of “family.”
- Increase the availability of programs paying family caregivers to provide direct care
- Include family caregiver expenses as medical expenses available for tax credit
- Partner with private sector on a national campaign to promote caregiver-friendly workplaces
- Introduce incentives to encourage employers to adopt caregiver-friendly workplace practices, including tax incentives, voluntary certification programs and more
- Advocate for Congressional action to support an LTSS social insurance program

State, Local and Private Sector Actions:
- States should expand policies supporting working caregivers, including enhanced FMLA and paid leave policies
- States should establish tax credits for family caregivers
- Employers and state agencies should create multi-stakeholder coalitions to support employers’ efforts to recognize and support working caregivers
- Employers should incorporate caregiver friendly policies including flexible work schedules, a culture of caring, Employee-Resource Groups, benefits specific to family caregivers and more.
- Employers should be encouraged to offer benefits that make LTSS more affordable for working caregivers (e.g., respite, adult day care, caregiver training, access to care coordination support, and voluntary LTC insurance.)
“When it gets to the point of [FMLA] eligibility requirements, [I suggest] it not be restricted to biological or legal family members… the older adults could designate who is eligible to receive these supports…”

[Advocacy organization]

...even though you offer more PTO or FMLA …people still need help with the challenge at hand. I can throw PTO at people all day…. but I’m still trying to figure out how to help my family. [FMLA is] basically giving me more time to spend with them, but I still might be lost as a caregiver in terms of what I should be doing to help them, what resources I have access to, you know, trying to get through

[Employer support service provider]

“I’d like to add something to leave policies… employers shouldn’t define who a caregiver provides caregiving to. It’s not just about biology or a spousal relationship.”

[Advocacy organization for African American elders]
"Why don’t we have the tax credit for medical expenses… including all the long-term care-related ones and make it a refundable credit up to some percentage of people’s actual out-of-pocket costs?"  
[Disability advocate]

“I like the idea of that tax incentive to an employer…. Because ultimately, you're helping your employees who are going to work longer and be happier and provide better service, …. So, tax credits are probably the way to do it.”  
[Health systems provider]
GOAL 5: Family caregivers are engaged stakeholders in a national research and data gathering infrastructure that documents their experiences, translates evidence into best practices, develops person- and family-centered interventions, and measures progress toward the National Family Caregiver Strategy

Federal Actions:
- Fund research to promote the use of caregiver assessment tools
- Coordinate and support data collection and research to improve the direct care workforce
- Support research on the value of working caregivers and the value to employers of investment in workplace supports
- Support research and demonstration programs on ways to support family caregivers
- Convene a task force to develop a uniform set of data items addressing family caregivers and integrate them into existing national data collection efforts

State, Local and Private Sector Actions:
- Private sector leaders supportive of caregiver-friendly policies should identify and disseminate effective strategies
- Academics, business leaders, philanthropy and others should collaborate to build the business case for caregiver-friendly workplaces
- Health systems should link caregiver supports to patient outcomes
- States should collect more and better data on family caregiving and the LTSS workforce
- Business coalitions should encourage private sector entities to use standardized data collection tools
- Private philanthropy, hospitals systems, and academic institutions should support research to identify best practices to support the CARE Act
- Hospitals should disseminate information on best practices around family caregiver engagement
Illustrative Quotes – Goal 5

“The thing I see… is more data collection using a standardized question and definition of caregiving. The national infrastructure is not to just have caregiver surveys… but there is so much more opened up if we can piggyback even… a small number of questions into other surveys that have already been established and have additional information that we would want to find out about family caregivers.”

[Non-profit aging services provider]

“One of the best ways to increase family caregiver research… is to either require or incentivize it.”

[Health systems provider]

“[We need] research-based interventions and… studies that show [how] involving the caregivers, educating and empowering them changes outcomes.”

[Health care provider]

“It will be enlightening to see just how many people are doing this [direct care] work. Because that is really what is going to open the eyes and potentially the budgets on a state-by-state basis…learning just how few people there are doing this. …the fact that home carers work for multiple agencies is the worst kept secret in the world.”

[Home care agency]
“I think it’s fascinating to look at outcomes when it comes to screening tests. So if you have caregivers in your organization taking care of a loved one at home, they’re more likely to have missed their mammogram this year or [their] colonoscopy in 10 years. So that’s something that you can really look at that really matters to overall… utilization of preventive care. “

[Large employer]

“We need to be able to quantify that. What are those health care costs for you the employer, if you don’t provide supports for your caregiving employees? Because yes, they can be more costly. Overall, they shouldn’t be, if you provide the right benefits.”

