



AMERICAN ACADEMY
of NURSING

ADVANCING POLICIES TO SUPPORT FAMILY CAREGIVERS

IN THIS REPORT

- 1 INTRODUCTION
- 2 MAIN SESSION AND SPEAKERS
- 4 BREAKOUT SESSIONS
- 5 Q+A PANEL
- 6 KEY TAKEAWAYS AND RECOMMENDATIONS
- 7 ACKNOWLEDGEMENTS AND REFERENCES

ADVANCING POLICIES TO SUPPORT FAMILY CAREGIVERS

Hosted by the Expert Panel on Aging

Published October 2022

Dialogue Occurred November 2021

INTRODUCTION

In November 2021, the American Academy of Nursing (Academy) hosted a policy dialogue on “Advancing Policies to Support Family Caregivers.” The Academy’s Expert Panel on Aging convened this dialogue to discuss the critical and growing role that family caregivers play in providing care. Family caregivers provide the vast majority of services and support for older adults and persons with disabilities. Caregivers represent all segments of society and all demographic groups, with over 60% of family caregivers employed (MetLife, 2010). The demand for family caregivers will only increase in the coming decades and there will be fewer numbers of caregivers in relation to persons who need support. Public and private organizations are grappling with policies to support the vital role of caregivers in long-term care delivery as well as policies to promote the health and well-being of caregivers.

Dr. Heather Young, PhD, RN, FAAN, Professor and Dean Emerita, Betty Irene Moore School of Nursing at the University of California, who served as moderator for this dialogue, explained that family caregiving is an often-overlooked yet critical topic. “Family caregiving is on the rise and remains somewhat invisible in our communities, our workplaces, health systems, and society in general. Yet 1 in 5 households in the US are providing care and support to a person over 18. Over 40 million family members and friends are in this important role, and this is a family experience across all racial and ethnic groups and across generations,” Dr. Young stated (Caregiving in the US, 2020).

This policy dialogue highlighted policies at the federal, state, and health system levels that support family caregivers and identified opportunities for nursing leadership to champion health equity and quality outcomes for patients as well as their caregivers.

This document contains highlights of the event, including:

- Summaries of the guest speaker content, as well as a panel Q&A;
- Key take-aways; and
- Recommendations for the future of caregiving.



ABOUT THE AMERICAN ACADEMY OF NURSING

The American Academy of Nursing (Academy) serves the public by advancing health policy through the generation, synthesis, and dissemination of nursing knowledge. Academy Fellows are inducted into the organization for their extraordinary contributions to improve health locally and globally. With more than 2,900 Fellows, the Academy represents nursing’s most accomplished leaders in policy, research, administration, practice, and academia.

Expert panels are one of the major forces within the Academy for developing new knowledge, promoting collaboration, and shaping policy. Fellows leverage their expertise in developing outcomes that provide the critical knowledge, and analysis, summary, and integration for transforming health policy and practice. The Expert Panels advance evidence-based innovations in health care delivery to address health needs. The Academy's Expert Panels host Policy Dialogues on leading healthcare topics to engage on policy proposals and their impact.



MAIN SESSION SUMMARY



Edwin Walker
JD
Deputy Assistant
Secretary for Aging,
Administration for
Community Living

As Deputy Assistant Secretary for Aging at the Administration for Community Living (ACL), Edwin Walker guides and promotes the development of home and community-based long-term care programs, policies, and services for older people and their caregivers. He spoke to the mission and overarching goal of the ACL, which is to support older adults and persons with disabilities to live where they want: in their own home or community.

For over 20 years, the ACL has administered the National Family Caregiver Support Program, designed to invest in support for family caregivers and formally acknowledge the importance of family caregivers in the long-term services system. Since 2019, the ACL has been working to implement the requirements of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (PL 115-119). These efforts included the formation of an advisory council to provide a report and recommendations to Congress that identified the many characteristics of the family caregiver experience. Mr. Walker highlighted the report's findings, noting that the nature of family caregiving is growing ever more complex.

