Family Caregiving Advisory Council Meeting

November 18, 2020

Call to Order

Lance Robertson

Administrator/Assistant Secretary for Aging

Administration for Community Living

Roll Call

Agenda Overview and Updates

Greg Link, Director
Office of Supportive and Caregiver Services
Administration for Community Living

Agenda

12:45–1:00	**Agenda Overview and Updates**
1:00 – 1:20	**Caregiver Voices:** **Overview of the NAC "Caregiver Stories Project"**
1:20 – 4:20	**Presentation of Recommendations** [2:30-2:40 Break]
4:20 – 4:30	**Final discussion, next steps, adjourn**

Caregiver Voices: Overview of the NAC "Caregiver Stories Project"

Michael Reese Wittke
Senior Director, Public Policy and Advocacy
National Alliance for Caregiving (NAC)

RAISE Council Meeting: Caregiver Vignette Project

Prepared by Mike Wittke, MPA

November 18, 2020

National Alliance for Caregiving

Vision:

A society that values, supports, and empowers family caregivers to thrive at home, work, and life.

Mission:

We build partnerships in research, advocacy, and innovation to make life better for family caregivers.

Today's Presentation Overview

1. About the Caregiver Vignette Project
2. Collecting the Story Details
3. Featured Caregivers
4. Next Steps

About the Project

- Caregivers Selected Reflect the Wide Diversity of Caregivers Across the United States
- Caregivers Have Some Knowledge About the Policy Landscape
- The COVID Spin – Zoom!
- Summarizing in 350 Words or Less
- Elevating the Work of the RAISE Council
- National Family Caregiver Month

NAC Network

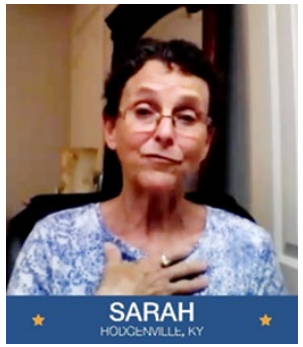
ADVOCACY
COLLABORATIVE

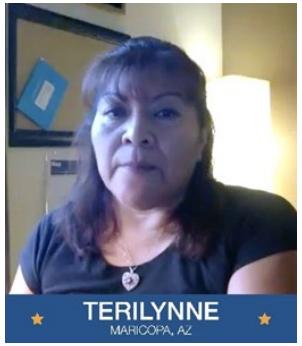
RESEARCH
COLLABORATIVE

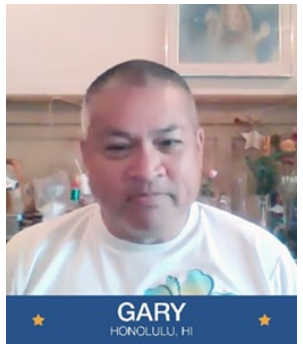
INNOVATION
COLLABORATIVE

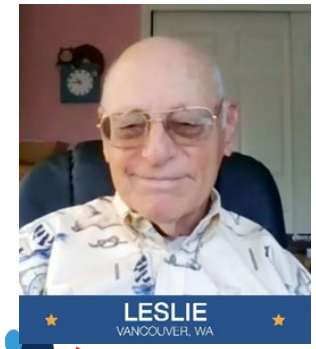
Interview Questions

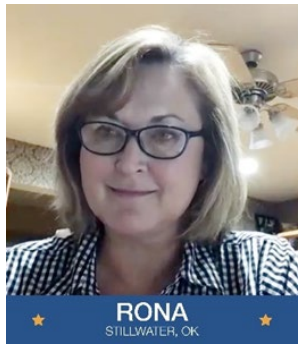
- About the Care Recipient
- About the Caregiver
- Challenges and Hurdles
- What Would Have Helped
- What Should Policy Makers and Society Know











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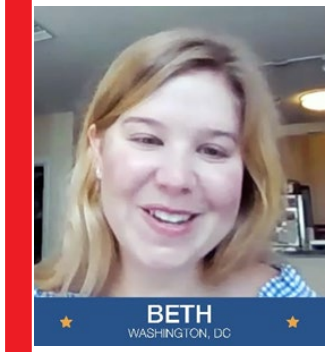