[Large employer]
We welcome your comments, questions, and discussion!
Appendix

Detailed Work Plan Discussion Topics
# Phase II Detailed Work Plan

<table>
<thead>
<tr>
<th>Population</th>
<th>Topics</th>
<th>Key Informant Interviews</th>
<th>Listening Sessions</th>
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<tbody>
<tr>
<td>Employers (including intermediaries, academics, and public policy representatives)</td>
<td>Financial and workplace accommodations: Strategies for advancing caregiver-friendly workplaces; How are the needs of diverse caregivers met? Making and disseminating the business case; Identifying and overcoming barriers; Strategies for making policy change.</td>
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<tr>
<td>Respite Care</td>
<td>Supply side issues: Increase the supply of quality, appropriate respite services; Expand use of vetted volunteers and volunteerism; Demand side issues: Raise awareness and acceptance of respite care; Identify barriers and strategies.</td>
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<tr>
<td>LTSS Providers/Direct Care Workforce</td>
<td>What will it take to grow, strengthen and sustain the direct care workforce? Meet with representatives of organizations that work with, support, advocate for and understand the direct care workforce, Explore strategies such as expanding the use of volunteers; strengthening the paid LTSS workforce; creating career ladders; and more</td>
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### Phase II Detailed Work Plan (2)

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<th>Key Informant Interviews</th>
<th>Listening Sessions</th>
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<tbody>
<tr>
<td>Health Care providers</td>
<td>How to include the family caregiver in the health care process. Explore with representatives from health care provider organizations and institutions that can provide insight into the implementation of the CARES Act in the 45 states where it is in place. While intended to provide inclusion for the family caregiver in their loved one’s health care, what do we know about whether and how it is working? What improvements are needed? How can we better identify and integrate the family caregiver as a partner in the care team?</td>
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<td>Counties</td>
<td>What specific resources and policy changes do counties need to better support family caregivers? How are counties supporting family caregivers through family-friendly workplaces?</td>
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### Phase II Detailed Work Plan (3)

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<th>Key Informant Interviews</th>
<th>Listening Sessions</th>
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<tr>
<td>Community-based and Faith-based Organizations (CBOs and FBOs)</td>
<td>Understand how CBOs/FBOs support family caregivers, including racially, ethnically and linguistically diverse populations; identify how they can more effectively address family caregiver needs. Are there examples of best practices? What are the biggest challenges? What is the role of FBOs in providing and expanding volunteerism to fill caregivers needs? Understand the unique aspects, benefits and limitations of these organizations as they support family caregiving. Identify how they engage diverse caregivers (e.g., grandparents/kinship care, non-English speakers, LGBTQ, etc.)</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Geographically-based Listening Sessions: Rural CBOs Urban/Suburban CBOs</td>
<td>Explore models of cooperation and collaboration and how CBOs do caregiver outreach and referrals to care. Issues explored as described above.</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Population-specific Listening Sessions with CBOs</td>
<td>Specific sessions to explore these issues with organizations specifically serving the following populations: Aging, Disability, Indigenous communities, People of Color and Faith-Based Organizations</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>16</td>
<td>17</td>
</tr>
</tbody>
</table>
Break
Panel Presentation & Discussion - Family Caregiver Employment and Financial Preparedness: Considerations for the National Strategy Presentation

Dr. Jennifer Olsen – RCI – Working While Caring
Greg Olsen – NYSOFA – NY’s Employer and Caregiver Campaign
Alzheimer’s Association – Financial Literacy and Preparedness
Employment Findings

Dr. Jennifer Olsen
Chief Executive Officer
Roslyn Carter Institute for Caregivers (RCI)
Working While Caring

Jennifer Olsen, DrPH

January 25, 2022
Applying a public health framework
We’ve gathered data of employed caregiver challenges through two national surveys

**PREVALENCE OF EMPLOYEE CAREGIVERS:**

**ONE IN FIVE**

full-time workers cares for a family member who is ill, aging, or disabled

**WORKPLACE EFFECTS:**

Nearly 20% had to quit their job

More than 40% had to go part-time
The biggest challenge for family caregivers who are employed full-time is the emotional stress of handling both their job and caregiving responsibilities.

