

Joint Meeting of the RAISE & SGRG Advisory Councils

September 19, 2023

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at the bottom of your screen.**



Call to Order

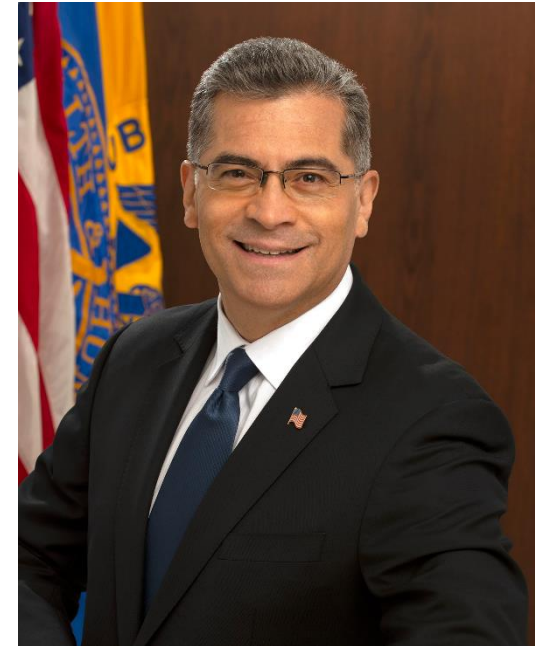


Alison Barkoff

Senior Official Performing the duties of
Administrator and Assistant Secretary for Aging
Principal Deputy Administrator

HHS Secretary Welcoming Remarks

Honorable Xavier Becerra
Secretary of Health and Human Services



Welcoming Remarks

Announcement of Council Co-Chairs



Alison Barkoff

Senior Official Performing the duties of
Administrator and Assistant Secretary for Aging
Principal Deputy Administrator

Roll Call

Council Collaborators

Overview of Resources



The
John A. Hartford
Foundation



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

*Public-Private Collaboration to Support the National
Strategy to Support Family Caregivers*

September 19, 2023



Rani E. Snyder, MPA
*Vice President, Program
The John A. Hartford Foundation*



The
John A. Hartford
Foundation

A private philanthropy
based in New York City,
established by family
owners of the A&P
grocery chain in 1929



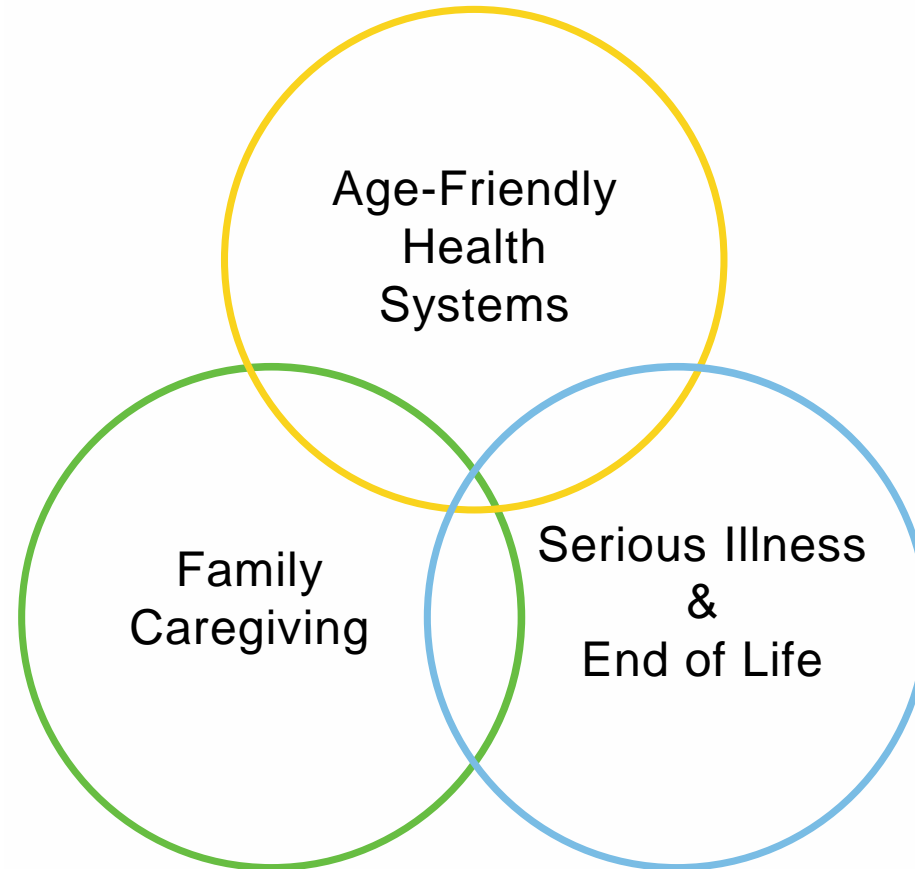
Mission & Priorities



The
John A. Hartford
Foundation

DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS

PRIORITY AREAS



NASHP: The RAISE Act Family Caregiver Resource and Dissemination Center



The
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Foundation

Supporting work of the RAISE Act Advisory Council assembled by the Administration for Community Living

- Research policies and evidence-based programs, convene experts, provide information to the public
- Test the Advisory Council's recommendations for family caregiving policies and programs in select states
- National Strategy released in September 2022

OCTOBER 2022

Supporting Family Caregivers: A Roadmap for States

The 2022 National Strategy to Support Family Caregivers provides a roadmap for states to better support family caregivers. This overview highlights policy strategies and promising practices for states.

The Challenge

The pandemic heightened reliance on family caregivers and the shortage of direct care workers who provide care. States are being called upon to address these crises.

A Historic Solution

The [National Strategy to Support Family Caregivers](#), as required by the RAISE Act, was presented to the U.S. Congress in September 2022. The strategy lays out actions — by federal and state governments, communities, employers, and others — to increase recognition and support for family caregivers.

