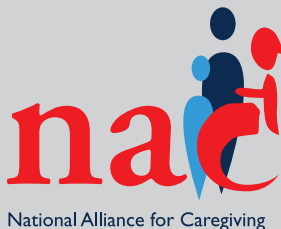




2018-2019 IMPACT: MOVING THE NEEDLE FOR AMERICA'S FAMILIES

RESEARCH | INNOVATION | ADVOCACY





ABOUT NAC

MISSION

Established in 1996, the National Alliance for Caregiving (NAC) is a 501(c)(3) non-profit coalition dedicated to improving quality of life for friend and family caregivers and those in their care, by advancing research, innovation, and advocacy.

In advancing our mission, NAC provides technical assistance to a national network of caregiving coalitions representing nearly 30 states and localities in the United States and has founded the International Alliance of Carer Organizations (IACO).

GOVERNANCE

Our Board of Directors represents the non-profit, corporate, and academic leaders committed to improving the lives of family caregivers across the lifespan. Each Director accepts significant responsibility to proactively carry out NAC's mission.

MEMBERSHIP

While governance and voting privileges reside with our Board of Directors, all National Alliance for Caregiving Members have many opportunities to engage with our broad constituency of providers, researchers, medical product innovators, state and local caregiving advocates, and other professionals and stakeholders engaged in the family caregiving field.

Report Author: Charlotte Davidson,
Fellow (Fall 2018 – Fall 2019)

A NOTE FROM THE PRESIDENT'S DESK

It's no exaggeration to say that friends and family are the backbone of our longterm care system in the United States. Time and time again, we see health, social, and long-term care systems relying on unpaid caregivers to improve the health of those in their care. As we increasingly rely on caregivers to bridge gaps, we also need to protect the caregiver as a unique individual with their own needs. Roughly 43.5 million Americans provide care each year, and these caregivers need advocates armed with evidence to address the needs of an aging nation.

That's why for more than twenty years the National Alliance for Caregiving (NAC) has worked to improve the quality of life for the family caregiver and those in their care through research, innovation, and advocacy. In 2018 and 2019, with nearly 60 organizational members committed to supporting caregivers by our side, we shared new knowledge, created new tools, advocated for our nation's families, and advanced a global strategy for family caregiving. For the first time, we also provided new caregiver benefits to our own workforce, including a paid family/medical leave benefit, a caregiver respite benefit, and flex-time/telework schedules.

We live our mission -- inside the office, out in the field, up on Capitol Hill, and with stakeholders who share our passion for improving lives for families. I'm a firm believer that "a rising tide lifts all boats" and grateful for your role in this movement. Together, we can pave the path for a kinder, more caring world.

Kind regards,

C. Grace Whiting, J.D.
President and CEO, National Alliance for Caregiving
Governing Board, International Alliance of Carer Organizations



"Advocating for families and representing the needs of caregivers with policymakers and persons of influence is an honor - we are helping those who are often so selfless that they don't ask for help for themselves,"
– C. Grace Whiting, President and CEO of NAC.



MOVING THE NEEDLE FOR AMERICA'S FAMILIES:

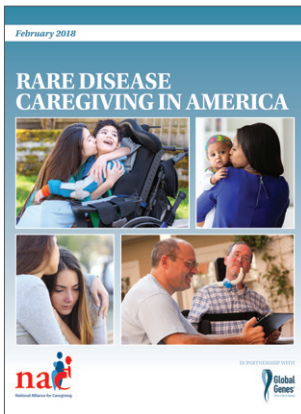
STRATEGIC GOALS

For 2018-2020, we identified three strategic goals to guide our work and key accomplishments:

- 1** Build momentum for a national caregiving movement that will empower families across the lifespan.
- 2** Create system-wide pathways for caregivers, recognizing their unique role as a member of the care team.
- 3** Align with global partners to recognize, respect, and support the caregiver's needs for self-determination.

MOVING THE NEEDLE FOR AMERICA'S FAMILIES:

KEY ACCOMPLISHMENTS

BUILDING MOMENTUM TO EMPOWER
AMERICA'S FAMILIES, ACROSS THE LIFESPAN***Rare Disease Caregiving in America, February 2018***

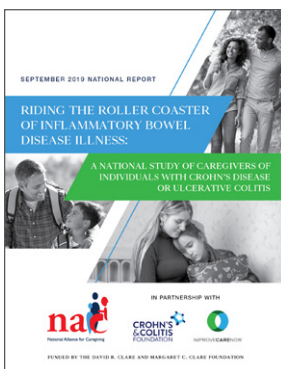
- In partnership with the leading rare disease patient advocacy organization, Global Genes
- First national policy study of rare disease caregivers
- Captured perspectives covering more than 400 orphan diseases and rare conditions, with insight from over 1,400 adults who provide care to a child or adult with a rare disease or condition