### Biggest Challenges – Ranked by 1st Choice

<table>
<thead>
<tr>
<th>Challenge</th>
<th>1st Choice</th>
<th>Combined 1st/2nd Choices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional stress of handling both job and caregiving responsibilities</td>
<td>39%</td>
<td>62%</td>
</tr>
<tr>
<td>Too time-consuming handling both job and caregiving responsibilities</td>
<td>14%</td>
<td>24%</td>
</tr>
<tr>
<td>Lack of time for self-care</td>
<td>13%</td>
<td>27%</td>
</tr>
<tr>
<td>Difficulty with scheduling loved one’s doctor’s appointment/treatments around job</td>
<td>9%</td>
<td>20%</td>
</tr>
<tr>
<td>Dealing with interruptions or distractions related to my loved one’s care while at work</td>
<td>6%</td>
<td>16%</td>
</tr>
<tr>
<td>Lack of a support system/assistance at home with caring for loved one</td>
<td>5%</td>
<td>12%</td>
</tr>
<tr>
<td>Difficulty affording care for loved one</td>
<td>4%</td>
<td>10%</td>
</tr>
<tr>
<td>Unable to get time off work or other accommodations from employer to care for your loved one</td>
<td>3%</td>
<td>9%</td>
</tr>
<tr>
<td>Employer, supervisor, or co-workers not understanding your situation</td>
<td>3%</td>
<td>9%</td>
</tr>
<tr>
<td>Unable to keep up with job demands or standards of performance at work</td>
<td>3%</td>
<td>8%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
<td>2%</td>
</tr>
</tbody>
</table>

What would you say is/was the biggest challenge with being employed full-time and managing care for your loved one? / And what is/was the next biggest challenge with being employed full-time and managing caring for your loved one?
Employed family caregivers are experiencing many of these situations frequently or sometimes while caring for their loved one and being employed full-time:

<table>
<thead>
<tr>
<th>% Total Happens – Ranked By National Caregivers</th>
<th>National Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had to leave work early or unexpectedly</td>
<td>73%</td>
</tr>
<tr>
<td>Had to call out from work for one day</td>
<td>70%</td>
</tr>
<tr>
<td>Did not take on additional responsibilities or projects</td>
<td>68%</td>
</tr>
<tr>
<td>Felt the quality or timeliness of your work suffered</td>
<td>60%</td>
</tr>
<tr>
<td>Had to take two or more days off in a row from work</td>
<td>59%</td>
</tr>
<tr>
<td>Experienced a loss of income due to having to miss work</td>
<td>52%</td>
</tr>
<tr>
<td>Were unable to complete a job function, responsibility, or task</td>
<td>49%</td>
</tr>
<tr>
<td>Had to postpone, reschedule, miss, or cancel your loved one’s doctor’s appointment or treatment because of work</td>
<td>49%</td>
</tr>
<tr>
<td>Did not seek a promotion</td>
<td>48%</td>
</tr>
<tr>
<td>Experienced strained relationships at work with co-workers or supervisors</td>
<td>46%</td>
</tr>
<tr>
<td>Experienced stigma/prejudice from your supervisor or co-workers</td>
<td>39%</td>
</tr>
<tr>
<td>Experienced stigma/prejudice from your employer</td>
<td>38%</td>
</tr>
</tbody>
</table>

Thinking some more about your experiences caring for your loved one while being employed full-time... Thinking only about the last one-year time period when you were employed full-time while caring for your loved one, please record on average how often, if at all you felt typically experience/experienced each of the items listed below:
Biggest challenge, generational differences and financial impacts

**BIGGEST CHALLENGE:**

Their biggest challenge by far was the emotional stress of trying to balance work with caregiving responsibilities.

**GENERATIONAL DIFFERENCES:**

The survey found significant differences by age, race, income, and business size when it looked at how caregiving affected work.

**FINANCIAL IMPACTS:**

More than half said they lost income due to missing work and nearly half said they passed up opportunities for promotions.

Low-wage workers are most at risk of losing their jobs.
Younger employed caregivers and people of color are more likely to report quitting, reducing their hours or staying in their job longer than they wanted in order to care for their loved one.

<table>
<thead>
<tr>
<th>National Caregivers - %Yes</th>
<th>National Caregivers</th>
<th>Ages 18-44 (43%)</th>
<th>Ages 45-54 (24%)</th>
<th>Ages 55-70 (33%)</th>
<th>Non-Hispanic Whites (68%)</th>
<th>People of Color (32%)</th>
<th>Hispanics (13%)</th>
<th>Blacks (12%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quit job</td>
<td>19%</td>
<td>23%</td>
<td>20%</td>
<td>14%</td>
<td>16%</td>
<td>26%</td>
<td>30%</td>
<td>21%</td>
</tr>
<tr>
<td>Reduce hours or go part-time</td>
<td>44%</td>
<td>57%</td>
<td>40%</td>
<td>29%</td>
<td>39%</td>
<td>54%</td>
<td>67%</td>
<td>53%</td>
</tr>
<tr>
<td>Staying in your job longer than you may have wanted</td>
<td>40%</td>
<td>46%</td>
<td>39%</td>
<td>33%</td>
<td>36%</td>
<td>47%</td>
<td>55%</td>
<td>46%</td>
</tr>
</tbody>
</table>
## Caregiving Impact on Job Decisions by Education, Income, Pay and Size of Company