Caregivers must navigate insurance, medication management, new electronic equipment, among other logistical and financial hurdles. The experience is often stressful, exhausting, and emotionally depleting, even more so due to the lack of recognition given to those in the family caregiving role. In response, Mr. Walker discussed the RAISE Family Caregivers Act Advisory Council's report to Congress (ACL, 2021), which included 26 recommendations under five overarching goals: increasing awareness of family caregiving; integrating the caregiver into systems from which they have been excluded; making services and supports to assist family caregivers accessible; increasing financial and workplace protections for caregivers; and improving research and data collection.

"We realize that we must seize this moment because there is a national focus on and appetite for strengthening our nation's caregiving infrastructure...to make sure we treasure and support caregivers in every community throughout the nation."

Edwin Walker, JD



C. Alicia Georges
EdD, RN, FAAN
Professor and Chairperson
of the Department of
Nursing, Lehman College

C. Alicia Georges currently serves as the Chairperson of the Department of Nursing at Lehman College of the City University of New York. Dr. Georges is a Living Legend of the American Academy of Nursing, served as AARP's National Volunteer President through June 2020, and is a leader in health policy development, community engagement, organizational development, and healthy aging. During her remarks, Dr. Georges shared her perspective as a family caregiver and a member of the RAISE Family Caregivers Act Advisory Council. She spoke to the importance of the Advisory Council's findings concerning the issues and challenges faced by family caregivers nationwide.

"Some of the issues that are very, very prominent that became such a big part of our discussion in the Council is that caregiving is so costly, and more than just financially. It is challenging for those of us who are caregivers and have been caregivers," Dr. Georges shared.

Serving as a caregiver costs families mentally and emotionally, in addition to financially, with \$522 billion lost in income each year nationally due to the need for family caregiving (ACL, 2022). Often, caregivers feel invisible. "The pandemic created a new urgency for us, and a momentum for us in the Family Caregiving Council to address caregiving. [The report] highlighted that older adults and family caregivers were adversely affected by the pandemic in this country," Dr. Georges noted, adding that a national strategy is forthcoming.



Meg Kabat
LCSW-C, CCM
Senior Advisor for Families,
Caregivers, and Survivors
US Department of
Veterans Affairs

Meg Kabat serves as the principal advisor to the Secretary and Deputy Secretary of the US Department of Veterans Affairs (VA) on the development, adoption, and implementation of Department-wide programs and policies related to families, caregivers, and survivors of veterans. Ms. Kabat highlighted that the VA serves 9 million veterans per year and that 27% require some level of assistance from a family member or friend in order to stay at home. She discussed the VA's Program of Comprehensive Assistance for Family Caregivers, which provides a stipend and health insurance coverage for caregivers. Due to recent legislation, the number of veterans and their caregivers enrolled in the program has increased to about 35,000.

One major challenge discussed by Ms. Kabat was assessing the needs of the caregiver in relation to the needs of the veteran. Ms. Kabat emphasized that although these needs overlap, caregivers require specialized training and unique resources. For example, a veteran newly diagnosed with dementia may not need a heightened level of care but the caregiver will need additional resources on making decisions in regard to the care of the veteran. By providing resources to both the veteran and family caregiver, outcomes have improved.

"That's really important. We're talking about improving outcomes for, in my case veterans, but in other cases patients, by training and supporting those caregivers at the same time," Ms. Kabat highlighted.



Terry Fulmer
PhD, RN, FAAN
President
The John A. Hartford
Foundation

Terry Fulmer is a Living Legend of the American Academy of Nursing and President of the John A. Hartford Foundation. Dr. Fulmer serves as the chief strategist for the Foundation, which is a national philanthropic organization dedicated to improving the care of older adults. In partnership with the Institute for Healthcare Improvement, American Hospital Association, and the Catholic Health Association of the United States, Dr. Fulmer has worked to advance the Age-Friendly Health System initiative dedicated to bringing evidence-based practices and person-centered care to health systems.

In her remarks, Dr. Fulmer highlighted the importance of the care that family caregivers bring to the nursing home setting. She discussed the effects of the COVID-19 pandemic on nursing homes when critical personal protective equipment and personnel were directed to ICUs first, rather than nursing homes. At the same time, caregivers were no longer allowed to visit and provide care for their family members.

