

Chronic Disease Family Caregiving Through a Public Health Lens

**THE FRAMEWORK FOR FAMILY
CAREGIVING AND PUBLIC HEALTH**

SEPTEMBER 2022 REPORT



NATIONAL ASSOCIATION OF
CHRONIC DISEASE DIRECTORS
Promoting Health. Preventing Disease.

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About the National Alliance for Caregiving (NAC)

The National Alliance for Caregiving (NAC) is a 501(c)(3) charitable nonprofit organization dedicated to improving quality of life for unpaid friend or family caregivers through research, innovation, and advocacy. For more than twenty years, we have conducted public policy research on the family caregiving experience of unpaid friends and family members, including our long-running research series, *Caregiving in the U.S.*, conducted in partnership with AARP. The NAC is the founder of and Secretariat for the International Alliance of Carer Organizations (IACO). In this role, we support a global coalition that includes sixteen nongovernmental organizations, including: Australia, Canada, Denmark, Finland, France, Hong Kong, India and Nepal, Ireland, Israel, Japan, New Zealand, Sweden, Taiwan, and the United Kingdom.

About the National Association of Chronic Disease Directors

The NACDD is a 501(c)(3), capacity-building nonprofit organization. For more than thirty years, NACDD has been providing support and technical assistance to state and territorial health departments. The NACDD mission is to improve public health by strengthening state-based leadership and expertise for chronic disease prevention and control in states and at the national level. NACDD works with national, state, and local partners to lead and influence the ways in which chronic disease prevention and health promotion shapes the future health landscape.

About The John A. Hartford Foundation

Based in New York City, The John A. Hartford Foundation is a private, nonpartisan philanthropy dedicated to improving the care of older adults. Established in 1929, the Foundation has three priority areas: creating age-friendly health systems, supporting family caregiving, and improving serious illness and end-of-life care.

Executive Summary

The importance of considering family caregiving from a public health perspective is more relevant and timely than ever. With higher rates of childlessness among baby boomers, smaller and more geographically dispersed families, and increased participation of women in the labor force, the need to address continued availability of family caregivers is critical.

At the same time, advances in medicine that save and extend lives also happen to increase the duration, complexity, and technical difficulty of care required for individuals with chronic disease, serious illness, and disability. The COVID-19 pandemic has further underscored the important role family caregivers play for those with serious or chronic conditions.

Their ability to provide care and their effectiveness in doing so will, however, depend on fundamental changes in the extent to which we formally recognize them as key contributors to the health of those for whom they care, integrate them into formal provider systems, and provide support that recognizes their risk factors. Family caregiving is an important public health issue not only for those they care for, but the caregivers themselves. They face an increased risk of deteriorating health and financial insecurity—making the role of caregiving itself a social determinant of health.

To address these challenges, we call attention to two specific root-level issues - 1) Family caregiver health and wellness is an issue that must be addressed. 2) Care coordination efforts are an increasing concern for both the family caregiver, as well as the person with complex conditions. A public health approach to supporting family caregivers is critical given the downstream effects that family caregiving has on individuals and communities. Framing family caregiving from the public health perspective makes issues related to serving in the family caregiver role a lifespan concern. Although many family caregivers are adult children caring for parents experiencing challenges related to old age, proven support tactics and techniques can be implemented to ensure that family caregivers across chronic conditions and serious illnesses do not incur undue health implications. Actions such as The Healthy Brain Initiative and Building Our Largest Dementia (BOLD) Infrastructure initiatives, both driven by a partnership between the Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association, as well as the Age-Friendly Public Health Systems (AFPHS) Initiative driven by the Trust for America's Health (TFAH), demonstrate a track record of effort and interest in addressing family caregiving as a public health issue.

The Framework for Family Caregiving and Public Health (The Framework) offers an action-oriented approach to strengthening connections and coordination between these efforts with the family caregiver as the focal point. The Framework provides policy recommendations, implementation opportunities, and messaging content aimed at enhancing the national family caregiver support infrastructure through a public health lens. It identifies appropriate mechanisms and practices to implement family caregiver supports via public health entities such as chronic disease directors and state health departments, often in coordination with the direct care workforce and community-based organizations that typically deliver supports and services to family caregivers. The information gathered in this report was driven and informed by data collected via surveys of chronic disease directors, informational interviews with subject matter experts, and an in-depth environmental scan of current initiatives within public health to address the needs of family caregivers on from a population health perspective.

The Framework was designed in tiers to address actions that are likely to be driven by different sectors of the public health system. Tier 1 focuses on data, research, and awareness activities most effectively driven at the national level. Tier 2 focuses on services and care support activities best implemented at the state or local level. The overarching goal of The Framework is to improve the health, wealth, and equity of family caregivers to ensure person and family-centered care and address issues related to social determinants of health.

Finally, the report outlines policy actions to increase the coordination and support of public health entities, community-based organizations, and health systems in integrating the caregiver perspective into public health programming and policies. The report also outlines an implementation framework for public health stakeholders to pilot actions in support of family caregivers across the lifespan. In tandem, these policy and implementation actions are designed to strengthen the public health community's ability to respond to the growing challenges and opportunities of family caregiving.



Family Caregiver Spotlight

Jennifer, a family caregiver in Florida, first noticed her mother was having trouble with her short-term memory. Over time, her condition escalated to include paranoia, getting lost or confused easily, suffering from hallucinations, making calls to 911 to report serious crimes that hadn't happened, and leaving home for days at a time without telling anyone where she was going. Jennifer eventually moved her mother into an assisted living facility.

The COVID-19 pandemic brought new concerns about the care Jennifer's mother was receiving. Visits to the assisted living facility weren't allowed so Jennifer couldn't witness the care her mom received, nor was she informed of her mother's health changes. Jennifer learned her mother had become completely incontinent only after her mother had been hospitalized. When she asked the assisted living facility staff about it, they said her mother really needed plastic mattress pads. Jennifer worried her mother had been lying on a soiled mattress for months.