<table>
<thead>
<tr>
<th>National Caregivers - %Yes</th>
<th>HS or Less (18%)</th>
<th>Total &lt; College (49%)</th>
<th>College + (51%)</th>
<th>&lt;$40K (24%)</th>
<th>$40K - $80K (36%)</th>
<th>$80K+ (40%)</th>
<th>Salary (39%)</th>
<th>Hourly (53%)</th>
<th>&lt;50 Employees (27%)</th>
<th>50-500 Employees (34%)</th>
<th>501+ Employees (39%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Quit job</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35%</td>
<td>25%</td>
<td>14%</td>
<td>28%</td>
<td>21%</td>
<td>12%</td>
<td>11%</td>
<td>26%</td>
<td>24%</td>
<td>17%</td>
<td>18%</td>
<td></td>
</tr>
<tr>
<td><strong>Reduce hours or go part-time</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45%</td>
<td>47%</td>
<td>41%</td>
<td>57%</td>
<td>47%</td>
<td>33%</td>
<td>31%</td>
<td>54%</td>
<td>52%</td>
<td>45%</td>
<td>37%</td>
<td></td>
</tr>
<tr>
<td><strong>Staying in your job longer than you may have wanted</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>49%</td>
<td>42%</td>
<td>38%</td>
<td>47%</td>
<td>39%</td>
<td>37%</td>
<td>30%</td>
<td>48%</td>
<td>35%</td>
<td>44%</td>
<td>40%</td>
<td></td>
</tr>
</tbody>
</table>
We’re raising up the context of care with employers:

**IT’S NOT EASY BEING A CAREGIVER**

Caregiving is a **multifaceted and varied experience** and there are substantial differences across workplaces and workforces.

**OUR HEALTHCARE SYSTEM IS FRAGMENTED + EXPENSIVE**

While the private sector can do more to recognize and support their employee caregivers, **they cannot solve all the challenges** stemming from the fragmented and expensive long-term care system in the U.S.
RCI is taking action:

WE’RE PARTNERING WITH EMPLOYERS

With a goal of **piloting and evaluating a range of benefits** that could aid full-time employees in distinct industry sectors who are caring for a loved one at home.

WHAT EMPLOYERS CAN DO

Employers can be **an influential voice in advancing structural public policy reforms** that move caregiver concerns from the margins to the center, resulting in a healthier, engaged, and productive workforce.
We need a better understanding of:

- Employee caregiver preferences
- Availability of supportive services
- Variables, characteristics and supports
- A roadmap for employee caregivers
Thank You

Twitter: @RCICaregiving
Linked In: RCI Caregiving
Email: jennifer@rosalynncarter.org
NYSOFA Caregiver Initiative

Greg Olsen
Director, New York State Office For the Aging
NYSOFA Caregiver Initiative

A coordinated program to identify working caregivers in need and connect them to existing and funded services

Greg Olsen
Director
New York State Office for the Aging
Purpose of Initiative

1. To help HR departments understand the impact of caregiving on employees and to provide resources to link to services

2. To understand better the impact of caregiving on employees from their perspective, who, what where, how often, tasks, etc

3. To assess CaregivingIntensity and link to resources

4. To make caregiving a statewide, all systems issue – public and private sector – top levels of state government – all agencies
Why Now?

Caregivers are defined as family, friends and neighbors who provide a variety of tasks to help an individual with their daily living. ANY CARE COUNTS

• There are an estimated 4.1 million caregivers in New York State who provide 2.68 billion hours of unpaid care that if paid for at the market rate, would cost $32 billion annually.

• In the U.S. today, one in six employees is a caregiver for a relative or friend and spends on average more than 20 hours a week providing some kind of care.

• The costs of caregiving to business and industry exceed $50 billion annually

The percentage of adult children providing hands on tasks to a loved one to help them remain independent such as personal care, grocery shopping and meal preparation, transportation, assistance with medical and other appointments and/or financial assistance to a parent has more than tripled during the past 15 years.
Why Now? – CDC Data

- 90%+ of HR departments want to do more to support working caregivers but are not sure what to do
- 85% of caregivers with children and caring for an older person experienced mental health symptoms – 52% reported suicidal thoughts
- 75% of people trust their employer and are more likely to use information provided by their employer
- 70% of working caregivers suffer work related difficulties due to their dual roles
- 70% of working caregivers reported at least one mental health symptom (anxiety, depression, suicidal thoughts, COVID induced trauma)
- 69% of caregivers report having to rearrange their work schedule, decrease their hours, or take unpaid leave in order to meet responsibilities
Why Now? – CDC Data