State Roadmap

To inform the National Strategy, the National Academy for State Health Policy (NASHP) created the [RAISE Act State Policy Roadmap for Family Caregivers](#). The roadmap helps states interested in expanding supports for family caregivers by offering the following policy strategies and promising practices.

NASHP | NATIONAL ACADEMY
FOR STATE HEALTH POLICY

<https://nashp.org/policy/aging-and-disabilities/family-caregiving/>

A Public-Private Collaboration to RAISE Up Family Caregivers



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RAISE Act Family
Caregiver
Implementation
and Technical
Assistance Center



ActOnRAISE.org





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Thank You!

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DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS

Supporting Implementation of the National Strategy

*RAISE & SGRG Councils Meeting
September 19, 2023*



The
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nashp.org

Wendy Fox-Grage

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National Academy for State Health Policy

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About NASHP

The National Academy for State Health Policy (NASHP) is a nonpartisan, nonprofit organization committed to developing and advancing state health policy innovations and solutions.

NASHP provides a unique forum for the productive exchange of strategies across state government, including the executive and legislative branches.




RAISE Family Caregiver Resource and Dissemination Center

HOME < AGING AND DISABILITIES < FAMILY CAREGIVING

TOPIC

Family Caregiving


The RAISE Act Family Caregiver Resource and Dissemination Center



SHARE ↗

Across the nation, state health programs depend on caregivers who provide critical support to help relatives, friends, and neighbors age in place while contributing about [\\$470 billion in unpaid health care services](#). To better support family caregivers, Congress passed the [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregivers Act](#) in 2018, which established the Family Caregiving Advisory Council tasked with creating the country's first national Family Caregiver Strategy. NASHP supports the council's work by providing resources, convening experts, and supporting states as they develop policies.

Funded by:
The John A. Hartford Foundation



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nashp.org/family-caregiving

Featured Content



[Roadmap for Family Caregivers](#)



[The Family Caregiving Advisory Council and Faculty](#)



[Council Meeting Materials and Resources](#)



[State Resources](#)



[Respite Care](#)

SupportCaregiving.org



RESOURCE GUIDES ▾

ABOUT

WHO WE ARE



A new, first-of-its-kind [National Strategy to Support Family Caregivers](#) provides hundreds of actions that federal, state, and local governments, businesses, and communities can take to support caregivers.

Explore the resource guides on this site to find out what you can do to help caregivers achieve the balance and stability they need for their families – and for themselves.

SupportCaregiving.org

What You Can Do

We all can work together to lighten the load for family caregivers. Explore the resource guides on this site for strategies that you can take to better support family caregivers.

Each guide provides concrete actions for a specific source of potential caregiver support – check back here as more are added!

Resources for:

[Family Caregivers >](#)

[Employers >](#)

[Funders >](#)

[Managed Care Plans >](#)

Resources for State Officials:

[Respite Care >](#)

[Direct Care Workforce >](#)

[State Policy Strategies >](#)



SupportCaregiving.org



Thank you!



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FOR STATE HEALTH POLICY

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NASHP | National
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Health Policy



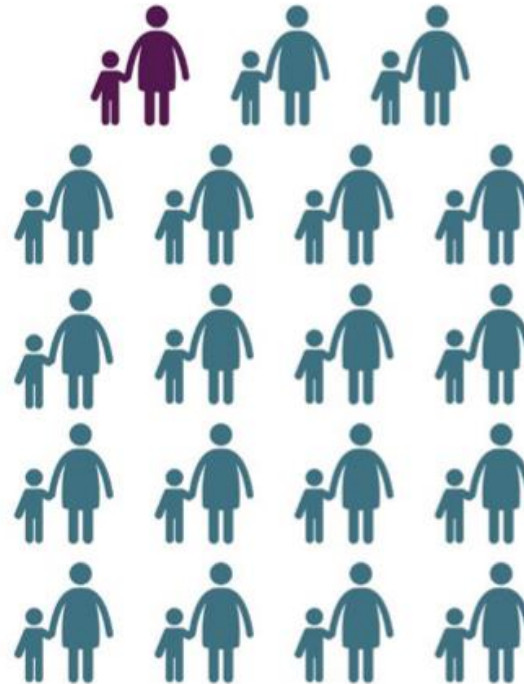
GRANDFAMILIES & KINSHIP SUPPORT NETWORK OVERVIEW

Ana Beltran, JD
Director, Grandfamilies & Kinship Support Network
abeltran@gu.org