Although Jennifer's challenges were exacerbated during the COVID-19 outbreak, millions of other family caregivers faced similar challenges prior to the pandemic and will continue to do so in the future. Like other family caregivers, Jennifer was surprised by the insensitivity she encountered from specialists. She believes that health care and community services need systemic improvements that address the interconnected challenges related to the care of those with serious or chronic health conditions and associated social determinants of health.

INTRODUCTION

Foundation for The Framework and Project Background

By prioritizing the expansion of the national family caregiver support infrastructure into new jurisdictions such as the public health sector, there is potential to reach family caregivers across the range of chronic conditions—from Alzheimer’s disease and dementia to cancer, ALS, stroke, heart disease, and beyond. The Framework for Family Caregiving and Public Health not only recognizes the contributions family caregivers make for those with chronic conditions, it also views family caregivers as a distinct at-risk population requiring intervention and societal support.

Generally, our definition of “family caregiver” comes from the R.A.I.S.E. Family Caregivers Act, which defines a caregiver as “an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation.”

Family caregiver health and wellness is an issue that must be addressed

More than **40%** of family caregivers reported having two or more chronic diseases.ⁱ

23% of family caregivers find it difficult to take care of their own health.ⁱⁱ

Of those family caregivers who report difficulties in taking care of their own health, **60% report that caregiving has made their health worse.**ⁱⁱⁱ

34% of African American caregivers and **35%** of Latino caregivers were less likely to report their own health as excellent or very good as compared to white caregivers (45%).^{iv}

Although many family caregivers find some level of satisfaction in providing support to the person for whom they are caring, the support family caregivers provide is not without cost—sometimes referred to as a “burden”—to both the family caregiver and the person receiving care. Many family caregivers are overwhelmed and face financial, emotional, and psychosocial risks that increasingly result in a decline of their own health and wellness.

The stress of providing medical and personal care services is a major risk factor for developing numerous chronic conditions on the part of the family caregiver. Due to its stressful and demanding nature, the role of family caregiving can potentially lead to health problems related to a sedentary lifestyle, poor nutrition, social isolation, and overuse and abuse of substances such as alcohol or prescription drugs. Another common result of the burden of family caregiving is absenteeism or presenteeism at work (i.e., not going to work at all or going to work while ill) — an additional strain for the individual, family, and employer.^v

The decline in caregiver self-reported health is concerning, as the stress associated with caregiving may exacerbate declines in health that occur with age. This means that supports for caregivers and their recipients will be even more critical if this trend in declining caregiver health continues to hold. From a policy perspective, the strain of disease or disability on a family unit can endanger larger system goals to improve health care and reduce overall costs in an increasingly strained system.^{vi} The nature of family caregiving will become more complex as increasing life expectancies tax the ability of family caregivers to provide care. The challenge for public health systems is to understand more about those caregivers who are particularly vulnerable and why and then to design and implement evidence-based interventions to address identified needs.^{vii}

Disparities in support, caregiving intensity, health, and financial impacts among caregivers of color, LGBTQ caregivers, as well as caregivers across different income brackets and geographical areas are also evident and of particular concern. Meaningful person and family engagement in U.S. health and social care systems must also ensure a robust and inclusive system of services and supports that intentionally addresses health disparities and systemic barriers among diverse populations based on representative data. A critical component to ensuring a greater level of equity includes acknowledging, incorporating, and continually improving cultural literacy into the development of programs, resources, and services designed for family caregivers of diverse backgrounds.^{viii}

It’s important to address the strain placed on family caregivers, including measures to alleviate concerns about how to plan and manage the financial issues and expenses of family caregiving. Additionally, support is needed to help family caregivers manage the physical, mental, and emotional stress of the family caregiving role.

“Intense caregiving lends itself to a variety of public health concerns. For example, caregivers may not obtain routine health care or undergo health screenings, and thus they may encounter health problems that could have been averted.”

— *“Framing the Public Health of Caregiving,”
Talley and Crews*

Care coordination efforts are of particular concern as the complexity of care is increasing

Most family caregivers report the reason for providing care is due to issues related to either “old age”, “mobility issues”, “Alzheimer’s or dementia”, “cancer”, “mental or emotional illness”, “stroke”, “diabetes”, and “heart disease”.^{ix}

A greater proportion of family caregivers of adults report their recipient is dealing with multiple condition categories, with 45% reporting two or more condition categories, compared to 37% in 2015.^x

There is a need to better equip state-level public health entities to play a greater role in coordinating family caregiver supports and services across sectors and siloed systems recognizing challenges related to co-morbidities for the care recipient. This is critical because family caregivers can be key partners in improving health outcomes, reducing costs, and ensuring a greater level of person-centered care for people with chronic conditions and disabilities. In fact, about 32% of family caregivers provide care for 21 hours or more each week. More than half (57%) of America’s family caregivers are providing health care services to individual patients, through medical/nursing tasks such as giving injections, tube feedings, catheter and colostomy care, and other complex care responsibilities. Many others help with managing medication (46%) and medical care related transportation (78%).^{xi}

Some family caregivers even play a defined role in supporting clinical trials, helping with activities such as completing paperwork, coordinating care, researching trial opportunities, and paying for related costs. Individuals and families who face highly stigmatized, medically complex health conditions often face long diagnostic journeys and numerous hurdles to find the right health improvement interventions. Handling the complexity of care requires more intentional planning and communication around care coordination, a critical aspect to helping family caregivers ensure the person they are caring for is safe.