• 61% of caregivers worry about caring for a family member, friend or neighbor
• 55% don’t self identify as caregivers
• 50% use food to cope and reduce stress
• 49% of working caregivers report arriving to work late, leaving early or taking time off
• 33% use substances to cope vs. 6% of general population
• 31% contemplated suicide vs. 3% of general population
• 15% have taken a leave of absence
• 14% switched from full-time to part-time
• 10% left the workforce completely


3. Distribute the Caregiver Intensity Index to Employees - [https://www.archangels-cii.me/weloveworthyork/](https://www.archangels-cii.me/weloveworthyork/)
## Employed Family Caregiver Survey

**Number of employees who responded to survey:** 88  
**Deployment dates:** September 6 - September 13, 2019  
**Proportion of caregivers among employees surveyed:** 60%, 53/88

### Profile of Caregiving Employees

1. **Have you provided any of the following tasks for an adult (18 years or older) family member or friend who is chronically ill, disabled, aged, or frail in the past 6 months? (Check all that apply)**

<table>
<thead>
<tr>
<th>Task</th>
<th>Answer (n=53)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Driving to doctor appointments or other services</td>
<td>73.68</td>
<td></td>
</tr>
<tr>
<td>Completing forms or documents (legal, insurance)</td>
<td>71.70</td>
<td></td>
</tr>
<tr>
<td>Housekeeping tasks (cleaning, laundry)</td>
<td>58.49</td>
<td></td>
</tr>
<tr>
<td>Assisting with home maintenance, repairs or yard work</td>
<td>56.60</td>
<td></td>
</tr>
<tr>
<td>Grocery shopping</td>
<td>52.83</td>
<td></td>
</tr>
<tr>
<td>Arranging or preparing meals</td>
<td>45.28</td>
<td></td>
</tr>
<tr>
<td>Assisting with bill payment</td>
<td>33.96</td>
<td></td>
</tr>
<tr>
<td>Assisting with medications (setup, dosing)</td>
<td>32.08</td>
<td></td>
</tr>
<tr>
<td>Providing personal care (bathing, dressing, feeding)</td>
<td>26.42</td>
<td></td>
</tr>
<tr>
<td>Arranging services for long distance friend or relative</td>
<td>18.87</td>
<td></td>
</tr>
</tbody>
</table>

2. **For how many adults do you currently provide care?**

<table>
<thead>
<tr>
<th>Number of Adults</th>
<th>Answer (n=49)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>67.35</td>
<td></td>
</tr>
<tr>
<td>Two</td>
<td>30.61</td>
<td></td>
</tr>
<tr>
<td>Three</td>
<td>2.04</td>
<td></td>
</tr>
<tr>
<td>Four</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Five or More</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>

3. **Is the person you are providing care for a:**

<table>
<thead>
<tr>
<th>Person</th>
<th>Answer (n=49)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent or Parent-in-Law</td>
<td>67.35</td>
<td></td>
</tr>
<tr>
<td>Grandparent</td>
<td>10.20</td>
<td></td>
</tr>
<tr>
<td>Other Relative</td>
<td>6.12</td>
<td></td>
</tr>
<tr>
<td>Friend</td>
<td>6.12</td>
<td></td>
</tr>
<tr>
<td>Brother or Sister</td>
<td>2.04</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>4.08</td>
<td></td>
</tr>
<tr>
<td>Adult Child</td>
<td>2.04</td>
<td></td>
</tr>
<tr>
<td>Neighbor</td>
<td>2.04</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>
4. Are you the primary caregiver for the individual indicated above?

<table>
<thead>
<tr>
<th>Answer (n=49)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>57.14</td>
</tr>
<tr>
<td>Yes</td>
<td>42.86</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
</tr>
</tbody>
</table>

5. Does this person have a memory impairment, such as Alzheimer's Disease or another form of dementia?

<table>
<thead>
<tr>
<th>Answer (n=49)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>77.55</td>
</tr>
<tr>
<td>Yes</td>
<td>22.45</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
</tr>
</tbody>
</table>

6. Where does the person for whom you have caregiving responsibility live?

<table>
<thead>
<tr>
<th>Answer (n=49)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>In own residence 63.27</td>
<td></td>
</tr>
<tr>
<td>With you           12.24</td>
<td></td>
</tr>
<tr>
<td>In a care facility (nursing home, assisted living facility, etc.) 10.20</td>
<td></td>
</tr>
<tr>
<td>With another family member 12.24</td>
<td></td>
</tr>
<tr>
<td>with an unrelated person, such as a friend 0</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
</tr>
</tbody>
</table>