In response, the John A. Hartford Foundation awarded an emergency grant to the National Academies of Sciences, Engineering, and Medicine to fund a study on the quality and safety of care in nursing homes to be released in 2022. Dr. Fulmer shared that during the pandemic, those in nursing home settings without their family caregiver suffered from four "M"s: limited mobility; mental suffering due to isolation and cognitive decline; the possibility of medications being provided inadequately; and missing what matters most and increased feelings of abandonment that older adults experienced during the pandemic.

"For our nursing homes in this country, this is not new. The pandemic shone a critical light on this. So I ask you all, as nurses, to reflect on what your role is as an educator, as a nurse executive, to support caregivers and people in nursing homes."

Terry Fulmer
PhD, RN, FAAN



Susan Reinhard
PhD, RN, FAAN
Senior Vice President and
Director of the Public Policy
Institute
AARP

Susan Reinhard directs the Public Policy Institute at AARP and is a nationally recognized expert in health and long-term care, with extensive experience in conducting, directing and translating research to promote policy change. Dr. Reinhard discussed several key pieces of legislation concerning family caregiving: the RAISE Act (PL 115-119); the Caregiver Advise, Record, Enable (CARE) Act (signed into law in 44 states and the District of Columbia); paid family leave (FMLA), and a caregiver tax credit known as the Credit for Caring Act.



“Just wait: in about a year, we are going to get this strategy, which will then tee up action at the national, state, and local levels that nurses really need to get engaged in,” Dr. Reinhard shared in reference to the RAISE Act implementation strategy forthcoming from the ACL Family Caregiving Advisory Council, which will provide a national roadmap for support of family caregivers (ACL, 2022).

Another key component Dr. Reinhard highlighted is the recognition of the caregiver as an essential member of the health care team. This recognition is a central component in the CARE Act structure, which requires hospitals to include the family caregiver on a patient’s record and care strategy. The CARE Act has been implemented in 44 states and D.C., and Dr. Reinhard urged action to expand implementation to all states. Regarding FMLA, Dr. Reinhard shared that it is a critical time to move towards action. Provisions for paid family leave were previously included in a draft of President Biden’s Build Back Better Act under consideration, but ultimately removed.* Finally, Dr. Reinhard discussed the Credit for Caring Act, introduced as bipartisan legislation in May 2021.** This Act would provide a tax credit on long-term care expenses for family caregivers.



J. Nicholas Dionne-Odom
PhD, RN, ACHPN, FPCN, FAAN
Assistant Professor
The University of Alabama at
Birmingham School of Nursing

J. Nicholas Dionne-Odom, Assistant Professor at the University of Alabama at Birmingham School of Nursing, has extensively researched caregiving for persons receiving palliative care throughout his career. In his remarks, Dr. Dionne-Odom highlighted that the need for caregiving is increasing as life expectancy expands and care coordination continues to grow even more complex. He shared that palliative care, once a specialty, has become mainstream. Policies and resources, he says, are needed to improve the caregiving system including public awareness campaigns to educate the public on palliative care; public health surveillance measures and tools to inform decision-makers; quality measures including quality metrics; and payment models linked to quality measures.



Melissa O'Connor
PhD, MBA, RN, FGSA, FAAN
Professor
Villanova University M. Louise
Fitzpatrick College of Nursing

Melissa O'Connor, Professor at the Villanova University M. Louise Fitzpatrick College of Nursing, is an expert on older adults living in the community, home health decision support, and geriatric nursing. Dr. O'Connor discussed the current phenomenon: as the care needs of older adults are increasing, caregivers are being called upon to provide both skilled and unskilled services for their family members. She noted that many caregivers are millennials in the workforce with their own unique needs. Policy interventions she recommended include generating evidence for providing care to diverse caregivers; investment in the community-based workforce; and messaging outreach tailored to different audiences.



Linda Burnes Bolton
DrPH, RN, FAAN
Senior Vice President & Chief
Health Equity Officer
Cedars-Sinai Medical Center

Linda Burnes Bolton is a Living Legend of the American Academy of Nursing and has impacted health care policy, clinical practice and patient care nationally over a career spanning more than four decades. Dr. Burnes Bolton is an expert in providing quality care and addressing health disparities in underserved and diverser populations. At the time of this dialogue, she served as the Senior Vice President and Chief Health Equity Officer at Cedars-Sinai Medical Center. Dr. Burnes Bolton spoke to the increased need for caregiving services, including 24-hour caregiving services, that most major medical centers are not able to provide. She shared that the Cedars-Sinai Medical Center has been involved in a Patient-Centered Outcomes Research Institute (PCORI) project aiming to keep elders in the community, and emphasized the need for these types of services and care. In recommending the training of all health care professionals on caring for older adults, she added that care is a team effort and must incorporate members at all levels.