Of key concern for policy makers and other stakeholders is whether this arrangement is sustainable with the care gap looming on the horizon, as more people need care and fewer potential family members are available to provide that everyday help. Without greater explicit support for family caregivers in coordination among the public and

private sectors and across multiple disciplines, overall care responsibilities will likely intensify and place greater pressures on individuals within families, especially as baby boomers move into old age.^{xii}

An important consideration for engaging family caregivers is that the role of the family caregiver in the patient journey may change over time. For example, the parent of a child may have less of a role in patient care as the child reaches adulthood. By contrast, the family caregiver of an individual with a neurodegenerative disease such as Alzheimer’s disease will have a more involved role as the disease progresses and the patient declines. The role of the family caregiver may also fluctuate over time, such as in the case of caregivers of individuals with severe mental illnesses such as schizophrenia where the patient may be highly functional at times but require substantial support during an acute episode. There is an opportunity for public health experts, policy makers, health and social providers, researchers, employers, financial institutions, and other stakeholders to work together to improve the health care and Long-Term Services and Supports (LTSS) so they can address the needs of caregivers.^{xiii}

“The chief risk of institutionalization is not a decline in the health of care recipients but a decline in the health of family caregivers themselves. If the caregiver is healthy, the quality of life of the care recipient will be substantially improved.”

— *“Framing the Public Health of Caregiving,”*
Talley and Crews

Developing The Framework

In 2020, NAC began working with the National Association of Chronic Disease Directors to develop an action plan for expanding the family caregiver support infrastructure within in the public health sector. Many of the components in this framework intentionally align with the actions already outlined and defined in the public health sector, such as the CDC’s Healthy Brain Initiative and Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act, as well as TFAH’s Age-Friendly Public Health Systems (AFPHS) Initiative.

We envisioned a framework that would identify the appropriate mechanisms and practices which could be administered to implement family caregiver supports via entities such as public health departments, community-based organizations, faith-based organizations, direct care workers, insurers, health care providers, and employers. These practices would be aimed at addressing the health and wellness of family caregivers, ensuring patient and family-centered care, and identifying and addressing relevant components of social determinants of health and health equity. Components covered in developing this framework include:

- Public health funding mechanisms for expanded support to family caregivers through new or existing programs or initiatives.
- Enhanced coordination of public health stakeholders, providing services and support to family caregivers at the national, state, and local levels.
- Strategies for public health messaging around the challenges facing family caregivers.
- Improved use of data collection tools such as the Behavioral Risk Factor Surveillance System (BRFSS) and the like.

Public health agencies and private, nonprofit, and government partners at the national, state, and local levels can work together on the actions needed to make family caregiving the next public health success story in a way that considers both the needs of the care recipient and the health and well being of the family caregiver. These populations are interlinked and require coordinated engagement and action.

The effort to better integrate family caregivers into the public health aligns with the following key essential public health services according to the Center’s for Disease Control and Prevention:

- Assess and monitor population health status, factors that influence health, and community needs and assets
- Investigate, diagnose, and address health problems and hazards affecting the population
- Communicate effectively to inform and educate people about health, factors that influence it, and how to improve it
- Strengthen, support, and mobilize communities and partnerships to improve health
- Create, champion, and implement policies, plans, and laws that impact health
- Improve and innovate public health functions through ongoing evaluation, research, and continuous quality improvement.

“Individuals with good sources of caregiving support are less likely to be institutionalized than care recipients without such support. Absence of family caregiving is a leading predictor of institutionalization.”

— *“Framing the Public Health of Caregiving,”
Talley and Crews*

The current national landscape brings with it a unique opportunity to leverage recent work that has been done to establish and implement policy recommendations for family caregiver issues. Two critical aspects in the policy landscape highlight this opportunity:

- 1 The COVID-19 pandemic made society more aware of the contributions that family caregivers provide and the hardships they experience. An infrastructure for public health that includes and understands the needs of family caregivers will be better prepared to interact with them during other public health emergencies.
- 2 The Recognize, Assist, Include, Support, and Engage Family Caregiver Act (R.A.I.S.E.) requires the Secretary of Health and Human Services to develop, maintain, and update an integrated national strategy to recognize and support family caregivers. This strategy can help bring together relevant federal agencies and others from private and public sectors to advise and make recommendations regarding the national strategy. The initial congressional report for this National Strategy was released in fall of 2021.

As a National Family Caregiving Strategy is being finalized, and as public health reforms in the post-COVID-19 era are being examined, the framework described in this report offers immediate actions that can help the public health community better serve family caregivers and improve population health outcomes for this growing community.

To further define actions for integrating caregivers and caregiving into public health practice and aligning existing initiatives, we surveyed fifty-nine chronic disease directors from all U.S. states and territories (see Appendix A) to understand:

- How that network of professionals within the public health eco-system is currently serving family caregivers.
- Their familiarity with existing family caregiver programs.
- Whether they were familiar with their state's intent to implement the BRFSS caregiver module.

Two focus groups (See Appendix B) were held with those in the chronic disease director network to probe deeper into how family caregiver services and supports, messaging tactics, and data collection efforts could potentially be administered in alignment with essential public health functions.

Finally, we held a thought leader roundtable (See Appendix C) of distinguished experts in public health, aging, chronic disease, and family caregiving related issues to explore two concerns:

- How family caregiver data collection, messaging, and service delivery would best be implemented; and
- How to ensure public health leaders prioritize the recommendations outlined in the framework.