7. How far from you does the person for whom you have caregiving responsibility live?

<table>
<thead>
<tr>
<th>Answer (n=45)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than an hour away 84.44</td>
<td></td>
</tr>
<tr>
<td>One hour or more away 15.56</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
</tr>
</tbody>
</table>

8. How long have you been providing care for this person?

<table>
<thead>
<tr>
<th>Answer (n=49)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than one year 20.41</td>
<td></td>
</tr>
<tr>
<td>1-5 years 51.02</td>
<td></td>
</tr>
<tr>
<td>6-10 years 18.37</td>
<td></td>
</tr>
<tr>
<td>11-15 years 6.12</td>
<td></td>
</tr>
<tr>
<td>16 years or more 4.08</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
</tr>
</tbody>
</table>

9. In a typical week, about how many hours of care do you provide for this person?

<table>
<thead>
<tr>
<th>Answer (n=49)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 7 hours per week 69.39</td>
<td></td>
</tr>
<tr>
<td>8-14 hours per week 14.29</td>
<td></td>
</tr>
<tr>
<td>15-21 hours per week 10.20</td>
<td></td>
</tr>
<tr>
<td>22 hours or more per week 6.12</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
</tr>
</tbody>
</table>
## Effects of Caregiving Responsibilities on Employment

11. When was the last time you were able to take a vacation that allowed you time away from your caregiving responsibilities?

<table>
<thead>
<tr>
<th>Answer (n=48)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 6 months ago</td>
<td>64.58</td>
</tr>
<tr>
<td>Between 6 - 12 months ago</td>
<td>18.75</td>
</tr>
<tr>
<td>Between 13 months- 2 years ago</td>
<td>6.25</td>
</tr>
<tr>
<td>More than 2 years ago</td>
<td>10.42</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
</tr>
</tbody>
</table>

12. In the past year, have your caregiving responsibilities caused you to: (*Check all that apply)*

<table>
<thead>
<tr>
<th>Answer (n=42)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leave work early</td>
<td>59.52</td>
</tr>
<tr>
<td>Respond to calls or emergencies during work hours</td>
<td>59.52</td>
</tr>
<tr>
<td>Be at work but feel unable to focus</td>
<td>50.00</td>
</tr>
<tr>
<td>Miss days of work</td>
<td>47.62</td>
</tr>
<tr>
<td>Use break or lunch times to arrange for caregiving services</td>
<td>47.62</td>
</tr>
<tr>
<td>Rearrange your work schedule</td>
<td>45.24</td>
</tr>
<tr>
<td>Arrive at work late</td>
<td>30.98</td>
</tr>
<tr>
<td>Consider changing employer</td>
<td>11.90</td>
</tr>
<tr>
<td>Cut hours of work</td>
<td>7.14</td>
</tr>
<tr>
<td>Take leave of absence</td>
<td>4.76</td>
</tr>
<tr>
<td>Consider leaving work entirely</td>
<td>4.76</td>
</tr>
<tr>
<td>Turn down work-related travel</td>
<td>2.38</td>
</tr>
<tr>
<td>Turn down a promotion</td>
<td>0</td>
</tr>
<tr>
<td>Turn down work relocation</td>
<td>0</td>
</tr>
</tbody>
</table>
# Employee Demographics

## 17. Gender

<table>
<thead>
<tr>
<th>Answer</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>88.89</td>
</tr>
<tr>
<td>Male</td>
<td>8.64</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>2.47</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100</td>
</tr>
</tbody>
</table>

## 18. Age

<table>
<thead>
<tr>
<th>Answer</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>25 and under</td>
<td>2.47</td>
</tr>
<tr>
<td>26-35</td>
<td>17.28</td>
</tr>
<tr>
<td>36-45</td>
<td>14.81</td>
</tr>
<tr>
<td>46-55</td>
<td>25.93</td>
</tr>
<tr>
<td>56-65</td>
<td>22.22</td>
</tr>
<tr>
<td>66-75</td>
<td>11.11</td>
</tr>
<tr>
<td>76 and older</td>
<td>0</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>6.17</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100</td>
</tr>
</tbody>
</table>

