

NATIONAL FAMILY CAREGIVING POLICY – WHAT MIGHT THE RAISE ACT INSPIRE?

Grace Whiting, President and Chief Executive Officer, National Alliance for Caregiving

Denise Brown, Founder, Caregiving.com

Lois Simon, EVP Policy and Programs, Seniorlink

Laura Sankey, Staff VP Operations – Complex Care, Centene

THE INVISIBLE ARMY

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SPEAKERS



C. Grace Whiting, J.D. is the President and Chief Executive Officer at the National Alliance for Caregiving, where she continues her tenure from previous roles including Chief Operating Officer and the Director of Strategic Partnerships. Ms. Whiting led the launch of the *Caregiving in the U.S. 2015* report with AARP and directed the first national study of rare disease caregiving with Global Genes. She has spoken on caregiving at national and international conferences, including the 7th International Carers Conference in Adelaide, Australia and at three national summits at the National Institutes of Health. Ms. Whiting has also served as a resource to major media on the topic of caregiving and aging, including C-SPAN, *The Wall Street Journal*, *Time Magazine*, and *Kiplinger's Retirement Report*.

Named an “Outstanding Law Student” by the National Association of Women Lawyers, Whiting earned her law degree from the University of Memphis School of Law and her undergraduate degree with honors in Communication Studies from Louisiana State University.



@NA4Caregiving @CGraceTweet

SPEAKERS



Denise M. Brown launched CareGiving.com in 1996 to help those who care for a family member or friend. CareGiving.com features the blogs of family caregivers, weekly words of comforts, daily chats, podcasts and free webinars. The site hosts a 36-hour chat over the Christmas holiday staffed by volunteers.

In 2016, Denise organized and hosted the National Caregiving Conference which now takes place annually. In January 2016, Denise debuted the Certified Caregiving Consultant training program which helps former family caregivers launch a business to help current family caregivers.



@Caregiving

SPEAKERS



Lois Simon Lois Simon is the Executive Vice President of Policy and Programs at Seniorlink. Previously, Lois was the Founder and Principal of L. Simon Solutions LLC, a healthcare integration strategies consulting firm based in Boston, MA and the Co-Founder of Commonwealth Care Alliance and its former President.

Lois has over three decades of leadership experience serving complex and high cost government supported populations in clinical program development, government service and executive management roles, including a variety of Massachusetts government positions, most notably as the Director of Long Term Care for the Medicaid program and as the Assistant Secretary of the Executive Office of Elder Affairs responsible for the agency's vast array of programs. She went on to serve as Senior Vice President and Regional General Manager for The Mentor Network, Chief Operating Officer at the East Boston Neighborhood Health Center, and on the executive leadership team at Neighborhood Health Plan.

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SPEAKERS



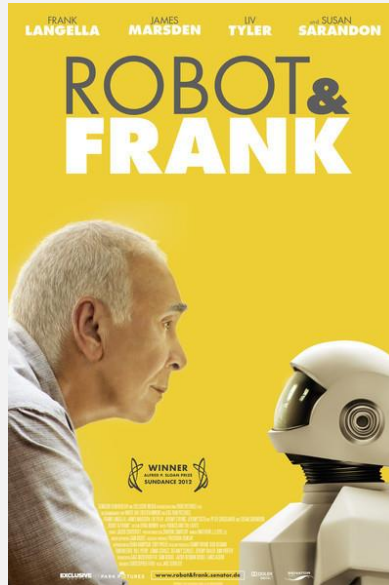
Laura Sankey has more than twenty-five years' experience in the managed care industry across a wide range of functional areas including commercial and government claims, training and auditing and health plan operations.

Ms. Sankey has been at Centene for fourteen years and joined the Complex Care team in May of 2014 to lead the Duals Demonstration product implementing three of Centene's six Medicare-Medicaid Plans (MMPs). As Vice President of Product Strategy and Social Determinants of Health Innovation she leads the ABD/SSI Product team and is responsible for the development and execution of Centene's social determinants of health strategy. In addition, she is tasked with identifying and sharing best practices across the organization, working with federal and state regulatory bodies to provide feedback on dual integration efforts and testing care management models to improve health outcomes and reduce costs for these vulnerable populations.



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CAREGIVING IS EVERYWHERE!



CAREGIVING IS A PUBLIC HEALTH ISSUE



Roughly the
same number of
people as the
population of
Argentina!