The R.A.I.S.E. Family Caregiver Act and National Strategy

The September 2021 initial report of the Recognize, Assist, Include, Support and Engage Family Caregiver Act (R.A.I.S.E.) to Congress identified five unifying characteristics of the experience of family caregiving that drive the need for a more holistic approach to supporting family caregivers:

- There is a significant personal relationship (or connection) between family caregivers and the people who receive support. Family caregivers provide care in response to tradition, culture, family expectation, and other factors.
- Family caregivers provide support so that family members and close friends can maintain their independence, dignity, engagement, and/or quality of life.
- Support is often provided without a formal assessment of the needs of the person receiving care or the family caregiver's own needs. This means they may have to take on tasks they do not know how to do, or do not feel comfortable doing, and have little access to training or assistance.
- The nature of family caregiving is becoming more and more complex as it expands further into medical, administrative, and care coordination activities. Whereas caregiving at one time might have meant helping with activities of daily living (ADLs), now it can include medication management, dealing with insurance payers, technical support for electronic equipment and medical devices, coordinating care across systems, and much more.
- Because they often are overlooked and have few consistent supports, the experience of being a family caregiver, no matter how emotionally rewarding, can leave caregivers financially, emotionally, and physically depleted and socially isolated.

STRATEGIES AND RECOMMENDATIONS

The Framework for Family Caregiving and Public Health

The Framework for Family Caregiving and Public Health is designed to indicate activities that can be taken within different sectors of the public health system and doesn't prescribe a specific level of priority.

Tier 1 focuses on data, research, and awareness activities that can most effectively be driven on the national level.

Tier 2 focuses on services and care support activities that can best be implemented via partnerships on the state or local level.

The “implementation opportunities” highlighted in this section describe potential avenues to build on currently existing efforts using the recommendations in this framework. There is no one-size-fits-all approach to how each of the identified opportunities may be utilized but they offer suggestions for further innovative engagement by those in the field of public health.

STRATEGY 1.1:

Family Caregiver Population Health Surveillance

OBJECTIVE: *Gather timely and essential national and state-level data to assess and monitor the health status of family caregivers, factors that influence their health outcomes and disparities, and evaluate family caregiver support and education programs to determine accessibility, effectiveness, equitability, and impact.*

Recommendations:

1. Strengthen family caregiver data collected via the Behavioral Risk Factor Surveillance System (BRFSS).
 - Include questions in the core sections of the BRFSS to gather family caregiver data.
2. Explore further use of tools such as National Health and Nutrition Examination Survey, the National Health and Aging Trends Study, and the National Health Interview Survey.
3. Improve data collection on family caregiver health conditions and risk factors.
4. Improve data collection on family caregivers of people with multiple conditions.
5. Construct additional channels on the local level that can gather detailed patient and family caregiver experience data to inform public health program and policy development.
6. Collect disaggregated data on diverse family caregiver populations and address the lack of segmentation and intersectionality in family caregiver research.
7. Ensure family caregiver data is collected on a consistent basis to track trends over time.

**IMPLEMENTATION OPPORTUNITY****National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)**

The CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) is dedicated to preventing chronic diseases and promoting health across the life span. Funds channeled through the NCCDPHP establish science-based programs that prevent chronic diseases and reduce unhealthy behaviors in communities across the nation. These efforts improve health-related quality of life and save money in medical costs and lost productivity. Through the NCCDPHP, the CDC conducts surveillance of chronic diseases to:

- Better understand the extent of health risk behaviors, preventive care practices, and the burden of chronic diseases.
- Monitor the progress of prevention efforts.
- Help public health professionals and policy makers make more timely and effective decisions.

STRATEGY 1.2:

Family Caregiver Public Health Research & Education

OBJECTIVE: *Integrate and improve family caregiver research and literature within schools of public health and professional public health associations and institutions to evolve and adapt the systems wherein family caregivers interact, as well as the future public health workforce focused on care and support for those with serious or chronic conditions.*

Recommendations:

1. Design and implement public health research analyzing interventions for family caregivers of those across the range of chronic conditions to better understand how to address issues related to social determinants of health, health equity, improved health outcomes, and person and family-centered care.
2. Incentivize schools of public health to improve data collection on family caregiver health and risk factors and integrate findings into the public health curricula.
3. Improve and innovate on existing public health functions through ongoing evaluation, research, and continuous quality improvement to more effectively reach and support family caregivers of those with chronic conditions.

**IMPLEMENTATION OPPORTUNITY****The National Institute of Nursing Research (NINR)**

NINR leads nursing research to solve pressing health challenges and inform practice and policy – optimizing health and advancing health equity into the future. NINR identified five complementary and synergistic research lenses that best leverage the strengths of nursing research and promote multilevel approaches, cross-disciplinary and cross-sectoral collaboration, and community engagement in research. The research lenses are: Health Equity, Social Determinants of Health, Population and Community Health, Prevention and Health Promotion, Systems and Models of Care.

In 2017, NINR and its partners hosted a two-day research summit, *“The Science of Caregiving: Bringing Voices Together”*, to examine the importance of caregiving across the lifespan, as well as current and future directions for research to improve the health of patients and caregivers.

**IMPLEMENTATION OPPORTUNITY****Caregiver Research at The National Institutes of Health Clinical Center**

At the NIH Clinical Center, clinical research participants—more than 500,000 since the hospital opened in 1953—are active partners in medical discovery, a partnership that has resulted in a long list of medical milestones. Currently, there are about 1,600 clinical research studies in progress at the NIH Clinical Center. The NIH Clinical Center recognizes family caregivers and extensive work has been completed documenting the effects of caregiving.

TIER 1

PUBLIC HEALTH DATA GATHERING, RESEARCH, AND AWARENESS

STRATEGY 1.3:

Family Caregiver Public Health Awareness

OBJECTIVE: *Implement messaging through public health channels to inform and educate systems involving health care, social services, employers, and emergency response officials that underscores the essential role of family caregivers and the importance of maintaining their health and well-being.*

Recommendations:

1. Conduct awareness efforts describing the value of the family caregiver in chronic disease management and intervention.
2. Conduct awareness efforts that describe health conditions and risk factors experienced by family caregivers.
3. Highlight public health functions that can be implemented to improve culturally competent outreach and awareness efforts among diverse family caregiver populations.
4. Ensure awareness efforts that are separately targeted at health practitioners, social service entities, employers, and emergency response systems.
5. Increase awareness among health practitioners, social service entities, etc of available resources and best-practice interventions to support family caregivers.