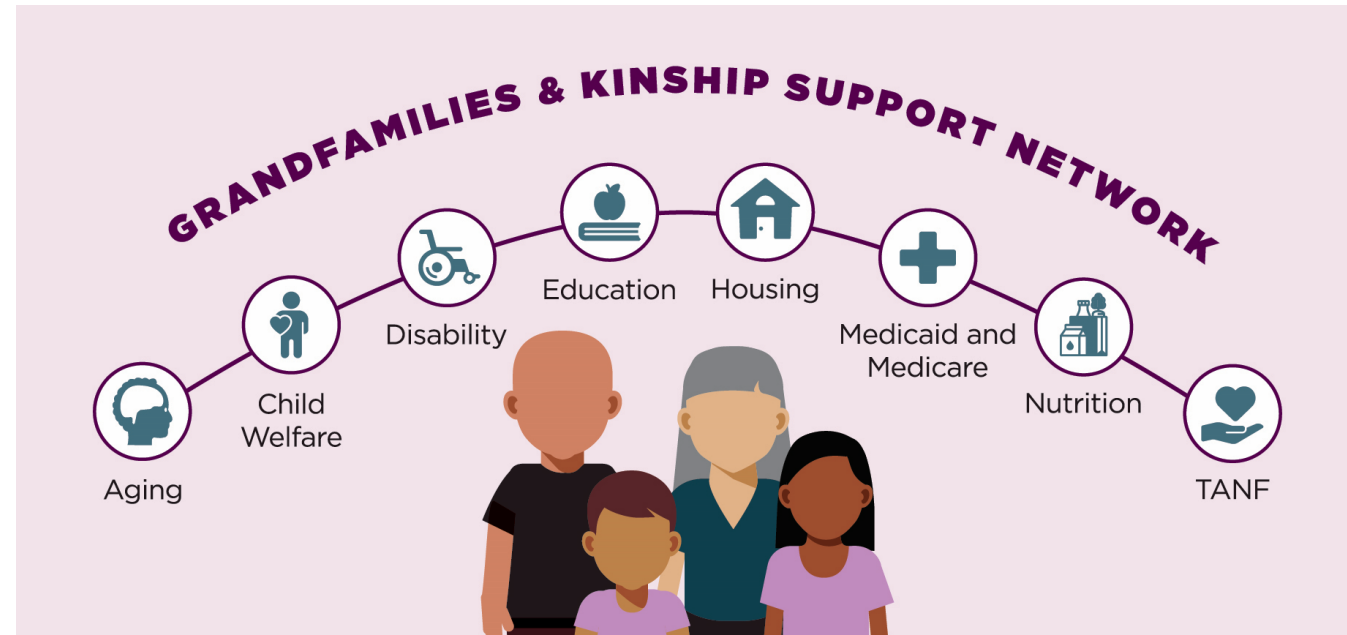
Joint Meeting
Supporting Grandparents Raising Grandchildren (SGRG)
and RAISE Family Caregiving
Advisory Councils
September 19, 2023

Children in Kinship/Grandfamilies

For every **1 child** being raised by kin in foster care, there are **18 children** being raised by kin outside of foster care



- 5-year (2021-2026) cooperative agreement with ACL
- Purpose is to provide technical assistance to the array of tribal, state, and territorial government agencies, as well as non-profit organizations that serve kinship families
- Not designed to serve the families directly – working to improve systems for families



How We Help



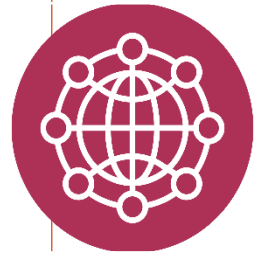
Learning Collaboratives and Information Dissemination

The Network hosts webinars and facilitates learning collaboratives.



Individual Assistance

We respond to individual requests for help from government agencies, and nonprofit organizations.



A Centralized Hub

The Network is elevating exemplary kinship/grandfamily practices and programs from around the country on its new accessible website, www.GKSNetwork.org.

Individual Assistance & Resource to Councils

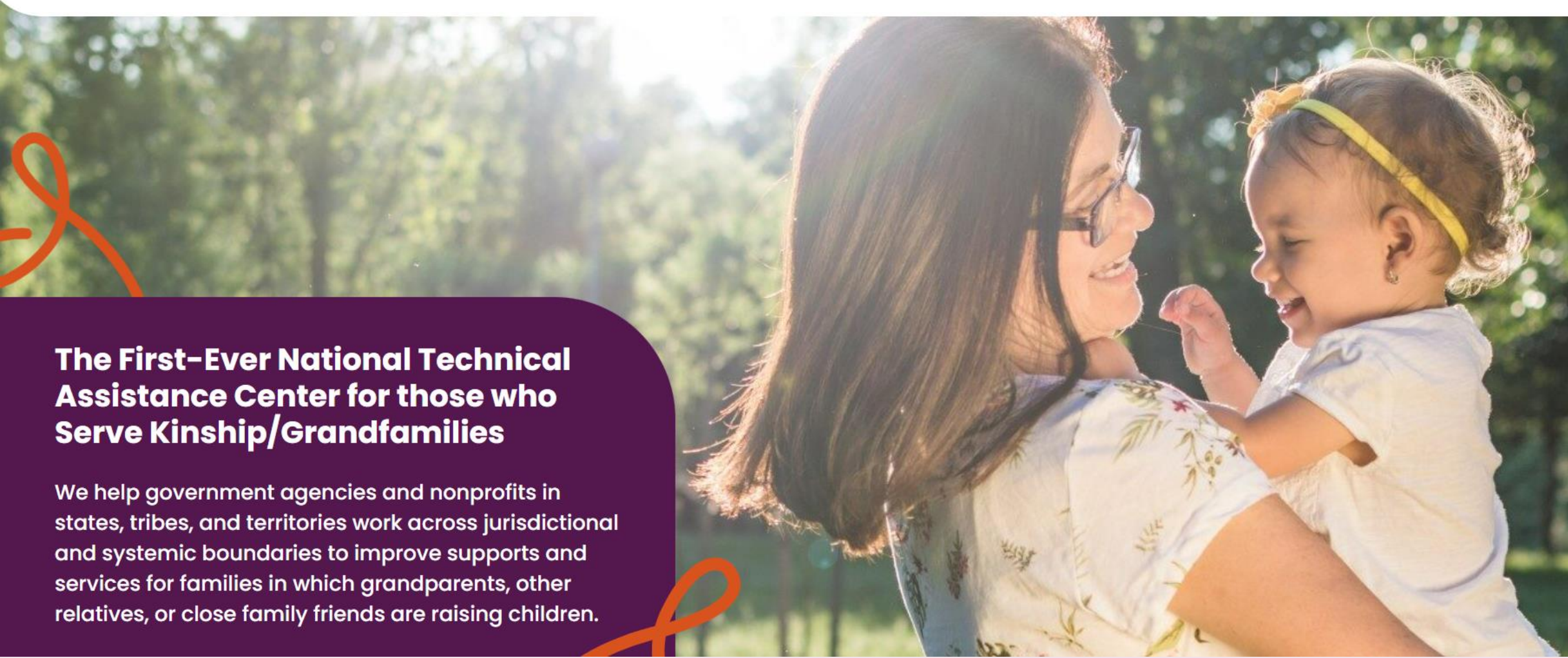
47

**States/Territories
(including DC) Have
Submitted TA Requests**

**Child Welfare is the
System Most Frequently
Requesting TA**



**Legal/Custody Remains
the Most Frequently
Requested Topic for TA**



The First-Ever National Technical Assistance Center for those who Serve Kinship/Grandfamilies

We help government agencies and nonprofits in states, tribes, and territories work across jurisdictional and systemic boundaries to improve supports and services for families in which grandparents, other relatives, or close family friends are raising children.

