

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

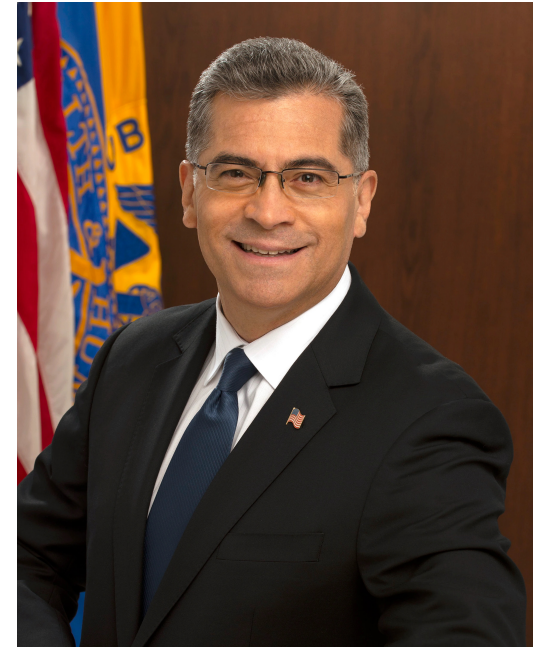
- **Primary task:** Finalize non-federal actions for the Strategy
- **Monthly meetings:** February, March, April (and TBD)
- **New subcommittees** (organized by goal):
 - Awareness and Outreach
 - Engagement and Partnership
 - Strengthening Services and Supports
 - Financial & Workplace Security
 - Data, 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

Phase II Workplan*

POPULATION/TOPIC	KEY INFORMANT INTERVIEWS	LISTENING SESSIONS
EMPLOYERS: Intermediaries, academics, HR reps, and public policy perspectives	5	3
RESPIRE CARE	3	1
LTSS PROVIDERS/DIRECT CARE WORKFORCE	2	2
HEALTH PROVIDER	3	1
COUNTIES	1	1
COMMUNITY-BASED ORGANIZATIONS (CBOs) and FAITH-BASED ORGANIZATIONS (FBOs)	3	
GEOGRAPHICALLY-BASED LISTENING SESSIONS: Rural/Urban/Suburban CBOs		2
POPULATION-SPECIFIC LISTENING SESSIONS: Aging, Disability, Indigenous communities, People of Color and Faith-Based Organization		5
Total	17	16

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]

Illustrative Quotes – Goal 2

“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 programming opportunities for respite care.

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.

Illustrative Quotes – Goal 3

“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 be 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).

Illustrative Quotes – Goal 4

“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]

Illustrative Quotes – Goal 4

“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]

Illustrative Quotes – Goal 5

“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

Population	Topics	Key Informant Interviews	Listening Sessions
Employers (including intermediaries, academics, and public policy representatives)	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.	5	3
Respite Care	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.	3	1
LTSS Providers/Direct Care Workforce	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	2	2

Phase II Detailed Work Plan (2)

Population	Topics	Key Informant Interviews	Listening Sessions
Health Care providers	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?	3	1
Counties	What specific resources and policy changes do counties need to better support family caregivers? How are counties supporting family caregivers through family-friendly workplaces?	1	1

Phase II Detailed Work Plan (3)

Population	Topics	Key Informant Interviews	Listening Sessions
Community-based and Faith-based Organizations (CBOs and FBOs)	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.)	3	
Geographically-based Listening Sessions: Rural CBOs Urban/Suburban CBOs	Explore models of cooperation and collaboration and how CBOs do caregiver outreach and referrals to care. Issues explored as described above.		2
Population-specific Listening Sessions with CBOs	Specific sessions to explore these issues with organizations specifically serving the following populations: Aging, Disability, Indigenous communities, People of Color and Faith-Based Organizations		5
Total		16	17

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)