CAREGIVING IN THE U.S. RESEARCH SERIES

The National Alliance for Caregiving (NAC) and AARP Public Policy Institute provide nationally representative and up-to-date research trends of family caregivers via its research series, Caregiving in the U.S., conducted approximately every five years. According to Caregiving in the U.S. 2020, **23% of Americans say caregiving has made their health worse.**



TIER 1

PUBLIC HEALTH DATA GATHERING, RESEARCH, AND AWARENESS

STRATEGY 1.3 CONTINUED: Messaging Strategies



MESSAGING STRATEGY #1: To Reach Public Health Practitioners

Focus on care support and disease prevention.

- Highlight family caregiver risk factors.
- Highlight challenges caring for those with multiple conditions.

Provide context: Family caregiver supports can reframe “you vs. me” to “us vs. the disease.”

Focus on common chronic conditions such as dementia, cancer, physical disability, behavioral health, stroke, ALS, heart disease, asthma, diabetes.



MESSAGING STRATEGY #2: To Reach Employers and the Business Community

Focus on the population level impact for the workforce and productivity to employers.

Focus on the impact of the inability to work because of caregiving responsibilities.

Provide context: Employers are concerned about how often caregivers are not at work or need time off.



MESSAGING STRATEGY #3: Design Messaging Around Family Caregivers of Care Recipients with Chronic Conditions

Data point: A greater proportion of caregivers of adults report their recipient is dealing with multiple condition categories, with 45 percent reporting two or more condition categories, compared to 37 percent in 2015.

Make the case that funds are needed to strengthen care coordination capacity.

- Especially for addressing social determinants of health related to dementia, heart disease, cancer, diabetes, ALS, etc.

Increase the focus on health equity.

Strengthen messaging of the adverse down-stream effects related to the absence of a family caregiver.

Focus on caregiver needs: Caregivers want information about keeping their recipient safe at home and about managing their own stress.



MESSAGING STRATEGY #4: Design Messaging Around Family Caregivers with Their Own Chronic Conditions

Message: The role of the family caregiver can in and of itself be considered a social determinant of health.

Message: Family caregiving is an important public health issue that affects the lives of millions of people.

Message: Family caregivers face their own risk of deteriorating health.

Data point: Family caregiving can be emotionally and physically demanding. Over half (53 percent) of caregivers indicated that a decline in their health compromises their ability to provide care.

Data point: Family caregivers are at increased risk for having multiple chronic diseases as they may neglect their own personal health needs while providing care to others. 40.7 percent of caregivers report having two or more chronic diseases.

Data point: Just 13 percent of caregivers say a health care provider has asked what they need to care for themselves.

“Providers must have easy access to information about family caregiver support systems so they can communicate such information to people caring for their patients.”

— *A Call to Preventive Action by Health Care Providers and Policy Makers to Support Caregivers, Hoffman & Zucker*

STRATEGY 2.1:

Entry-Point Service Coordination for Family Caregivers Across Sectors

OBJECTIVE: *Strengthen, support, and mobilize communities and partnerships to implement policies and practices that ensure the health and wellness of family caregivers as well as the persons receiving care by convening multi-sector stakeholders. Coordinate existing local supports and services to help family caregivers navigate and access services and supports, facilitating an integrated system of care focused on addressing social determinants of health and systemic inequities.*

Recommendations:

1. Incorporate actions that can be prioritized to reach and support family caregivers into state health improvement plans.
2. Appropriate federal public health funding to state level public health offices with the purpose of building the capacity needed to implement a strategic alignment of care providers across settings to coordinate family caregiver services.
3. Ensure family caregivers of all chronic or serious conditions are eligible for services.
4. Ensure family caregivers of those across the range of conditions are identified, assessed, and referred to services early in their care journey.
5. Invest in programs increasing culturally competent health literacy to promote better health outcomes.
6. Ensure family caregivers are aware of available clinical trial opportunities to support their health and the health of their care partners and ensure equitable access and representation in these trials.
7. Improve emergency preparedness and emergency response strategies to provide family caregivers with support and information during public health disasters, crisis, or other emergency situations.



IMPLEMENTATION OPPORTUNITY

The BOLD Act

The BOLD Act is existing law that was designed to award funding to public health departments for the following purposes:

- Help state, local and tribal public health departments implement effective Alzheimer's interventions.
- Help public health departments implement strategic actions like those identified in the Healthy Brain Initiative's Public Health Road Map.



IMPLEMENTATION OPPORTUNITY

The CURES 2.0 Act

The CURES 2.0 Act is proposed legislation that includes provisions which establish initiatives to enhance the federal support infrastructure for family caregivers. It does so by better including them in efforts related to medical and device development, training and information on how to perform specialized skills, ensuring person and family centered care, and contributing to a better field of data collection on how to best reach this population.

- Educational programs and training for caregivers
- Increased health literacy to promote better outcomes for patients
- Increased diversity in clinical trials
- Improved patient experience data
- Ensuring coverage for clinical trials under existing standard of care

STRATEGY 2.2:

Expanded Service Delivery for Family Caregivers

OBJECTIVE: Increase funding and capacity for home and community-based services that are critical for family caregivers, including home care and direct care services, transportation, congregate and home-delivered meals, and family caregiver support. Public health investments in the aging services workforce will help improve and modernize the infrastructure required for providers to continue operations and develop the supports and services, research and data collection, and technical assistance needed to ensure services for family caregivers are getting to those in greatest economic and social need, including marginalized or underserved populations.

Recommendations:

1. Implement educational programs for family caregivers across all chronic conditions, allowing for the training and development of additional skills that would allow them to augment a care team and complement, not compete with, a clinical visit.
2. Establish partnerships among care providers, community-based organizations and/or faith-based organizations, and state/county/local public health departments with the purpose of both expanding existing family caregiver programs and establishing new, innovative family caregiver support programs that can reach family caregivers across the range of all chronic conditions.