“We want to make sure that we’re training and retraining health care professionals. We need the entire workforce engaged and educated on what it is like to care for an older person...I am a big believer in health care as a team sport, and it takes the entire village of healthcare professionals to be able to care for caregivers and their family members.”

*The Build Back Better Act did not advance in Congress. Several provisions of the Build Back Better Act were incorporated into the Inflation Reduction Act of 2022 (PL 117-169), however, paid family leave provisions were not included.

**As of this report’s publication date, the Credit for Caring Act is still pending in Congress.



Q+A PANEL

What do you see as the biggest challenges to advancing supports for caregivers?

In practice, Dr. Reinhard shared that it can be challenging to implement changes such as those from the CARE Act at the systems level and recommended that nurses be proactive in anticipating questions from their patients and family caregivers.

Mr. Walker concurred and shared that the challenges are broad, as outlined in the RAISE Family Caregivers Act Advisory Council report. “From awareness, knowing where to go for help, to understanding that on an individual basis that you are a caregiver. Many people don’t even realize it. They just think ‘I’m being a good son’ or ‘it’s what a spouse would do.’ But they have to understand that they are on a journey and they need support, and that to the degree we are able to provide it, we are trying to do that but more is needed.”

Dr. Georges agreed that more must be done to expand public awareness on family caregiving. Ms. Kabat added that much of the challenge behind family caregiving stems from the lack of long-term care and community services available in the current health care system, which can create an undue burden on family caregivers. Dr. Fulmer shared that more nurses must use their voices to share and move action on these issues.

What are some considerations surrounding caregiving for individuals with mental illness?

Ms. Kabat shared her experiences at the VA regarding mental health care needs of veterans and making mental health care more inclusive for veterans and their caregivers. Challenges Ms. Kabat identified included ensuring that the caregiver is given the tools to effectively communicate with the veteran and improve outcomes.

Dr. Reinhard shared that caregivers for persons with mental illness often feel especially isolated and stigmatized, although there are almost as many caregivers of people with mental illness as there are of people with dementia. She added that the CARE Act helps to address this issue by including the caregiver in the patient’s care strategy.

What non-traditional stakeholders do you envision playing a greater role in the redesign of family caregiving delivery and policies?

Dr. Fulmer shared that venture capitalists and for-profit organizations are moving into this space. Mr. Walker emphasized that caregiving impacts all socioeconomic and ethnic groups and that an all-society approach must be put into place by having public and private entities involved. Dr. Georges highlighted that 30% of caregivers are from racial and ethnic minorities, and crafting approaches for greater support by looking at different communities will be key. Ms. Kabat shared that telehealth will also be critical in this space moving forward. Dr. Reinhard added that state assistive technology plans will also play a role.

How can caregiving policies be designed to respect cultural diversity?

Dr. Reinhard discussed the need for advancement in data to accurately guide policies. She added that AARP’s family caregiving videos showcase diversity and that all tip sheets are translated into numerous languages as well. Dr. Georges concurred that more data is needed and spoke to the value of the group forums conducted with the RAISE Family Caregivers Act Advisory Council. Dr. Fulmer discussed the critical work that the Commonwealth Fund is undertaking on modernizing race and ethnicity data in federal health programs.

What is the role of home health aides in addressing the care needs of older adults?

Dr. Reinhard discussed the importance of recognizing home health aides as vital members of the caregiving team, as they are able to observe and report the individual needs of the older adult in their care. Dr. Georges added that home health aides are critical, yet the issue surrounding home health aides is their cost and who is responsible for paying for their services. She shared that many individuals, especially in rural areas, do not have access to these services or cannot afford it if they are not covered through Medicaid.



