

NOVEMBER 2021

**Minnesota Serious Illness
Action Network**

Fall Forum on Caregiving



MINNESOTA NETWORK OF
HOSPICE & PALLIATIVE CARE



Executive Summary

November is National Family Caregivers Month. Focusing the Serious Illness Action Network November Fall Forum on Caregiving was a fitting time to both honor efforts and acknowledge challenges faced by family caregivers of those with serious illness.

Close to 150 participants, representing providers, state agencies, health plans and advocates, joined together to learn about policies and services that can support family caregivers, co-convened by the Minnesota Network of Hospice & Palliative Care and Stratis Health. Through the lens of reducing burdens faced by family caregivers, participants heard from local and national family caregiving experts about innovative local and national programs and organizations.

The forum focused around five priority areas identified by the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregiving Advisory Council. The RAISE Advisory Council was formed under the RAISE Family Caregivers Act, which became law January 22, 2018, and was tasked with developing a national family caregiving strategy.

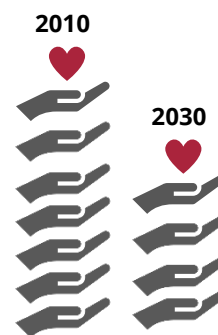
The RAISE Council submitted their initial report to Congress on September 22, 2021. Their report identified twenty-six (26) recommendations falling under five goals¹ calling for:

- Increased awareness of family caregiving.
- Increased emphasis on integrating the caregiver into processes and systems from which they have been traditionally excluded.
- Increased access to services and supports to assist family caregivers.
- Increased financial and workplace protections for caregivers.
- Better and more consistent research and data collection.

Participants heard from family caregiving experts including Dr. Joe Gaugler with the University of Minnesota School of Public Health, Dr. Jennifer Olsen with the Rosalynn Carter Institute for Caregivers, and Beth Wiggins with FamilyMeans.

Participants also learned about Minnesota resources for caregivers during a panel discussion with local leaders and advocates. Panelists included Dawn Simonson with Trellis, Sheryl Fairbanks with Dementia Caregiver Re-Entry Initiative, and Dorothea Harris, with Volunteers of America.

“The family care gap is widening. Defined as the ratio between the number of unpaid caregivers for every 1 patient, the current projection forecasts that by 2030, there will only be 4 unpaid caregivers for every elderly or seriously ill patient, down from 7 in 2010.”²



As Minnesota strives to become an age-friendly state, the advice to Minnesota state leaders and policymakers to support and ease the burden of our state's caregivers included:

- *Find innovative ways to refinance long-term supports and services (LTSS) for Minnesota.*
- *Pursue the federal Program of All-Inclusive Care for the Elderly (PACE) in Minnesota.*
- *Build public health infrastructure for preparedness, response, and recovery for caregivers.*
- *Break down silos between the Medicaid system and the Older Americans Act systems.*
- *Provide paid leave for caregivers.*
- *Pay attention to the caregiver after caregiving (re-training, financial hardship, etc.).*
- *Look at matching caregiving respite care dollars.*

By the conclusion of the forum, three common themes emerged from presenters, panelists and participants:

1. **Caregiving is personal.** Each of us has a personal story about caregiving, whether it's also our profession or not.
2. **Alignment is a key word for improvements for family caregivers.** We must align our resources around stakeholders, research, communication, payments, and workforce.
3. **Caregiving is a social determinant of health.** We need to keep the momentum going by recognizing and framing caregiving as a critical social determinant of health.

The following pages contain highlights from the presentations, panel discussion, and breakout sessions.

HIGHLIGHTS FROM PRESENTATIONS AND PANEL DISCUSSION

BRIDGING THE FAMILY CARE GAP presented by Joe Gaugler, PhD, Professor and Robert L. Kane Endowed Chair in Long-Term Care and Aging, School of Public Health, University of Minnesota

Long term care in the US does not revolve around nursing homes, home health or other formal services. It revolves around a vast unpaid network of family members and others who provide assistance to those who are chronically or seriously ill, or elderly.

From a public health perspective, **receiving caregiving is a social determinant of one's health and contributes to better health outcomes for the patient.** Family caregivers provide essential support for seriously ill and aging relatives and friends.