Stay Connected & Access Support

Sign up for our monthly newsletter, which will provide you with updates on new Network resources.



Visit our website GKSNetwork.org





The Network is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$9,950,000 with 95 percentage funded by ACL/HHS and \$523,684 and 5 percentage funded by non-government sources. The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.



**Analysis of Public Comments
on the National Strategy
And Inventory of Federal Actions
September 19, 2023**

Public Comments

- Over 580 responses
- Researchers analyzed open-ended responses to three questions:
 - Q3 asked what are “the three most important topics/issues for the Advisory Councils”
 - Q4 asked “what’s missing” from the National Strategy
 - Q5 asked for “additional comments”

Who Commented?

Table 1: Respondents by Category

Respondent category	Number	Proportion
A family caregiver	256	44%
An advocate for family caregivers	267	46%
A researcher on caregiving topics	74	13%
Employed by a government program that serves family caregivers	54	9%
Employed by an organization that serves family caregivers	212	37%
Other/Prefer not to say	56	10%
Chose more than one category	207	36%
Total responses	581	

Note: Numbers do not sum to 581 because respondents could choose more than one category.

What Did They Comment On?

Table 2: Section Commented Upon		
Response category	Number	Proportion
Actions for States, Communities, and Others	73	13%
Federal Actions	89	15%
First Principles	40	7%
Global Comments	232	40%
Project Narrative	147	25%

Top Three Issues for the Councils

- **Goal 3** (Caregiver services and supports) received the most attention. The most frequently mentioned top priorities were:
 - Improving the quality, supply, and wages of direct care workers
 - Expanding:
 - Caregiver training and support
 - Respite care
 - Increasing the supply and affordability of LTSS

Illustrative Quotes

“We agree that there is a shortage of medical and direct support professionals and that rates must be increased to retain them.. well-trained should also mean that their training includes the lived experience of diverse family caregivers.”

“The HCBS LTSS industry has a massive workforce shortage that could partially be met through the recognition of and payment to family caregivers.... CMS needs create some sort of incentive for states to utilize this model more.”

“Demand for direct care workers drastically exceeds the number of available workers. Federal agencies have a particular role to play in increasing wages, expanding benefits, providing career ladders, and addressing shortages through other strategies.”

“Prioritize addressing the Direct Care Workforce shortage with enhanced training; increase appeal of a direct care career path through wage and benefit improvements and increased social regard; advocate for immigration policies that support the entry of interested workforce.”

“We strongly agree with the concept of making a career out of being a DCW. It is essential to make training consistent across each individual state and preferably all states. It is also important to create a path to job promotion and job retention. It is not going to be easy, but it is certainly worth a national effort.”

Illustrative Quotes

“The single most requested service from family caregivers is respite.”

“Respite services for family caregivers are important to their mental and physical health and ability to continue providing care. Respite allows a social life as well, thereby reducing social isolation and loneliness linked to premature death and disease.”

“An important component of the strategy is to encourage states to rebalance Medicaid spending to support caregivers in the community by adequately funding HCBS.”

“Respite Care should become a state plan service under Medicaid.”

We know that Caregivers need more than just acknowledgement and recognition! They need real, meaningful help offered by those who have been there, done that and have the stories to prove it.”

“Educating Caregivers is part of the solution.”

“As a family caregiver myself... the first rule is that the caregiver has to be supported for them to be an effective caregiver especially over the long term. A parent/caregiver may know their loved one best but nearly all of the caregivers I've met would welcome more training and are desperate for more support.”

“We recognize that some essential reforms, such as financing, may be politically challenging today but nonetheless must be pursued, even incrementally, to create the environment and conditions for more transformative change.”

Top Three Issues for the Councils

- **Goal 4** (Financial and workplace security) was also listed as a top priority. Here, respondents commented most frequently on:
 - Addressing the financial impacts of caregiving
 - Paying family caregivers
 - Creating caregiver-friendly workplaces and establishing policies such as paid leave

Illustrative Quotes

“Caregivers are forced to choose between staying employed or caring for their loved ones at home. When they forego full time employment, their ability to build wealth fades. For veteran caregiving families, as they age and once their loved one dies, caregivers are further isolated and fall deeper into poverty.”

“As a parent of a child with a disability, I was unable to work. As a result, my SSI when I retire will be very slim.”

“Supporting employed family caregivers is critical in terms of paid leave, other employment protections, and workplace flexibilities at the state and local levels and from employers.”

“The financial impact of caregiving is huge... We endorse policy & programmatic solutions, with a broad definition of family applied.”

“Caregivers need dedicated financial support, particularly those who are unable to work due to their caregiving responsibilities.”

“I was not afforded the same favor as higher-ranking employees when members of their families were in need of care. There is a great disparity in the workplace between those who are extended flexibility in their schedule and those who are not. It varies depending on your position in the company and the level of compassion of your boss. If it were policy, it would be more equitable.”