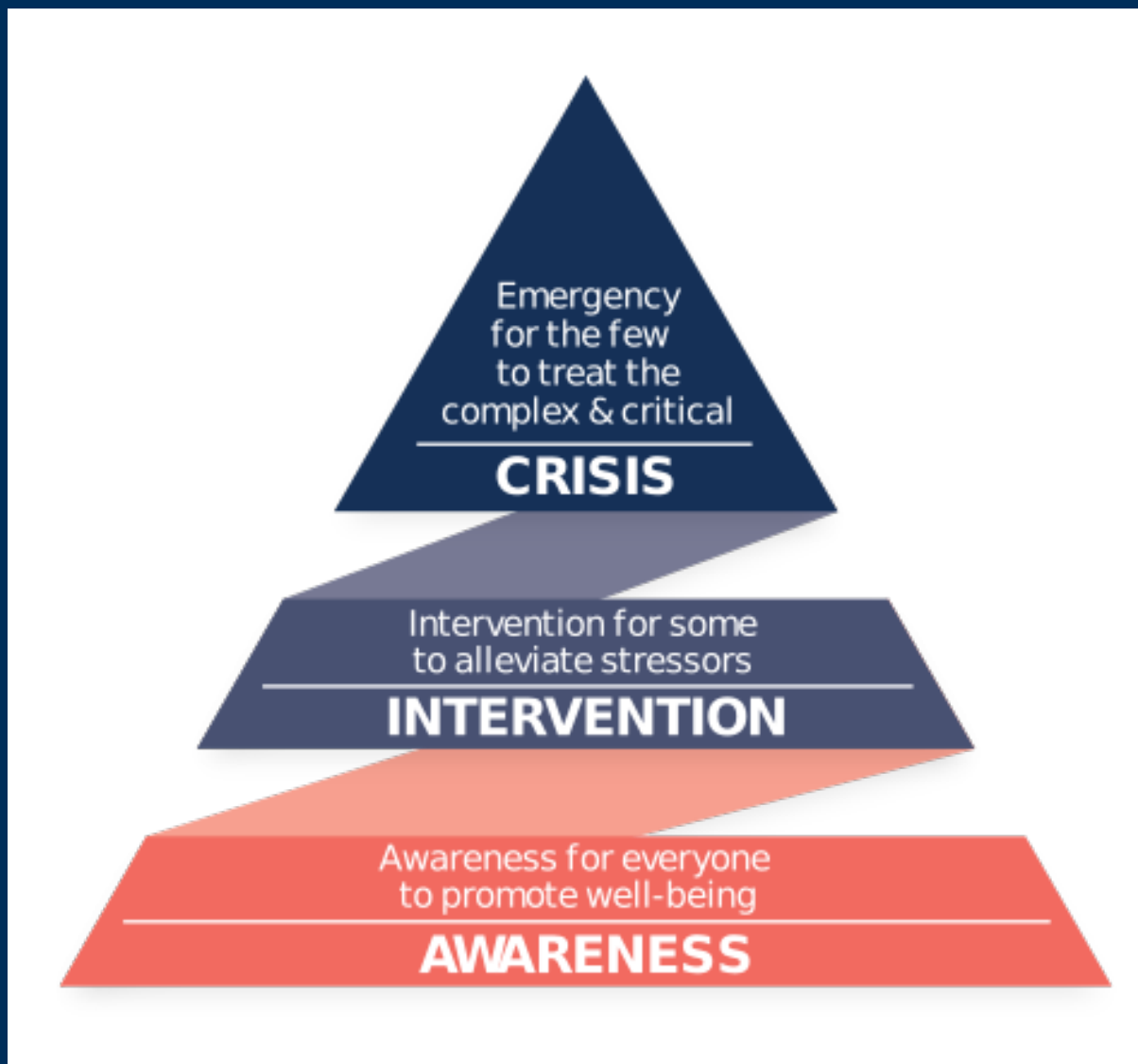
ROSALYNN **FOR**
CARTER **CAREGIVERS**
INSTITUTE 

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

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

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:

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

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.

<i>National Caregivers - %Yes</i>	National Caregivers	Ages 18-44 (43%)	Ages 45-54 (24%)	Ages 55-70 (33%)	Non-Hispanic Whites (68%)	People of Color (32%)	Hispanics (13%)	Blacks (12%)
Quit job	19%	23%	20%	14%	16%	26%	30%	21%
Reduce hours or go part-time	44%	57%	40%	29%	39%	54%	67%	53%
Staying in your job longer than you may have wanted	40%	46%	39%	33%	36%	47%	55%	46%

Caregiving Impact on Job Decisions by Education, Income, Pay and Size of Company

<i>National Caregivers - %Yes</i>	HS or Less (18%)	Total < College (49%)	College + (51%)	<\$40K (24%)	\$40K - \$80K (36%)	\$80K+ (40%)	Salary (39%)	Hourly (53%)	<50 Employees (27%)	50-500 Employees (34%)	501+ Employees (39%)
<i>Quit job</i>	35%	25%	14%	28%	21%	12%	11%	26%	24%	17%	18%
<i>Reduce hours or go part-time</i>	45%	47%	41%	57%	47%	33%	31%	54%	52%	45%	37%
<i>Staying in your job longer than you may have wanted</i>	49%	42%	38%	47%	39%	37%	30%	48%	35%	44%	40%