## 19. Number of years employed by organization

<table>
<thead>
<tr>
<th>Answer</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than one year</td>
<td>12.35</td>
</tr>
<tr>
<td>1-5 years</td>
<td>43.21</td>
</tr>
<tr>
<td>6-10 years</td>
<td>11.11</td>
</tr>
<tr>
<td>11-15 years</td>
<td>16.05</td>
</tr>
<tr>
<td>16-20 years</td>
<td>4.94</td>
</tr>
<tr>
<td>21 - 25 years</td>
<td>4.94</td>
</tr>
<tr>
<td>26-30 years</td>
<td>2.47</td>
</tr>
<tr>
<td>31 years or more</td>
<td>0</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>4.94</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100</td>
</tr>
</tbody>
</table>
1. University of Wisconsin Survey Closed Down, November 30th
   - NYSOFA replicating survey for continued use in NYS via Survey Monkey
   - https://www.surveymonkey.com/r/WorkingCaregiverSurvey


3. Develop online training to self identify as caregivers – public and private sector

3. Continue to speak with Workforce Development Boards and Businesses statewide to participate in survey – data collection

4. Work with Insurance Brokers to Connect to Businesses

5. Analyze Data – make recommendation - organize
Financial Literacy and Preparedness

Monica Moreno
Senior Director of Care and Support
Alzheimer’s Association

Dr. Katherine Judge
Professor of Psychology
Cleveland State University

Financial Literacy and Preparedness
Financial Literacy and Preparedness

January 25th, 2022

This project was supported, in part by grant number 90PPFL0001-01-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201.
The Impact

- Approximately 41.8 million adults provide informal care to an adult 50 years old or older

- Estimated time is 34 billion hours and cost is $470 billion per year

- Negative impacts:
  - significant out-of-pocket expenses
  - declines in income and savings
  - lost pension and entitlement benefits
  - decreases in future earnings
  - work-related strains
  - well-being (e.g., distress, burden, depression and anxiety symptoms)

- Difficulties have been amplified by challenges faced during the COVID-19 pandemic

- Several caregiver sub-groups differentially impacted:
  - dementia
  - Women
  - lower SES
  - LGTBQ

- Significant lack of evidence-based tools and programs
The Opportunity

Identified needs of caregivers:
- Understand current and future costs
- Plan ahead
- Identify appropriate resources
- Learn how to conduct key financial and legal transactions
- Have financial conversations
- Manage financial documents
- Protection from financial abuse and fraud
Grant Overview

Cooperative agreement with Department of Health and Human Services - Administration for Community Living (ACL)

<table>
<thead>
<tr>
<th>Project Title</th>
<th>Strengthening the Financial Literacy and Preparedness of Family Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal</td>
<td>To develop, implement and evaluate a caregiver education program and related resources that helps caregivers, including those impacted by dementia, ensure their own financial well-being, and better equips them to undertake “financial caregiving” tasks on behalf of a care recipient.</td>
</tr>
<tr>
<td>Grant Period</td>
<td>September 29th, 2018 – September 28th, 2021</td>
</tr>
<tr>
<td>No Cost Extension</td>
<td>Extended to March 31, 2022</td>
</tr>
</tbody>
</table>
Managing Money: A Caregiver’s Guide to Finances

Check Your Knowledge

What percentage of caregivers have out-of-pocket costs as a result of caregiving?

47% 67% 78% 95%

Lower Risk of Abuse and Fraud

- Agree to a spending limit on credit cards.
- Create a “slush fund” account.
- Set up auto-pay for bills.
- Set up automatic notifications for withdrawals or large charges.
- Request electronic bank and credit card statements.
- Sign up for the “Do Not Call” list.
- Ask credit card companies to stop sending balance transfer checks.

Covering Care Costs

Creating a monthly budget
The first step in covering care costs is to get an overall picture of income and expenses. Use this worksheet to create a monthly budget. The next page lists additional items to consider when adding up expenses in each category. Plan to revisit this budget every few months and make updates if necessary.

MONTH OF

- List income in the gold column below.
- List expenses in the teal column on the right.
- In the purple box at the bottom of the page, subtract total expenses from total income to build a budget.

<table>
<thead>
<tr>
<th>TYPE OF EXPENSE</th>
<th>AMOUNT OUT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing (rent, mortgage, residential care)</td>
<td></td>
</tr>
<tr>
<td>In-home care and adult day services</td>
<td></td>
</tr>
<tr>
<td>Utilities (gas, water, electricity, sewage)</td>
<td></td>
</tr>
<tr>
<td>Groceries and dining out</td>
<td></td>
</tr>
<tr>
<td>Medical expenses</td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
</tr>
<tr>
<td>Education and childcare</td>
<td></td>
</tr>
<tr>
<td>Prescription drugs</td>
<td></td>
</tr>
<tr>
<td>Internet, cable, and cell phone</td>
<td></td>
</tr>
<tr>
<td>Service animals and pets</td>
<td></td>
</tr>
<tr>
<td>Debt payments</td>
<td></td>
</tr>
<tr>
<td>Personal care</td>
<td></td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
</tr>
<tr>
<td>Entertainment</td>
<td></td>
</tr>
<tr>
<td>Other expenses</td>
<td></td>
</tr>
<tr>
<td>Total expenses this month</td>
<td></td>
</tr>
</tbody>
</table>