IMPLEMENTATION OPPORTUNITY

The Older Americans Act (OAA)

The Older Americans Act (OAA) programs, including the National Family Caregiver Support Program, supports our long-term care ecosystem in three key ways:

- Health care providers can rely on family caregiver supports in the OAA to improve the ability of friends and family to provide informal care.
- Employers who face productivity losses due to family caregiving can use OAA programs as a resource to support caregivers in the workforce.
- OAA programs can protect the health, wealth, and well-being of aging family caregivers.



IMPLEMENTATION OPPORTUNITY

The Primary Care and Public Health Initiative

The CDC's Primary Care and Public Health Initiative fosters linkages between public health and primary care by integrating population health into medical residency program curricula and competencies; increasing clinician understanding of public health problems and national initiatives offering potential solutions; and increasing clinician awareness and use of CDC resources.



PILOT PROGRAM

Implementing An Expanded Family Caregiver Support Infrastructure

To bring The Framework to life, some components can be incorporated into the design of future pilot programming that can be administered via State Health Departments (SHD) to build and support partnerships between state/county/local/territorial public health entities, community-based organizations (CBO) or faith-based organizations (FBO), direct care providers, health care and social service systems, persons with chronic disease, and those serving as family caregivers.

States can help develop sustainable strategies for these partnerships with the goal of implementing family caregiver-specific recommendations under this public health policy framework while also taking into consideration how to align with and further the adoption of actions under the purview of initiatives such as the BOLD Act initiatives, the Healthy Brain Initiative, and the Age-Friendly Public Health System initiative, as well as recommendations outlined under the National Family Caregiving Strategy. The strategies should be developed with the aim of creating the evidence-base need to advocate for appropriations sufficient to build capacity that will serve family caregivers across a range of chronic conditions, in all states and territories.

A pilot program should be aimed at addressing the health and wellness of family caregivers, ensuring patient and family-centered care, and identifying relevant components of social determinants of health and health equity that impact families across diverse populations of family caregivers. State and local level public health officials can convene a steering committee to provide guidance on project implementation and evaluation activities. Committee members may include family caregivers, primary care or direct care practitioners, representatives of rural areas, CBOs/FBOs, schools of public health and nursing, social workers, employers, chronic disease/serious illness policy and stakeholder organizations (across conditions), state departments/units on aging/disability, emergency services, representatives from DEI-focused organizations, hospitals/health systems, and so on.

The pilot programming should be aimed, where possible, at expanding existing supports and services to family caregivers on the local level, and establishing innovative awareness efforts and new channels for data collection that support national level policy development and improvement.



The Framework Components Primed for Implementation via a Pilot Program:

1.1 Examples: Family Caregiver Population Health Surveillance

- Participate in the administration and analysis of the BRFSS caregiver module.
- Collaborate with a school of public health to improve data collection on caregiver health and risk factors via existing public health data collection channels.
- Design and administer community-level survey's to better understand how many residents of a given locality are family caregivers, the resources and needs available for caregivers and the challenges and impact of family caregiving on their work lives.
- Review and report on community health needs assessments to identify those that include family caregiving.
- Crosswalk recommendations from the state health improvement plan, the state chronic disease plan, the state cancer plan, or a state plan on aging to identify opportunities for collaboration on data collection.

1.2 Examples: Family Caregiver Public Health Research & Education

- Research and report on employment policies and business practices related to supporting or recognizing family caregivers.
- Implement an employer/employee survey to better understand how many employees in a given locality are family caregivers, as well as the impact of family caregiving on their work lives.
- Develop and promote a public health state-specific website with family caregiver-focused data and information for use by family caregiver and public health researchers.
- Evaluate existing state or local level family caregiver programs or interventions that show promising best-practices in ensuring quality outreach to diverse family caregiver populations.

1.3 Examples: Family Caregiver Public Health Awareness

- Conduct public awareness efforts for practitioners and employers, describing the value of the family caregiver in chronic disease management and intervention as well as the risk factors that family caregivers experience.
- Integrate family caregiver awareness messaging into existing chronic disease programs and/or schools of public health.
- Partner with emergency response entities to determine and increase capacity to message to and communicate with family caregivers during public health emergencies.
- Develop an awareness campaign to promote understanding of the role of caregivers within underrecognized systems wherein they interact.
 - Collaborate with partners on the community level to implement the awareness campaign.



The Framework Components Primed for Implementation via a Pilot Program Continued:

2.1 Examples: Entry-Point Service Coordination for Family Caregivers

- Implement mechanisms to ensure family caregivers of those across the range of conditions are identified, assessed, and referred to services early in their care journey.
- Assess capacity of state-level chronic disease programs to develop and disseminate information about family caregiving across systems of care and supports.
 - Demonstrate competencies to address health equity and cultural responsiveness.
- Develop and promote an interdisciplinary, state-specific website designed to help navigate family caregiver resources.
- Improve family and family caregiver health literacy and disseminate resources and information to caregivers in marginalized or underserved communities using culturally appropriate materials.
- Collaborate with employers to distribute information to working family caregivers.
 - Use existing workplace wellness programs to link to available resources and supports.
- Convene a multi-sector coalition to provide guidance on implementation and evaluation activities to reach and supports family caregivers.
 - Committee members may include caregivers, primary care practitioners, representatives of rural areas, schools of public health and nursing, social workers, employers, and so on.
- Identify existing information and promote through integration with existing chronic disease programs.
 - Assess capacity of chronic disease programs to include information about family caregiving.