Dr. Fulmer shared that the public health system in the US has been underfunded even prior to the COVID-19 pandemic and added that more resources must be directed toward getting nurses and home health aides back into communities. Dr. Dionne-Odom added that lay navigators have been used in the cancer space to direct families to resources and information, which is another avenue for caregiving provision. Ms. Kabat shared that even when home health aide service costs are covered, there have been challenges in implementing these services and concluded that this area is one to explore with innovations.

KEY TAKEAWAYS

Health Professionals Must Receive Training on the Care Needs of Older Adults and their Caregivers Across the Entire Lifespan

Older adults have needs at home, in nursing homes, and across all settings. Family caregivers provide the vast majority of long-term care and should be engaged as vital members of the care team. Health professionals must be prepared with knowledge regarding different needs and their caregiving situations. Schools of nursing must continue to incorporate curriculum to produce professionals that are open, humanistic, and understand healthy aging, as well as how to support caregivers in the vital roles they have towards advancing this goal.

All Institutions Should Join the Age-Friendly Health System Movement

The Age-Friendly movement is for every older person, in any setting, including homeless shelters and nursing homes, to promote and receive proper care.

Investment in the Community Health Workforce is Critical

Federal and other investments must be made in supporting the education and training of health care professionals at every level to support the care of older adults and their caregivers.

An All-Society Approach to Long-Term Service Provision Must be Built

A system that acknowledges and accounts for the provisions of both informal and formal care, in homes, communities, and nursing homes, and across the lifespan must be constructed and implemented.

More Data and Research are Needed to Inform Supports for Older Adults

Research is imperative for making data-informed decisions regarding family caregiving.

RECOMMENDATIONS

1. Increase awareness of family caregiving and prepare all health professionals to support and include family caregivers in care of older adults.
2. Support age-friendly and caregiving scholarship, research, and curricula.
3. Implement the ACL 2022 National Strategy to Support Family Caregivers.
4. Advocate for increased investment in public and community health professionals.
5. Develop and apply an all-society approach to long-term service provision.
6. Expand efforts to recognize family caregivers as essential members of the care team.
7. Encourage institutions to become certified as an Age-Friendly Health System.





ACKNOWLEDGEMENTS

GUEST PANELISTS

Edwin Walker, JD
C. Alicia Georges, EdD, RN, FAAN
Meg Kabat, LCSW-C, CCM
Terry Fulmer, PhD, RN, FAAN
Susan Reinhard, PhD, RN, FAAN*

GUEST PRESENTERS

Linda Burnes Bolton, DrPH, RN, FAAN*
J. Nicholas Dionne-Odom, PhD, RN, ACHPN, FPCN, FAAN*
Melissa O'Connor, PhD, MBA, RN, FGSA, FAAN*

MODERATORS

Heather Young, PhD, RN, FAAN*
Melissa Batchelor, PhD, RN-BC, FNP-BC, FGSA, FAAN*

**Also served on Planning Committee*

JONAS POLICY SCHOLARS

Heather Bradford, PhD(c), CNM, FACNM
Lakeshia Cousin, PhD, APRN, AGPCNP-BC
James Muchira, PhD, MSN

ACADEMY STAFF REPRESENTATIVES

Christine Murphy, MA – Senior Director of Policy
Justin Cowling, MA – Policy and Inclusion Coordinator
Madeleine Rohrbach – Policy Assistant
Lauren Inouye, MPP, RN – Chief Program Officer
Rachael James, BSN, RN – Senior Business and Information Manager
Elena Dixon – Senior Events Manager
Caroline Kane, MS – Chief Advancement Officer
Ellie Cook – Strategic Outreach Manager

REFERENCES

Caregiving in the US. (2020). The National Alliance for Caregiving. Retrieved from <https://www.caregiving.org/research/caregiving-in-the-us/caregiving-in-the-us-2020/>.

MetLife Study of Working Caregivers and Employer Health Care Costs. (2010). Retrieved from https://www.caregiving.org/wp-content/uploads/2020/05/Caregiver_Costs_Study_Web_FINAL_2-12-10.pdf.

RAISE Family Caregivers Act Initial Report to Congress. Administration for Community Living. Retrieved October 18, 2022, from <https://acl.gov/RAISE/report>.

2022 National Strategy to Support Family Caregivers. Administration for Community Living. Retrieved October 18, 2022, from <https://acl.gov/CaregiverStrategy>.