BUILD A MONTHLY BUDGET

Total income this month - Total expenses this month = 

If the total income is more than the total expenses, there is money left to save or spend. If the total expenses are more than the total income, look for possible ways to reduce expenses. See page 7 for a list of suggestions.
Dissemination Plan

Alzheimer’s Association

- 24/7 Helpline
- Nationwide Chapter Network
- Community Partners

Other Channels

- Conferences
- Peer Reviewed Journal Article Submissions
The National Family Caregiving Strategy: Initial Framework and Development Process

Sarah Markel, PMP
Aging Service Program Specialist, AoA
Administration for Community Living
Key Sources of Input for the Strategy

• RAISE Family Caregivers Act Advisory Council report and recommendations
• SGRG Advisory Council Report and recommendations
• ACL RFI on family caregiving
• ACL analysis of key actions
• UMASS @ Boston & Community Catalyst’s “Findings from Stakeholder Listening Sessions and Key Informant interviews: Federal Actions and Actions for State, Local and Private Entities”
• Action sheets submitted by Federal agencies (next slide)
• NASHP Roadmaps
• NASHP Faculty discussions
• Council member input and feedback
Federal Actions To Support the Strategy

• Initial deadline: January 7, 2022.
• 7 agencies have submitted action sheets.
  – 282 actions received to date.
• 11 additional agencies will provide action sheets in coming weeks.
# Distribution of Federal Actions*

<table>
<thead>
<tr>
<th>Agency</th>
<th>Goal 1</th>
<th>Goal 2</th>
<th>Goal 3</th>
<th>Goal 4</th>
<th>Goal 5</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACL</td>
<td>41</td>
<td>26</td>
<td>42</td>
<td>13</td>
<td>12</td>
<td>134</td>
</tr>
<tr>
<td>ASPE</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>CDC</td>
<td>19</td>
<td>3</td>
<td>11</td>
<td>0</td>
<td>10</td>
<td>43</td>
</tr>
<tr>
<td>CFPB</td>
<td>6</td>
<td>3</td>
<td>6</td>
<td>4</td>
<td>2</td>
<td>21</td>
</tr>
<tr>
<td>CMS</td>
<td>8</td>
<td>6</td>
<td>8</td>
<td>0</td>
<td>0</td>
<td>22</td>
</tr>
<tr>
<td>HRSA</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>IHS</td>
<td>6</td>
<td>4</td>
<td>4</td>
<td>0</td>
<td>3</td>
<td>17</td>
</tr>
<tr>
<td>VA</td>
<td>8</td>
<td>5</td>
<td>8</td>
<td>2</td>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td><strong>Total Actions</strong></td>
<td><strong>92</strong></td>
<td><strong>52</strong></td>
<td><strong>86</strong></td>
<td><strong>20</strong></td>
<td><strong>32</strong></td>
<td><strong>282</strong></td>
</tr>
</tbody>
</table>

*Received by ACL as of 1/12/22.
Examples of Federal Actions Received

**Rec 1.1**
- [agency] will provide technical assistance to [entities] on developing state plans
- [agency] increase messaging through its Caregiver listservs and target specific messaging to …
- +24 more

**Rec 1.2**
- [agency] will provide ongoing support for the online Caregiving Resource library
- +20 more

**Rec 1.3**
- [3 agencies] will develop localized public messaging and outreach/training materials targeted to …
- +12 more

+20 more

+12 more
Analysis & Document Development Process

1. Review all actions submitted
2. Confirm assignment to recommendations
3. Identify patterns across types of actions
4. Identify and categorize primary actions and subordinate actions
5. Review actions for alignment with findings of consensus groups
6. Identify opportunities for expanding the proposed actions
7. Collaborate with federal agencies and council to revise/refine/expand actions
2022 National Family Caregiving Strategy Outline

- Front Matter
  - Letter
  - Vision Statement
  - Terminology
  - Acknowledgements
- Executive Summary (<4 pages)
- Introduction
- Cross-Cutting Themes
- Person-centered care
- The impact of trauma
- Diversity, equity, and inclusion
- Workforce considerations

- Strategic Actions by Goal (x5)
- The Road Ahead
- Conclusion (<3 pages)
- Appendix: Matrix of Federal Actions
Closing Remarks and Adjourn
Thank you