There are 43.5 million family caregivers across the lifespan in the U.S. providing an estimated economic value of \$470 billion in care annually

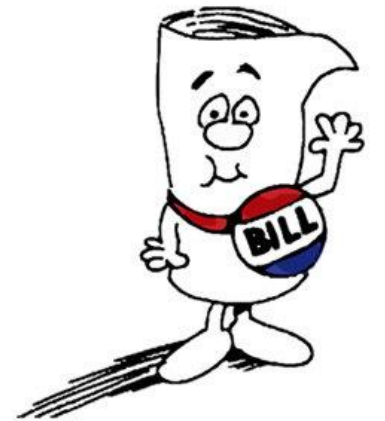
ENCOURAGING MOMENTUM IN CAREGIVING POLICY

Services and Supports:

- RAISE Family Caregivers Act (2018) (P.L.115-119)
- FY2018 Budget: Lifespan Respite Care program increases by \$700,000 for a total of \$4.1 million (a 20.6% increase) and the National Family Caregiver Support Program increases by \$30 million for total of \$180.6 million (a 19.9% increase).

Health System Integration:

- Care, Advise, Record, and Enable (“C.A.R.E. Act”) for hospital discharge passed in 39 states.



RAISE FAMILY CAREGIVERS ACT PUBLIC LAW NO: 115-119

- First introduced in 2015; signed into law January 2018
- Similar in concept to the National Alzheimer’s Project Act —creates a national Caregiving strategy with input from a national Advisory Council
- Definition: Family member or other individual who has a significant relationship with and who provides a broad range of assistance to individual who has a chronic condition, disability, or functional limitation.
- No new funding



RAISE ACT: PLAN AREAS OF FOCUS

- The plan identifies actions that federal, state/local governments, communities, healthcare and LTSS providers can take:
 - greater adoption of person and family-centered care;
 - assessment and service planning, including care transitions;
 - info, education & training on hospice, palliative care and advance care planning;
 - respite;
 - financial security and workplace issues; and
 - delivery of services based on performance and mission and eliminating redundancies.

RAISE ACT: STRATEGY REPORT WILL INCLUDE:

- Best practices and inventory of federal programs
- New developments, challenges and solutions
- Review of programs and recommendations to improve implementation
- Evaluation of how caregiving impacts Medicare, Medicaid, and other federal programs

RAISE ACT: ADVISORY COUNCIL

15 non-federal representatives; at least one in each category:

- caregiver
 - older adult needing LTSS
 - person with a disability
 - healthcare and social service provider
 - LTSS provider
 - employer
 - paraprofessional worker
 - state and local officials
 - accreditation bodies
 - military Veterans
 - experts and advocacy orgs
- And Feds:** CMS, ACL, VA, etc.

THE FAMILY CAREGIVER

What's the cause of your stress?

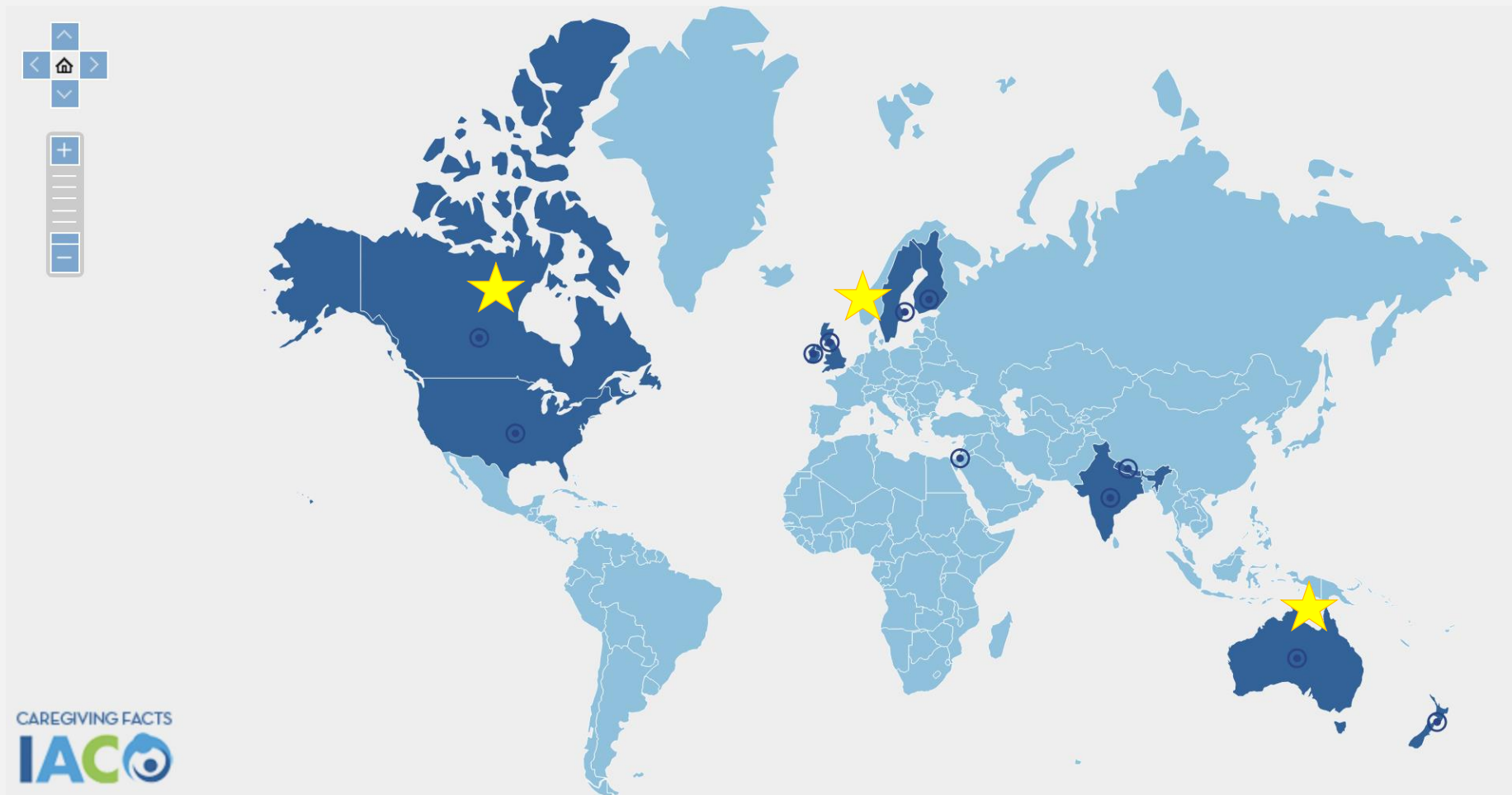
- No. 1 answer: **I miss my life: 72.42%**