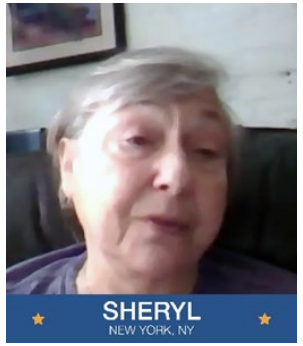

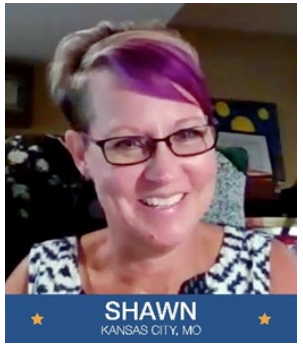

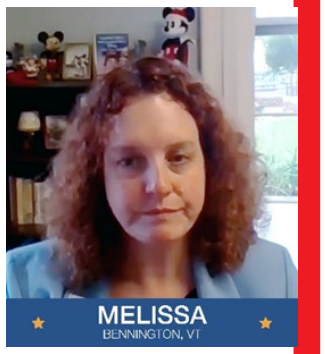

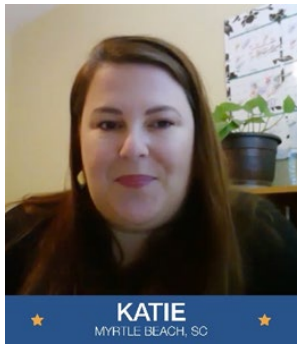

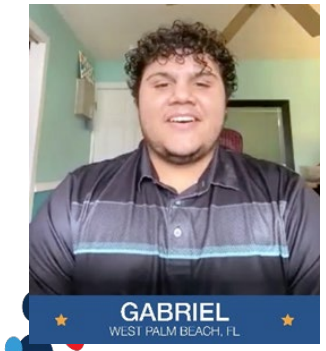

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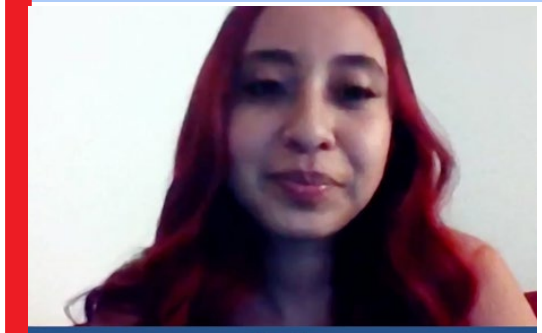
Social Media: National Family Caregiver Month



"I walk a fine line since I'm expected to be a sister, a daughter, a caregiver, and the family communicator. I agonize over what is going to happen when my parents are gone—I know I will be my sibling's caregiver for life."

Nayma | Los Angeles, CA

"Caregivers of cancer patients are often overlooked, due to the fact that cancer itself can be fairly well covered under health insurance. This does not mean that cancer caregivers would not benefit from policies that promote respite services, tax breaks, and financial incentives for employers to better accommodate caregivers."

Allen | Columbia, SC

"Caregivers run and run – they never know where the finish line is. I feel the hardest part of being a caregiver is learning how to be a caregiver."

TeriLynne | Maricopa, AZ

"I didn't realize I was a 'caregiver', and not just a daughter helping my parents, until I attended an Older American Title VI conference and took a quiz designed to identify caregivers."

Zuzette | Sacaton, AZ

"I'm not a stranger to hardship. My husband was a career marine and was often gone when our children were young. Our son requires 24/7 nursing, and it was difficult to find ethical and trained nurses. Sometimes he was harmed through negligence, causing more surgeries."

Debbi | Eagan, MN

"Our paid care providers do far more than just medical tasks. They offer meaningful care that has a profound effect on our family's quality of life. The cost of caring for someone at home is far less expensive than caring for them in an institution, making the Veteran Directed Care Program an ideal resource for veteran caregivers."

Jim | Apex, NC

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Next Steps: Work in 2021

- Full Vignettes to be Posted on NAC and the RAISE Resource and Dissemination Center (NASHP) Website
- Each Vignette to Link to RAISE Recommendations
- Interviews to be Edited into Video Clips
- 2 Listening Sessions
- Dissemination Activities Among Policy Makers

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Thank you!

Michael Reese Wittke, BSW, MPA
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National Alliance for Caregiving

Presentation of Council Recommendations

Greg Link, Director
Office of Supportive and Caregiver Services
Administration for Community Living

Wendy Fox-Grage Project Director

RAISE Family Caregiving Resource and Dissemination Center

National Academy for State Health Policy (NASHP)

GOAL 1

Family caregivers' physical, emotional, and financial well-being will improve as a result of expanded awareness, outreach, and education.

GOAL 1 - Recommendations

- **Recommendation 1.1:** Increase public awareness and recognition of the diverse needs, issues, and challenges family caregivers face and of the importance of recognizing and supporting them.

- **Recommendation 1.2:** Increase family caregivers' self-identification and awareness of, and access to, information, services, and supports across a range of topics.

- **Recommendation 1.3:** Improve outreach efforts to family caregivers to ensure early identification and access to services and supports.

GOAL 1 - Recommendations (Continued)

- **Recommendation 1.4:** Support the development, or revision of, state, territorial, Tribal and local planning that focuses specifically on recognizing, including, and supporting family caregivers of all ages and is aligned with the National Family Caregiving Strategy.