2.2 Examples: Expanded Service Delivery for Family Caregivers

- Integrate family caregiving issues and priorities into any state health improvement plan.
- Target outreach and services to family caregivers of those across the spectrum of chronic disease or serious illnesses.
 - Complement existing health-promoting programs.
- Review statewide community health needs assessments to identify those that include family caregiving.
- Adapt existing chronic disease programs to support caregivers of those with chronic disease.
- Select, disseminate and/or customize an evidence-based intervention to support family caregivers in a given healthcare setting, community, or region.
- Establish or build on existing public health, chronic disease, HCBS, LTSS, and other community-based systems or partnerships (e.g., Office of Rural Health, Departments of Human Services or Aging, community health centers, state medical and nursing organizations, employers/business) to expand reach and service referral.
- Collaborate with employers and workplace wellness programs to develop and adopt policies that support workers with caregiving responsibilities.

Appendix

DEFINITIONS

The Public Health Service Act

The Public Health Services Act provides authority to the U.S. Public Health Service (USPHS), a division of the Department of Health and Human Services (DHHS) concerned with public health.

Essential Public Health Services

The ten Essential Public Health Services provide a framework for public health to protect and promote the health of all people in all communities. To achieve equity, the Essential Public Health Services actively promote policies, systems, and overall community conditions that enable optimal health for all and seek to remove systemic and structural barriers that have resulted in health inequities. Such barriers include poverty, racism, gender discrimination, ableism, and other forms of oppression.

Framing The Public Health of Family Caregiving

Ronda C. Talley and John E. Crews set the context for how family caregiving aligns with the goals of public health in “Framing the Public Health of Caregiving.”

A Call to Preventive Action by Health Care Providers and Policy Makers to Support Caregivers

David Hoffman, MEd and Howard Zucker, MD, JD, LL.M., in 2016 issued the policy brief, “A Call to Preventive Action by Health Care Providers and Policy Makers to Support Caregivers,” which draws attention to the following considerations for those in the public health sector.

The Age-Friendly Public Health Systems (AFPHS) Initiative

In 2017, the Trust for America’s Health (TFAH) developed a framework for creating an Age-Friendly Public Health System (Framework, AFPHS). The original version was based on the results of a meeting of experts in public health, aging services, health care and aging studies. Since 2017, TFAH completed an AFPHS pilot in Florida, and has been working with multiple state and local health departments to expand their public health programs and policies and make healthy aging a core function of their departments. The framework in this report has

been developed in part by working with TFAH and closely following the development of what has been labeled the “Six Cs” of an Age-Friendly Public Health System, outlining specific actions that can be taken under the purview of public health to support older adults.

The Healthy Brain Initiative

The Healthy Brain Initiative’s (HBI) State and Local Public Health Partnerships to Address Dementia roadmap charts a course for state and local public health agencies and their partners to stimulate changes in policies, systems, and environments. Alignment of HBI Road Map actions with ESPH ensures that initiatives to address Alzheimer’s disease can be easily and efficiently incorporated into existing public health initiatives. The HBI categorizes actions that can address the needs of family caregivers into four traditional domains of public health action items contained in the ESPH.

The Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act

The BOLD Infrastructure for Alzheimer’s Act was passed into law in 2018 and amends the Public Health Service Act to create a uniform national public health infrastructure with a focus on issues such as increasing early detection and diagnosis, risk reduction, prevention of avoidable hospitalizations, and supporting dementia caregiving. The BOLD Project is designed to promote implementation of the CDC’s Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: The 2018–2023 Road Map and the Healthy Brain Initiative Road Map for Indian Country.

The RAISE Family Caregivers Act

Federal legislation enacted on January 22, 2018 that directs the Secretary of Health and Human Services to develop a national family caregiving strategy. The strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers.

APPENDIX A

Survey of Chronic Disease Directors

A brief questionnaire was developed and sent to the chronic disease directors of all states and territories asking them about their knowledge of family caregiver support and data collection efforts.

The survey questions were developed as one full survey but was administered in three phases between October–December 2020:

At-a-glance review of major takeaways:

Respondents from thirty states said they were aware of some programs in their state that involved family caregivers. Of those programs, conditions addressed included:

- old age/aging (20 states)
- cancer (12 states)
- physical disability (11 states)
- behavioral health (10 states)
- Stroke (6 states)
- ALS (3 states)
- heart disease (3 states)
- asthma (2 states)
- diabetes (at least 1 state)

States that have administered the Behavioral Risk Factor Surveillance Survey by year:

- 2015 24
- 2016 21
- 2017 12
- 2018 5
- 2019 10
- 2020 8
- 2021 43 (estimated)

Eighteen Chronic Disease directors said they were fielding the BRFFS caregiving module.

APPENDIX B

State Level Subject-Matter Interviews

Following our survey of Chronic Disease directors, we convened focus groups for state level chronic disease directors and an NACDD consultant with experience in public health systems and the larger role of chronic disease management. Both focus groups were held April – May 2021.

At-a-glance review of major takeaways:

Stakeholders that should be involved:

- Chronic disease advisory committees and entities in charge of determining priorities at the state level.
 - Need to engage entities such as palliative care workgroups.
- Employers and local Chambers of Commerce with the goal of getting buy-in from the business community where employment practices intersect with public health initiatives.
- Include the perspective of persons with multiple chronic conditions and practitioners serving dually eligible populations.
- State health department that could be funded directly to support improved surveillance of family caregivers, including information on how services and supports are reaching different demographics.
- With COVID, there has emerged a different population of family caregiver and that perspective should help inform COVID recovery strategies.
- Establish a cooperative agreement between the CDC and state-level health departments to coordinate activities that can take place on the national level with the goal of providing technical support to state level entities.