Kinship and Grandfamilies

- Systemic problem that Kinship caregivers cannot access the financial and other supports available to foster parents
 - Kinship caregivers want access to training and respite care resources
 - Also need peer support to share strategies to support their roles
 - Want information and referrals to resources about the conditions their children encounter (e.g., attachment disorders, acting out at school, specific disabilities, etc.)
 - Need for legal help and guidance

“Ensuring that those of us who provide kinship care have access to the same training and respite resources as foster care families. We’re thrown into these situations with very little support. You can save costs and streamline the system by just opening certain doors for us. “

Other Respondent Priorities

- Respondents endorsed the cross-cutting considerations identified by the Council
 - The strongest endorsement was for addressing direct care workforce issues
 - Strong support was expressed for ensuring diversity, equity, inclusion and accessibility
 - There was also support for person- and family-centered approaches

Overall

- All components of the Strategy were identified as a top priority by some respondents.
- Consistent support for other areas was found:
 - Raising awareness
 - Caregivers as partners in healthcare and LTSS
 - The need for data and research on caregiving
 - The need to develop an accountability structure for the Strategy
 - The need for strong partnerships across sectors

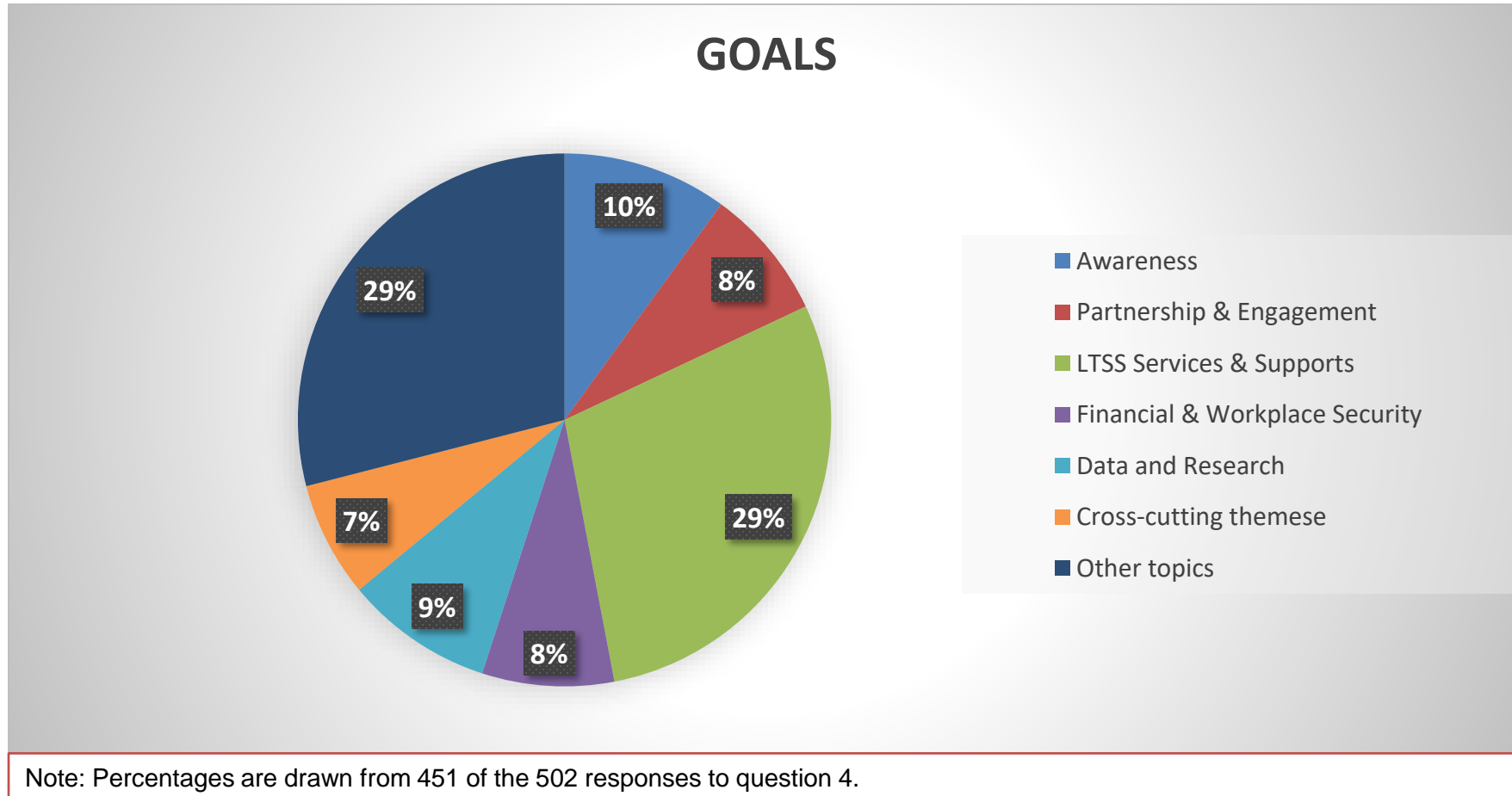
Findings from Q4 & Q5

WHAT'S MISSING?

WHERE CAN THE STRATEGY GO FURTHER?

WHAT TOPICS OR POPULATIONS ARE EXCLUDED?

Distribution of Q4 Responses by Goal



What Was Missing?

- Responses largely mapped responses to Q3, often noting specifics beyond the Strategy
 - Direct care workforce
 - Respite
 - Caregiver training and support
 - Pay family caregivers
 - Diversity, equity and inclusion
 - Financial impacts/reform
- In addition, respondents frequently raised the needs of specific populations they felt need more attention
 - People with ID/DD
 - Spouse caregivers
 - People with mental illness
 - Children who age out of the services/system

Overall, What Was Missing?

- Support research that evaluates the ROI for caregiver support programs
- Identify ways to share best practices and progress
 - Housing
 - Right to die

Illustrative Quotes

“The Strategy should continue to focus across the lifespan and more explicitly address the unique needs of caregivers of children and young adults with special needs, and adults between the ages of 18-60 with physical and intellectual/developmental disabilities, chronic conditions, and mental illness, and youth caregivers.”