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

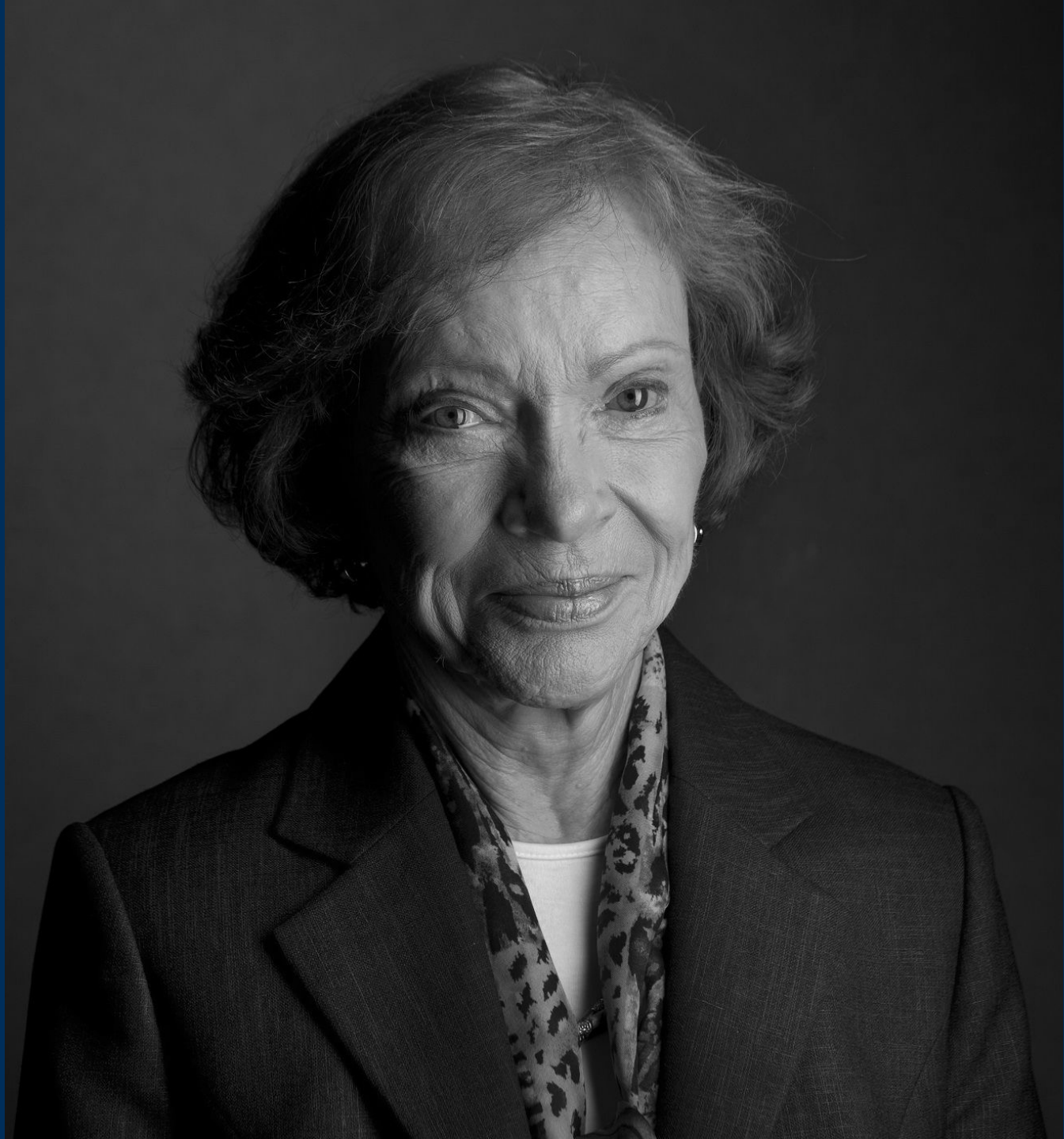
ROSALYNN **FOR**
CARTER **CAREGIVERS**
INSTITUTE 

Thank You

Twitter: [@RCICaregiving](https://twitter.com/RCICaregiving)