Addressing Family Caregiving as a Public Health Issue, January 2018

- Featured policy perspectives from the National Conference of Caregiving Advocates and subject-matter experts at Johns Hopkins Bloomberg School of Public Health, Appalachian State University, the University of Pittsburgh, and the Centers for Disease Control and Prevention Identified actions that can be taken by state and local coalitions, health systems, and policymakers to understand and address the impact of family caregiving on the public's health
- Focus of a Yale Alumni in Public Health briefing in New York, New York in partnership with thought-leaders from Yale School of Medicine

Summit on Public/Private Innovation and Family Caregiving, April 2018

- Convening of 25 subject-matter experts from the nonprofit, corporate, academia, philanthropy, and public sectors to support the establishment of a multi-stakeholder innovation fund for caregiving research, following Recommendation 3 in the 2016 *Families Caring for an Aging America* report from the National Academies of Sciences, Engineering, and Medicine
- Action items identified in the white paper, *Moving Forward on Behalf of Family Caregivers in the US: Designing a Public-Private Fund to Support Research and Innovation*, which provide insights into how a public-private research partnership for caregiving research might work

***Riding the Roller Coaster of Inflammatory Bowel Disease: A National Study of Caregivers of Individuals with Crohn's Disease or Ulcerative Colitis, September 2019***

- Conducted in partnership with patient advocacy organizations, including the Crohn's & Colitis Foundation and ImproveCareNow and disseminated with national autoimmune organizations including the American Autoimmune Related Diseases Association (AARDA)
- First-of-its-kind report looking at the impact of chronic, autoimmune conditions on friend and family caregivers
- Captured perspectives from over 700 individuals who provide unpaid care for someone living with Inflammatory Bowel Disease (IBD)

Sandwich Generation Caregiving in the U.S., November 2019

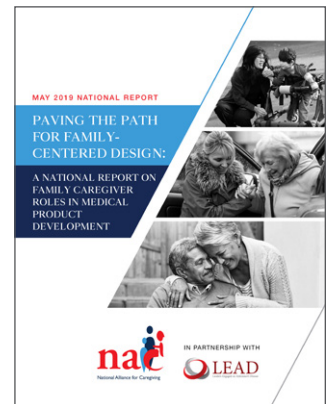
- In partnership with NAC members Caring Across Generations and MassMutual
- Provides a secondary analysis of data from *Caregiving in the U.S. 2015*, to provide new insights about “sandwich generation” caregivers balancing multiple care recipients
- Outlines the challenges facing caregivers with a minor child and an aging adult in the same household, with statistically representative data from U.S. caregivers
- Data was taken from the responses of 328 sandwich caregivers identified in the *Caregiving in the U.S. 2015* study conducted in partnership with AARP Public Policy Institute

The advocacy team at the National Alliance for Caregiving continued its efforts to advance our core advocacy principles.

CREATING SYSTEM-WIDE PATHWAYS FOR CAREGIVING AS MEMBERS OF THE CARE TEAM

Family Caregiver’s Role in Patient-Focused Medical Product Development, 2018-2020

- In partnership with Leaders Engaged on Alzheimer’s Disease (the LEAD Coalition), led a multi-stakeholder summit on the caregiver’s role in patient-focused drug and device development with industry partners, federal representatives, researchers, and patient advocates
- The report from that summit, *Paving the Path for Family-Centered Design: A National Report on Family Caregiver Roles in Medical Product Development*, was released in the summer of 2019 and has been shared at major biomedical conferences and with industry partners
- Ongoing implementation through the Caregiving Pathways Task Force including potential future work with the FDA and clinical trial developers



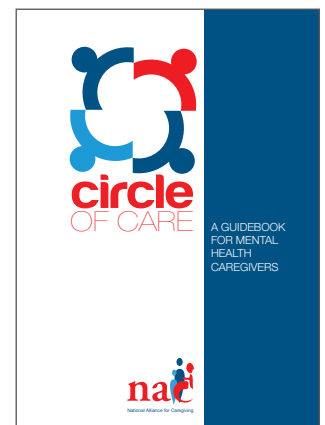
NAC partnered with other advocacy organizations to create new tools and supports that help family caregivers address and cope with the challenges of caring for a friend or family member:

Circle of Care: A Guidebook for Mental Health Caregivers, Spring 2018

- Emerged from the 2016 national study on mental health caregiving, *On Pins and Needles: Caregivers of Adults with Mental Illness*, conducted with the assistance of the National Alliance on Mental Illness and Mental Health America
- Designed to guide mental health family caregivers with subject-matter experts from NAMI, and disseminated to local chapters of NAMI and the VA throughout the country