Data collection recommendations:

- BRFFS module needs to be more consistently implemented and should better assess the types of activities provided by family, as well as the presence of other support.
- Measure economic impacts/workforce impacts/ability to work/how much caregivers are pulled away from work
 - Build on the Work@Health model, an evidence-based program that trains employers to develop and implement health promotion strategies to reduce chronic disease and improve productivity in the workplace.
- Coordinate among state BRFFS coordinators to determine strategies for collecting more robust data about family caregivers.
- There is a need to ensure funds for maintaining the uptake of the caregiver module in BRFFS given competition with other program areas for space on the questionnaire.
- Get family caregiver questions into the core BRFFS.
 - Including it in the core would allow for comparison across other data collected, such as demographics and other chronic diseases.
 - Leaving it as an optional module makes it difficult for states as there is much competition for those empty slots on the annual BRFFS.

Messaging Recommendations:

- Focus on prevention, specifically address the needs of those with multiple conditions.
- Focus on state plans based on condition such as Alzheimer's cancer.
- Expand outreach and support to family caregivers of those with heart disease, lung, cancer, and diabetes.
- Increase focus on health equity.
- Promote to employers as part of workplace wellness.
 - Document the return on investment (ROI) of a healthy family caregiver to employers (review utilization of benefits vs. absenteeism).
- Tailor messaging state by state (state employees) or via regional approaches (health systems).
- State health departments often serve as conveners of partners around a shared interest, such as genomics groups, those with IDD/DD and around mental health.
- Make the case for the benefits of a healthy family caregiver.
- Teach the role of family caregiver—create a Health and Lifestyle training platform; reward people for completing the training.

APPENDIX C

National Level Subject-Matter Expert Roundtable

Following the state level interviews, NAC and NACDD convened a roundtable of thought leaders to further discuss the survey analysis and takeaways. The goal of the roundtable was to build a long-term strategy. Two thought leader roundtables were held in June 2021. Both were co-moderated by Mike Wittke and Leslie Best. This portion of the project was designed to fill in knowledge gaps that became apparent after reviewing the existing literature, examining the policy landscape, conducting the surveys, and speaking with the focus groups. The roundtable included experts in public health, chronic conditions, public policy, direct care, private sector health care, etc.

At-a-glance review of major takeaways:

- Identify stakeholders who should be involved; the National Center for Public Health Statistics could be a stakeholder.

- Currently, dollars follow the condition, (i.e., programs focusing on Alzheimer's Disease or Health Aging, programs focused on cancer control and prevention, programs focused on heart disease and stroke, and so on).
 - Separating groups might not be the best way to go.
 - Public health needs more education across the spectrum of chronic conditions.
- The CDC should have appropriations to fund state and local health departments that will implement and administer actions that can be administered at the state level.
 - Frame the issue from a public policy standpoint, emphasizing the role of public health, models for success, and strategies for program sustainability.
- Public health is not thinking about aging in general, or at least not enough.
 - Public health practitioners should realize family caregivers plays a role in their core mission.
 - Need to address the issue of soloing between public health and aging services networks.
 - Focus on the issue of sustainability.
 - Chronic disease units can help with sustainability.
- BOLD Act programs helps state health departments meet state plans; build on that model to meet the needs of family caregivers of those with other conditions.
- Build on successes in the palliative care movement.
- Identify efforts to recover from COVID to help in raising awareness.
- Coordination around Long-Term Services and Supports can occur between state health departments and CBOs, as well as counties and clinical care (and tribal).
- Funding for programs implemented by chronic disease directors is needed, multiple potential vehicles for funding, gauge interest via a pilot program.
- Work with employers around benefits under employer-provided health insurance; look at healthy employee programs.
- The CDC can do surveillance and help local public health departments.

Data collection recommendations:

- Include a question on family caregiving in the BRFSS core.
- Increase the number of states administering the BRFSS caregiver module and other surveys.
 - Frame data as a public health issue.
 - Look at adapting questions in NHANES, NHATS, NSAH to gather richer data and information.
- Work with Schools of Public Health.
- Increase NIH/NIA/NINR family caregiver-focused funding.
- Gather better data about caregivers of those with co-morbidities, both the family caregiver and care recipient.
- Gather richer data via cancer prevention studies, especially family caregiver-specific surveys.
- Identify where to invest dollars; look at working with employers and healthy employee programs.
- BRFSS needs advocacy in general.

Messaging

- Family caregivers need help navigating systems of care. Public health can help with that.
- Palliative care can bring the unit of care to the patient.
- Put more emphasis on definitions of family caregivers.
- Build on successful public health messages; tobacco cessation as an example.
- Focus on social determinants of health.
 - Look at successes with diabetes campaigns.

ENDNOTES

ⁱ <https://www.cdc.gov/aging/caregiving/caregiver-brief.html>

ⁱⁱ <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>

ⁱⁱⁱ <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>

^{iv} <https://www.diverseelders.org/wp-content/uploads/2021/12/DEC-Caregiving-Report-Final.pdf>

^v https://www.cdc.gov/pcd/issues/2016/16_0233.htm

^{vi} <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>

^{vii} <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1781412/pdf/0970224.pdf>

^{viii} https://www.caregiving.org/wp-content/uploads/2021/11/NAC_AmgenDiverseCaregiversReport_FinalDigital-111821.pdf

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^{xiii} <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>



National Alliance for Caregiving

About the National Alliance for Caregiving

NAC's mission is to build partnerships in research, advocacy, and innovation to make life better for family caregivers. Our work aims to support a society which values, supports, and empowers family caregivers to thrive at home, work, and life. As a 501(c)(3) charitable non-profit organization based in Washington, D.C., we represent a coalition of more than 60 non-profit, corporate, and academic organizations; nearly 40 family support researchers with expertise in pediatric to adult care to geriatric care; and more than 50 advocates who work on national, state and local platforms to support caregivers across the United States. In addition to our national work, NAC leads and participates in a number of global meetings on caregiving and long-term care, working closely with peer organizations from more than a dozen nations. Learn more at www.caregiving.org.

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