The stress comes from the experience and the systems.

With support and help, the stress can be reduced.

When a family caregiver is supported and helped, all the systems benefit.

OTHER NATIONS HAVE FOUND SUCCESS WITH A UNIFIED CAREGIVING STRATEGY



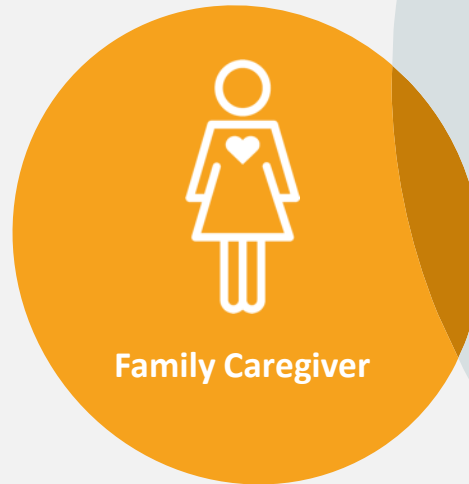
SOLUTIONS FOR THE FAMILY CAREGIVER

Caregivers are the most proximate and trusted individuals in the lives of their family members and well positioned to influence health outcomes.

Family Caregivers have context and longitudinal understanding of their loved one's needs.

They and are able to provide unique observations and insights to inform the professionals involved in providing and managing care.

This Invisible Army needs support, guidance, tools, inclusion and recognition.



People



Professional Care Teams Partnering With Family Caregivers

Innovative Case Management and Coaching model

Protocol



Vital Outcomes Inspired by Caregiver Engagement (VOICE)

Evidenced based protocols designed for Caregivers to inform their caregiving, e.g., Falls Management and Dementia Care

Product



Collaboration Technology designed specially for Family Caregivers that enables the gathering of actionable intelligence from the home

Engaged caregivers yield insight, insight leads to action

Vela's unique design improves collaboration between Care Teams & Family



RECOGNIZE, ASSIST, INCLUDE, SUPPORT, & ENGAGE (RAISE) FAMILY CAREGIVERS ACT

PROBLEM:

- Informal caregivers taking care of members with functional or cognitive limitations lack support. This can lead to caregiver burnout, which may impact the members' ability to remain living at home within their community and may decrease the members' quality of life.

PURPOSE:

- To establish a formal caregiver support program that allows our members to remain in the home as long as possible by providing encouragement, information and tools to the informal caregivers who tend to their needs.

The RAISE Family Caregivers Act is a good start, but you cannot wait to act.

PROGRAM DEVELOPMENT:

- Member identification/stratification
- Identification of non-paid caregivers
- Assessment of caregiver support needs
- Person-centered care planning and caregiver support
- Metrics collection
- Reassess and revise as needed



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