“Throughout the strategy there is minimal acknowledgment of family caregivers for people with intellectual and developmental disabilities, especially children. These caregiving situations are unique in that they are often the longest, and sometimes the most intense, journeys family caregivers endure with compounding stress and challenges through the years.”

“...Family caregivers of adults with intellectual disability, who have to leave their employment, [should] accrue Social Security quarter hours in recognition of the work that they do as a family caregiver...[They should be] eligible, trained family members to be paid as caregivers through Medicaid waivers. Any financial supports provided to caregivers will obviate higher cost care that will be borne by the federal and state government.”

“Patients need care navigation, links to resources, and advance care planning for what is coming.”

“It would be helpful to prioritize the huge number of recommendations. The casual reader might get the impression that everything is of equal importance, equal priority, and equally easy or difficult to implement.”

Findings from Q4 & Q5

WHAT'S MISSING? THE FEDERAL ROLE

Ensuring Accountability

- Respondents suggested ways to ensure accountability at the federal level
 - ACL should develop an implementation “dashboard” on the status of actions across agencies
 - Create federal cross-agency task force for implementation, including public meetings and progress reports

Federal Actions: Work for the ACL

- Close to 80 of the comments relate to ACL
- Often with regard to expanding or implementing the National Strategy
- Some mention more attention to specific populations or programs:
 - Veterans, Children with special needs, federal employees, tribal entities, people with rare diseases, low-income families, respite care, support for state plans, and more

Illustrative Quotes

“Guidance from ACL on how states can incorporate elements of the Strategy to align with their plans on aging and other caregiver initiatives, including support establishing public-private family caregiver coalitions, would be appreciated.”

“ACL [should] develop an implementation dashboard to educate the public about the implementation status of actions across agencies.”

“ACL should influence states or state agencies to create incentives to adopt the recommendations. Otherwise, many conservative states will ignore them.”

“Prioritize the need to pass legislation that includes provisions regarding education and training for family caregivers, pandemic preparedness, health literacy grants, increased shared decision-making...which would go a long way to enhance the federal support infrastructure for family caregivers.”

“Revise ACL grant rules (e.g, Dementia Capable, Lifespan Respite) to reduce administrative burdens, extend grant periods and increase ...funding to allow states to hire staff to support grant work and an independent robust evaluation to meet meaningful long-range goals.”

Other Federal Actions Suggested

- Medicaid changes:
 - Expand benefits. For example:
 - Make HCBS mandatory
 - Make “Money Follows the Person” permanent
 - Streamline eligibility
 - Streamline spend-down rules
 - Expand ability to pay family caregivers
- Include respite as a mandatory Medicare/Medicaid benefit
- Raise Medicaid/Medicare rates for mental health services – help deal with the mental health challenges of caregiving
- Expand use of the Medicare Supplemental Benefit for Chronically Ill
- Prioritize equity across federal actions to address health and economic disparities

Illustrative Quotes

We suggest CMS expand the option to pay family members who provide personal care services under section 1905(1)(24)...Current policy allows states to pay for extraordinary care...but prohibits payment under 1905(a) This creates fractured delivery system and confusion amongst participants and their caregivers."

"Expand SSBCI to individuals in fee-for-service Medicare in addition to Medicare Advantage."

"We ask CMS to provide states with the option to waive estate recovery for LTSS participants, this policy can result in...delaying enrollment in HCBS and place more strain on family."

"Respite Care should become a state plan service under Medicaid."

"[Medicare should] add a code for caregiver-focused health risk assessment. I have taken my mom to probably 100 doctor appointments and no one ever asked me about my health. If this is supposed to be used, it seems Medicare needs to educate doctors."

"Highlight the need for CMS to provide thorough, timely, and consistent review of all state plan amendments and waivers and waiver amendments to ensure compliance with ADA and Olmstead."

What Should Congress Do?

- Create a caregiver tax credit
- Immigration reform to expand the direct care workforce
- Expand benefits for working caregivers (including paid leave)
 - For federal government employees, at minimum
 - Nationally
- Expand funding
 - To support implementation of the National Strategy
 - Create federal grants for states to implement national strategy goals (e.g., worker wages)
 - To support LTSS more generally
- Establish a new Office of Caregiver Health at HHS
- Ensure that tribal entities are eligible for funding under programs supporting older adults and caregivers

Illustrative Quotes

“...the federal government should make changes to the immigration system so that it is easier for people to come to the U.S. ...to serve as a caregiver for a person with a disability...the changing of visa policies to allow au pairs to serve as caregivers...is mentioned in the narrative....but not in the recommended federal actions. “

“While the RAISE Strategy recommends that private sector employers step up and expand their support of employee caregivers, there is no parallel recommendation that the federal government strengthen its commitment to employee caregivers...Providing support to federal employees would reduce their burden...and signal a strong commitment of the federal government to leading efforts on behalf of caregivers.”

“Recommendations are only as good as the willingness of the Administration and Congress to implement them. Expecting the states and communities to move forward...without funding from the federal government is foolhardy.”

Findings from Q4 & Q5

WHAT ELSE IS MISSING?