Linked In: [RCI Caregiving](https://www.linkedin.com/company/rci-caregiving)

Email: jennifer@rosalynncarter.org



NYSOFA Caregiver Initiative

Greg Olsen

Director, New York State Office For the Aging





**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 Caregiving Intensity 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

The Ask

1. Share the Caregivers in the Workplace Guide with HR Departments and Staff - https://aging.ny.gov/system/files/documents/2021/04/rgb-4_21-final.pdf
2. Distribute the Working Caregivers Survey to Employees - <https://www.surveymonkey.com/r/WorkingCaregiverSurvey>
3. Distribute the Caregiver Intensity Index to Employees - <https://www.archangels-cii.me/welovenewyork/>

One Organizations Results – 100 Employees



Lifespan

Delivering health with care.®

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)

	Answer (n=53)	%
Driving to doctor appointments or other services		73.58
Completing forms or documents (legal, insurance)		71.70
Housekeeping tasks (cleaning, laundry)		58.49
Assisting with home maintenance, repairs or yard work		56.60
Grocery shopping		52.83
Arranging or preparing meals		45.28
Assisting with bill payment		33.96
Assisting with medications (setup, dosing)		32.08
Providing personal care (bathing, dressing, feeding)		26.42
Arranging services for long distance friend or relative		18.87

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

	Answer (n=49)	%
One		67.35
Two		30.61
Three		2.04
Four		0
Five or More		0
Total		100

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

	Answer (n=49)	%
Parent or Parent-in-Law		67.35
Grandparent		10.20
Other Relative		6.12
Friend		6.12
Brother or Sister		2.04
Spouse		4.08
Adult Child		2.04
Neighbor		2.04
Total		100

4. Are you the primary caregiver for the individual indicated above?	Answer (n=49)	%
	No	57.14
	Yes	42.86
	Total	100
5. Does this person have a memory impairment, such as Alzheimer's Disease or another form of dementia?	Answer (n=49)	%
	No	77.55
	Yes	22.45
	Total	100
6. Where does the person for whom you have caregiving responsibility live?	Answer (n=49)	%
	In own residence	63.27
	With you	12.24
	In a care facility (nursing home, assisted living facility, etc.)	10.20
	With another family member	12.24
	with an unrelated person, such as a friend	0
	Total	100
7. How far from you does the person for whom you have caregiving responsibility live?	Answer (n=45)	%
	Less than an hour away	84.44
	One hour or more away	15.56
	Total	100
8. How long have you been providing care for this person?	Answer (n=49)	%
	Less than one year	20.41
	1-5 years	51.02
	6 - 10 years	18.37
	11 - 15 years	6.12
	16 years or more	4.08
	Total	100
9. In a typical week, about how many hours of care do you provide for this person?	Answer (n=49)	%
	0 - 7 hours per week	69.39
	8 - 14 hours per week	14.29
	15 - 21 hours per week	10.20
	22 hours or more per week	6.12
	Total	100

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?

	Answer (n=48)	%
Less than 6 months ago		64.58
Between 6 - 12 months ago		18.75
Between 13 months- 2 years ago		6.25
More than 2 years ago		10.42
Total		100

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

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

Employee Demographics

17. Gender

	Answer (n=81)	%
	Female	88.89
	Male	8.64
	Prefer not to answer	2.47
	Total	100

18. Age

	Answer (n=81)	%
	25 and under	2.47
	26-35	17.28
	36 – 45	14.81
	46-55	25.93
	56-65	22.22
	66-75	11.11
	76 and older	0
	Prefer not to answer	6.17
	Total	100

19. Number of years employed by organization

	Answer (n=81)	%
	Less than one year	12.35
	1-5 years	43.21
	6-10 years	11.11
	11-15 years	16.05
	16-20 years	4.94
	21 - 25 years	4.94
	26-30 years	2.47
	31 years or more	0
	Prefer not to answer	4.94
	Total	100

Status

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>
2. Multi-Agency Push to get Surveys and Business Guide Out – December onward
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

alzheimer's  association®

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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)

Project Title	<i>Strengthening the Financial Literacy and Preparedness of Family Caregivers</i>
Goal	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.
Grant Period	September 29 th , 2018 – September 28 th , 2021
No Cost Extension	Extended to March 31, 2022

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.