- **Recommendation 1.5:** Promote the expansion and role of public/private partnerships at all levels that recognize, assist, include, support and engage family caregivers.

Non-Federal Council Members Vote on Goal 1 Recommendations

GOAL 2

Family caregivers are recognized, engaged, and supported as key partners with providers of healthcare and long-term services and supports.

GOAL 2 - Recommendations

- **Recommendation 2.1:** Ensure the impact of policy and practices on family caregivers are studied and understood before changes are made in healthcare systems.

- **Recommendation 2.2:** Identify and include family caregivers as essential members and partners in the care recipient's care team.

- **Recommendation 2.3**: Engage family caregivers through the use of evidence-supported and culturally sensitive family caregiver assessments to determine the willingness, ability, and needs of family caregivers to provide support.

GOAL 2 - Recommendations (Continued)

- **Recommendation 2.4**: Increase the integration of care through the inclusion of family caregivers in all relevant care coordination and transitions across providers and settings and when desired by both caregiver and care recipient.

- **Recommendation 2.5:** Strengthen the training of healthcare, social service, and allied professionals to maximize family caregiver engagement and referrals to services in the community.

Non-Federal Council Members Vote on Goal 2 Recommendations

GOAL 3

Family caregiver 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.

GOAL 3 - Recommendations

- **Recommendation 3.1:** Increase access to meaningful and culturally relevant information, services, and supports for family caregivers.

- **Recommendation 3.2:** Increase the availability of high-quality, setting-appropriate, and caregiver-defined respite services to give caregivers a healthy and meaningful break from their responsibilities.

- **Recommendation 3.3:** Increase the availability of diverse counseling, training, peer support, and education opportunities for family caregivers, including evidence-informed interventions.

GOAL 3 - Recommendations (Continued)

- **Recommendation 3.4:** Expand caregiver support programs and services that maintain the health and independence of families by increasing access to housing, safe living accommodations, food, and transportation, and by reducing social isolation.

- **Recommendation 3.5**: Encourage use of technology solutions as a means of supporting family caregivers.

- **Recommendation 3.6:** Expand the use of vetted volunteers and volunteerism as a means of supporting family caregivers.

GOAL 3 - Recommendations (Cont'd)

- **Recommendation 3.7:** Improve the support of family caregivers during emergencies (e.g., pandemics, natural/manmade disasters).

- **Recommendation 3.8:** Increase the prevalence and use of future planning as a means for ensuring family members have the needed supports in place throughout the care recipient's life.

- **Recommendation 3.9:** Increase and strengthen the paid long-term services and supports (LTSS) and direct support workforce.

Non-Federal Council Members Vote on Goal 3 Recommendations

GOAL 4

Family caregivers' lifetime financial and employment security is protected and enhanced.

GOAL 4 - Recommendations

- **Recommendation 4.1**: Decrease the negative financial impacts for family caregivers on both a short- and long-term basis.

- **Recommendation 4.2**: Advance the development and broad adoption of employee-centered flexible workplace policies and practices that support work/life balance and maintain performance when personal circumstances change.

GOAL 4 - Recommendations (Continued)

- **Recommendation 4.3:** Increase the availability, and use of, financial education and planning tools for family caregivers.

- **Recommendation 4.4**: Improve the affordability of long-term services and supports and reduce out-of-pocket costs for families through public and private payers.

Non-Federal Council Members Vote on Goal 4 Recommendations

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.

GOAL 5 - Recommendations

- **Recommendation 5.1**: Establish a national infrastructure using standardized data, questions, and a definition of “family caregiver” for obtaining, analyzing, and disseminating information about caregivers and their experiences.

- **Recommendation 5.2**: Increase family caregiver research that facilitates the development and delivery of programs and services that support and enhance the health and well-being of the caregiver and care recipient.

- **Recommendation 5.3**: Increase the promotion, translation, and dissemination of promising and evidence-supported practices to support family caregivers in the delivery of healthcare and long-term services and supports.

Non-Federal Council Members Vote on Goal 5 Recommendations

Next Steps

Continue Report Development

- Ongoing drafting of key sections (Nov/Dec)
- Preliminary review by select ACL staff (Dec)

Stakeholder listening sessions (December)

- No formal council activities scheduled

Tentative Upcoming Meeting Schedule and Related Activities*

- January: Full council meeting
  - Presentation: NASHP's Medicaid Paper
  - Review Federal Inventory Section
  - Listening Sessions Report out
  - Discussion: Council Review of Report Draft
- February: Subcommittee meetings
  - Review and discuss report
  - Prepare and provide feedback
- March: Full council meeting
  - Report review and discussion
  - Vote to move report into clearance

*Schedule subject to change

Thank you

ACL
Administration for Community Living
RAISE FAMILY CAREGIVING
ADVISORY COUNCIL