Support for Caregivers of Veterans

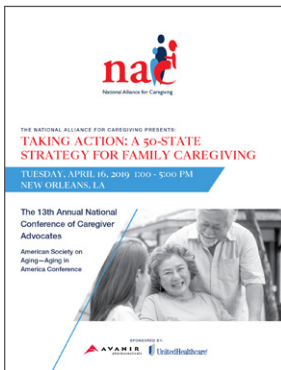
- Provided ongoing evaluation and recommendations for the National Veteran Caregiver Training Program at the U.S. Department of Veterans Affairs
- Supported new legislation under the VA Mission Act that expanded the reach of the Training Program for all veterans injured in conflicts prior to 1950 to veterans injured in post-9/11 conflicts



ALIGNING WITH GLOBAL EFFORTS TO RECOGNIZE, RESPECT, AND SUPPORT THE CAREGIVER'S NEEDS

The advocacy team at the National Alliance for Caregiving continued its efforts to advance our core advocacy principles:

- Expanding caregiver access to supports and services
- Investing in caregiver research and evidence-based practices
- Protecting the financial security of caregivers
- Including caregivers as vital members of the health and human service system
- Enhancing the health and wellness of caregivers



National Conference of Caregiving Advocates

- In 2018, over 100 advocates and thought-leaders attended the one-day meeting, which featured topics focused on building advocacy capacity for the network and a 21st century workforce
- Nearly 100 advocates attended the Conference in 2019 to share information on their state and local caregiving landscapes and to begin work to create and implement an effective 50-State Strategy on Family Caregiving
- Positive stakeholder feedback about the conference led to new funding to identify key elements of a model state caregiving strategy, launching in the final quarter of 2019

Multi-Stakeholder Advocacy Collaborative

- 31 state and local advocates are active members in the Collaborative; 80 organizations and advocates participate in the National Network of Advocates
- **Officially becoming the Advocacy Collaborative** in 2019, this group expanded its reach to include federal advocates from member organizations, national coalitions, and others

Educational Campaign for Medicare's LIS Program

- In 2019, NAC developed a virtual 'toolkit' to help educate state and local caregiving coalitions about the Low-income Subsidy (LIS) available under Medicare Part D
- The toolkit will be made permanently on the NAC website
- To date, NAC has engaged 50 caregiving coalitions and advocates with the project and will distribute the toolkit to caregiving coalition members during the Fall 2020 enrollment period



Reauthorization of the Older Americans Act (OAA), 2019 Campaign

- Developed new advocacy positions as part of the reauthorization effort that would expand the reach of the Older Americans Act to include:
 - An increase in funding to the National Family Caregiver Support Program
 - A federal caregiver resource center to align information and support
 - An extension of the RAISE Family Caregiver Act Advisory Council, housed at the U.S. Department of Health & Human Services, beyond 2021
 - A call for improved multi-agency research on caregivers
 - A call for increased use of caregiver assessment tools in the delivery of home- and community-based services

- NAC's CEO provided Congressional testimony in the U.S. House of Representatives on May 10th, 2019 to support the OAA recommendations at the hearing, ***Examining the Older Americans Act: Promoting Independence and Dignity for Older Americans***
- NAC supported the introduction of legislation in the U.S. House and U.S. Senate, including some components of NAC-proposed expansion

RAISE Family Caregiving Advisory Council

- Participated in a community-led working group to identify Congressional champions and advance the RAISE Act legislation ahead of its bipartisan enactment in January 2018
- NAC's CEO shared perspectives on the national caregiving landscape at the inaugural meeting of the **RAISE Family Caregiving Advisory Council** in August 2019
- NAC leadership will serve as expert faculty for the NASHP's RAISE Act Family Caregiver Resource and Dissemination Center

GLOBAL ENGAGEMENT

As the Founder of the International Alliance of Carer Organizations (IACO), NAC continued its efforts to align U.S. efforts with global partners by sharing important international information and best practices:

Living with Multiple Sclerosis: The Carers Perspective, 2018

- Participated in the design, fielding, and drafting of a multi-national study of caregivers of people who live with multiple sclerosis
- Distributed to NAC members and promoted to caregiving advocates across the U.S. in collaboration with the International Alliance of Carer Organizations (IACO) and the Embracing Carers global movement

Global State of Care Report, 2018

- Identified core components of the U.S. caregiving support system for inclusion in the multinational profile of caregiving policy around the world
- In partnership with IACO and the Embracing Carers global movement, incorporated the Global State of Care Report into national and grassroots policy positions
- Milestone report that provides an assessment of unique carer needs and existing programs, practices, and policies for unpaid carers across nine different countries

THANK YOU

NAC would like to thank its members and partners without whom the important work we do to advance family caregiving would not be possible.

We also gratefully acknowledge the funders and sponsors who supported the work described in this Impact Report as well as other activities undertaken in 2018-2019:

Alexion
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TechWerks
Vertex
Ultragenyx
UnitedHealthcare
University of Illinois at Chicago
(Family Support Research and Training Center)



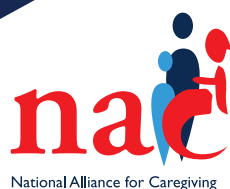


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About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The NAC conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the NAC supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at www.caregiving.org.