ACTIONS IMPORTANT TO IMPLEMENTATION OF THE STRATEGY

Comments on Collaboration

- Strategy is “full of suggestions for collaboration,” but this is “easier said than done”
- Infrastructure development across federal agencies will be needed
- Data collection should be coordinated, not just across federal agencies, but also across levels of government
- Identify a lead agency to shepherd the caregiver strategy
- Create National Resource Center on Family Caregiving with cross-agency collaboration

Comments on Accountability

- Mandate annual accountability on federal progress
 - ACL should develop an implementation “dashboard” on the status of actions across agencies
- Create a federal cross-agency task force for implementation, including public meetings and progress reports
- Prioritize equity across federal actions to address health and economic disparities
- Support research that evaluates the ROI for caregiver support programs
- Identify ways to share best practices and progress

Comments on State Actions

- States should move to ensure that family members can be paid as caregivers for their family members
- Adopt PFLM, CARE Act, and Medicaid expansion in states that have not yet done so
 - Improve implementation of CARE
- Track state implementation of the Strategy and share best practices
- Include family caregivers and a wide range of community-based organizations in state planning (and at all levels)
- Improve coordination of funding, payor of last resort, etc.
- Improve data collection on caregiver-related services and outcomes

QUESTIONS?



Project Team

- Eileen J. Tell
- Pamela Nadash
- Maryssa Pallis
- Shan Qu
- Marc Cohen

Facilitated Discussion

New areas the Strategy should address

1. Possible new goals and/or outcomes
2. New sectors or actions that should be addressed

Opportunities for the Strategy to be bolder in its approach to being the “roadmap for change”

1. Additional cross-cutting considerations
2. Opportunities for legislative and regulatory changes

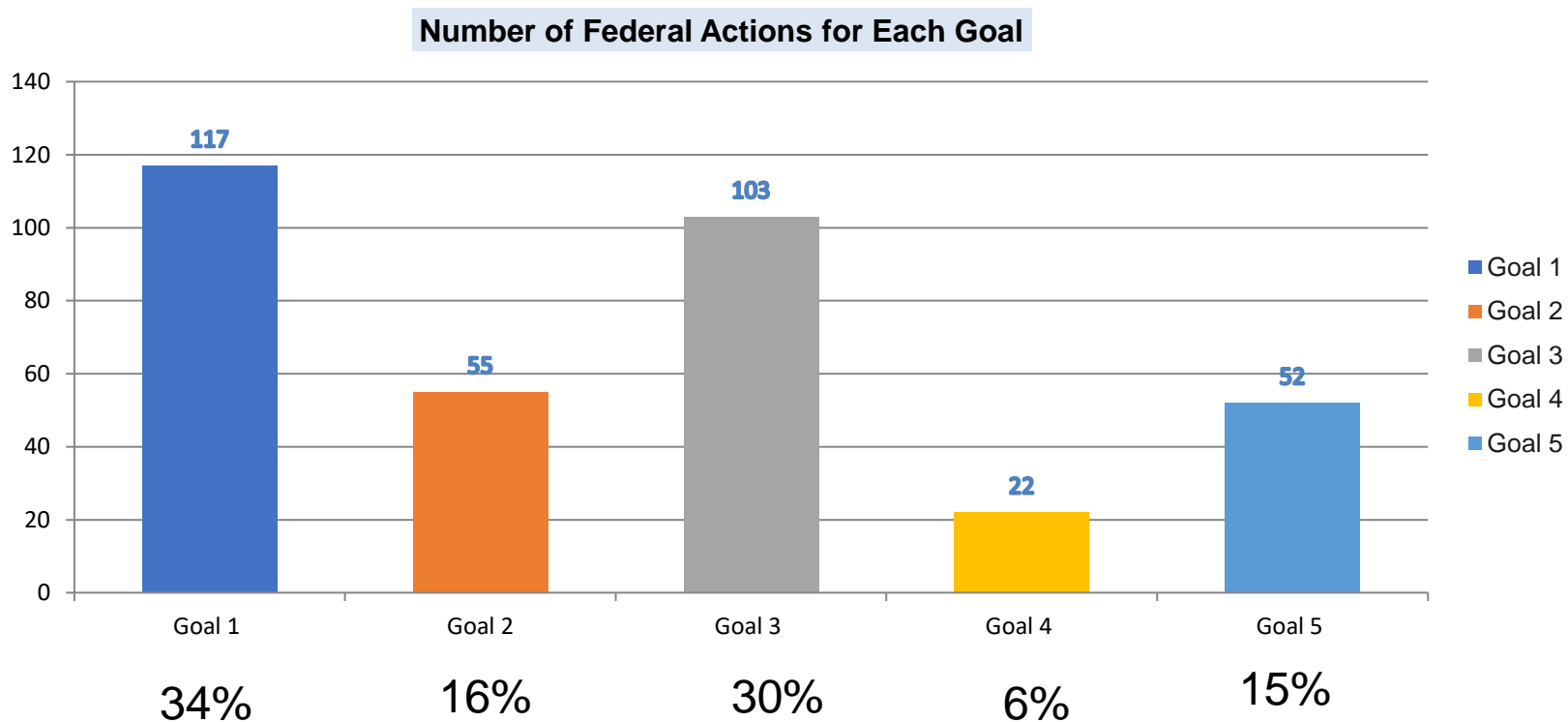
10 MINUTE BREAK

Federal Agency Actions Overview



AND MORE.....

Number of Federal Actions by Goal



Number of Federal Actions, by Responsible Agency

Entity	Number	Percent
ACF	14	4%
ACL	93	27%
ASPE	6	2%
AmeriCorps	18	5%
CDC	41	12%
CFPB	17	5%
CMS	30	8%
DOL	42	12%
ED	5	1%
FEMA	1	0%
HRSA	15	4%
IHS	12	3%
NIH	25	7%
SAMHSA	9	3%
VA	21	6%
<i>Total</i>	<i>349</i>	<i>100%</i>

Note: some actions have multiple federal agencies involved and some actions have been added since the Strategy has been published.