Activity



Hear From a Caregiver



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 _____

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

TYPE OF INCOME	AMOUNT IN
Job	
Social Security	
Disability benefits	
Long-term care insurance	
Other income	
Total income this month	

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

BUILD A MONTHLY BUDGET

$$\boxed{} - \boxed{} = \boxed{}$$

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



Article

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

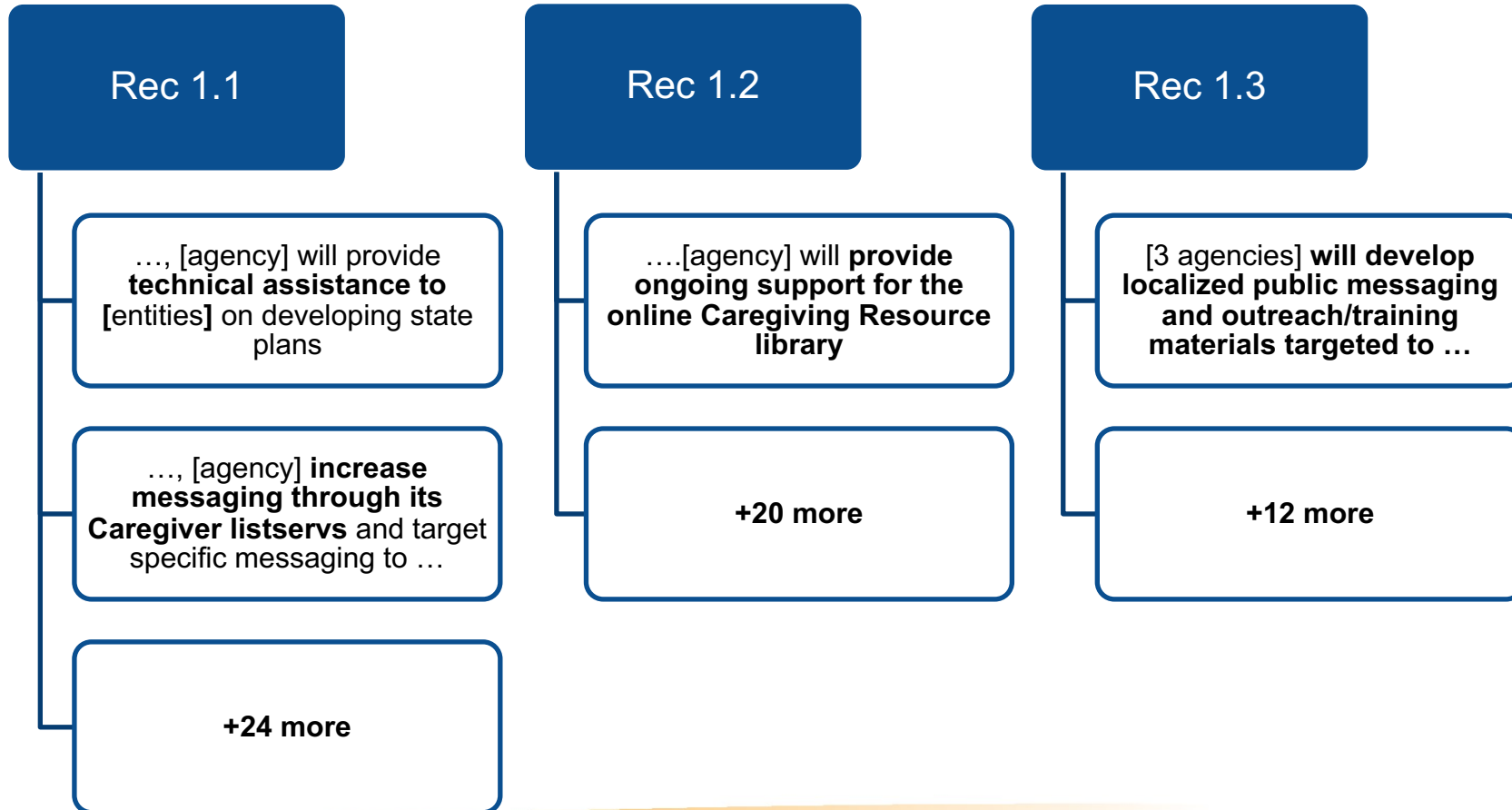
- Initial deadline: January 7, 2022.
- 7 agencies have submitted action sheets.
 - 282 actions received to date.
- 11 additional agencies will provide action sheets in coming weeks.

Distribution of Federal Actions*

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

*Received by ACL as of 1/12/22.

Examples of Federal Actions Received



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