About the Care Recipient and Caregiver Population

Actions Relating to Care Recipient Populations*		
	Number	Percent
All or Not Specified	196	56%
Kinship/Grandfamilies	29	8%
Medicare Beneficiaries	7	2%
Native American or Tribal Persons	12	3%
Older adults	26	7%
People Living with Dementia	34	10%
People with ID/DD	12	3%
Veterans	19	5%

* Groups with 5 or fewer actions not included

Actions Relating to Caregiver Populations*		
	Number	Percent
All or Not Specified	107	30%
Employee Caregivers	15	4%
Family Caregivers	41	12%
Kinship/Grandfamily Caregivers	29	8%
Caregivers of Medicare Beneficiaries	7	2%
Caregivers of Native Americans or Tribal Persons	12	3%
Caregivers of Older Adults	21	6%
Caregivers of People Living with Dementia	34	10%
Caregivers of People with ID/DD	12	3%
Caregivers of Veterans	19	5%

* Groups with 5 or fewer actions not included

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Progress Updates from Federal Agencies

2022 National Strategy to Support Family Caregivers

2
Councils



5
Shared Goals



1
Vision for
Holistic Support



GOAL 1
Increase awareness and outreach



GOAL 2
Advance partnership and engagement



GOAL 3
Strengthen services and supports



GOAL 4
Ensure financial and workplace security



GOAL 5
Expand data, research, and evidence-based practices

We all have a role to play in supporting our nation's caregivers.
[ACL.gov/CaregiverStrategy](https://www.acl.gov/CaregiverStrategy)



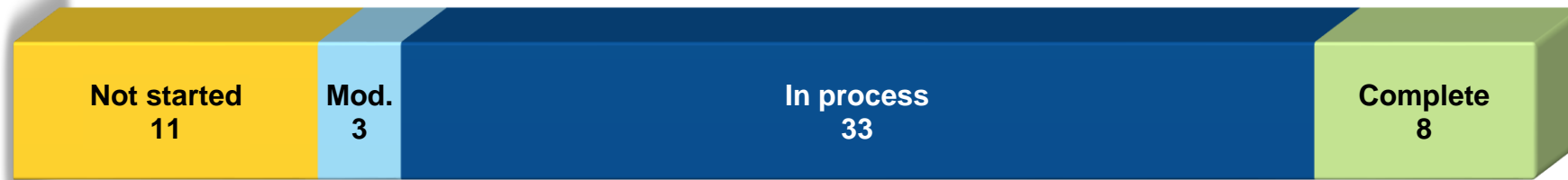
117 Federal Actions



Increase awareness and outreach

GOAL 1

55 Federal Actions



Advance partnership and engagement

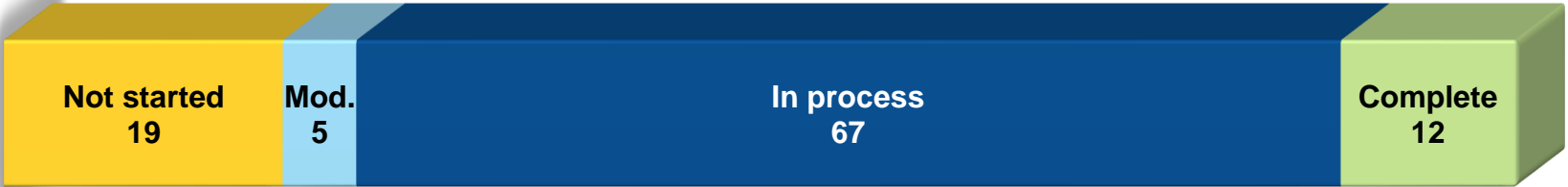
GOAL 2

We all have a role to play in supporting our nation's caregivers.

[ACL.gov/CaregiverStrategy](https://www.acl.gov/CaregiverStrategy)



103 Federal Actions



Strengthen services and supports

GOAL 3



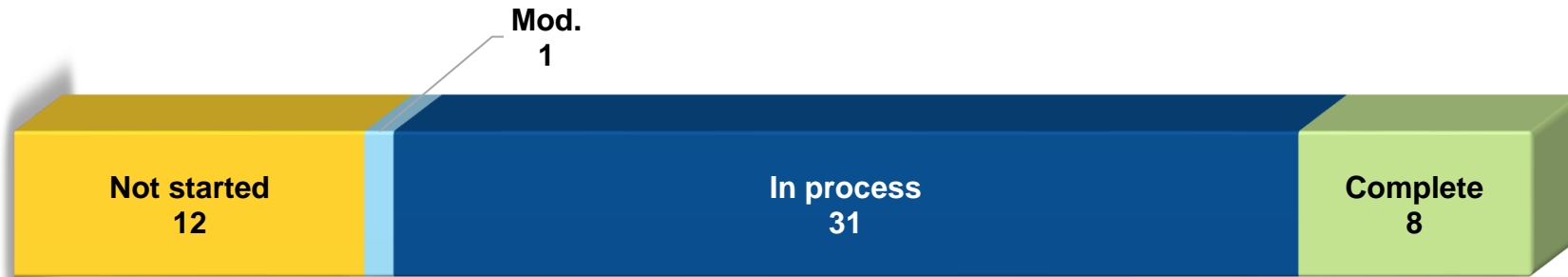
22 Federal Actions



Ensure financial and workplace security

GOAL 4

52 Federal Actions



Expand data, research, and evidence-based practices

GOAL 5

2022 National Strategy to Support Family Caregivers

2
Councils



5
Shared Goals



1
Vision for
Holistic Support



GOAL 1
Increase awareness and outreach



GOAL 2
Advance partnership and engagement



GOAL 3
Strengthen services and supports



GOAL 4
Ensure financial and workplace security



GOAL 5
Expand data, research, and evidence-based practices

We all have a role to play in supporting our nation's caregivers.
[ACL.gov/CaregiverStrategy](https://acl.gov/CaregiverStrategy)

Based on our discussion, your thoughts on:

1. Future presentations the councils need to hear
2. Materials and other information for your review
3. Technical assistance and support

Looking Ahead

ADJOURN