The **family care gap** can be seen in the following statistics:

- **83% of older people** in the US with health needs **rely solely on an unpaid individual(s)** to provide health assistance, most often a relative.
- **In 2010** the **care ratio** between the number of unpaid individuals supporting an older person with health needs during their chronic disease trajectory is approximately **7 unpaid caregivers for every 1 patient.**²
- **By 2030** the **care ratio is projected to drop to 4 unpaid caregivers for everyone 1 patient.**

The projected reduction in available family caregivers is called the family care gap.

How can we build a better bridge and best support family caregiving for older adults? How can we solve it? How can we address it?

In the public policy arena, it currently takes about twenty (20) years³ to move from an idea to actual implementation. How can we shorten the chasm between idea and actual implementation? How can we make research more scalable, more readily implementable to best help and address the needs of caregivers with quality evidence-based solutions that provide families with the support they need?

Recommendations for Minnesota include:

- Support the **RAISE recommendations.**
- Support **right sizing the National Family Caregiver Support Program.**
- **Pay family caregivers.** (*Explore the Washington state model*).
- **Increase financial and workplace protections** for family caregivers.
- **Move from person-centered to family-centered healthcare.**
- Evaluate and consider implementing policy innovations such as:
 - **Create private-public options** for long term services and supports.

- **Create Universal Family Care.**

The current model of relying heavily on unpaid caregivers to support seriously or chronically ill or older family members is not sustainable. Given the length of time it takes to move from idea to actual implementation, it's time to bridge the family caregiving gap now.

Note: There will be a national conference on the Public Health Opportunities and Challenges for Dementia Caregiver June 14th and 15th, 2022, University of Minnesota.

CAREGIVING AS A SOCIAL DETERMINANT OF HEALTH presented by Jennifer Olsen, PhD,
Chief Executive Officer at Rosalynn Carter Institute for Caregivers, Health and Aging Policy
Fellow

Rosalynn Carter founded the Rosalynn Carter Institute (RCI) thirty-four years ago at Georgia Southwestern. RCI focuses on supporting caregivers' strength and wellbeing, looking at how to engage caregivers from several types of conditions or experiences, and to determine what programs and policy interventions are needed.

RCI published the prescient report *Averting the Caregiving Crisis* in 2010.

When comparing that report to the RAISE Family Advisory Council recommendations, sadly there were many similarities that speak to the challenge of moving from ideas to recommendations to actual action.

Ms. Carter wrote an op ed, published November 7, 2021 in *The Hill*, calling for change in how we support **the invisible frontline, the nation's family caregivers.**

RCI is thinking about caregivers as a population who have not yet been recognized, supported, research funded, or interventions created at the same magnitude as other common public health challenges, e.g., tobacco use.

Great strides have been made in reducing the public health impact from tobacco use by:

- Engaging legislators.
- Enacting laws that created smoking sections.
- Enacting laws that banned smoking in restaurants, bars, and workplaces.
- Requiring employers to think about interventions, such as health fees, subsidies or discounts if you have not been a smoker or reduced your smoking.
- Engaging the entertainment industry to reduce the number of individuals smoking in TV shows and movies.

The reduction in tobacco use provides a known public health model that resulted in permanent change.

While family **caregivers are the invisible frontline, they must also be a public health concern. Family caregivers may experience their own physical, mental, and financial health decline because of their caregiving experience.**

Research into military families found that **caregivers often don't identify as a caregiver.** They self-identify with another role, such as parent, spouse, or partner. But they do identify with being excessively burdened by some activities in caring for someone else.

Caregivers in military families are more commonly caring for someone with "emotional or mental health concerns" rather than, or in addition to, physical concerns. Military caregivers are typically younger, caring for more than one care recipient, often kids with special needs, typically developing kids, and a parent or grandparent, "sandwiched" between the generations.

Employed caregiver challenges include:

- **Working double jobs** – being **both a paid, employed worker and an unpaid family caregiver.**
- **1 in 5 employees** are caring for an adult or someone who has an illness in their family; **20% report having to quit their job; 40% report they went to part-time work.**
- **Experiencing more emotional stress for workers under the age 40** where peers believe caregivers would not be able to put their all into their work.
- **Experiencing added emotional stress for all employed caregivers** when considering **promotions, extra work, or changing jobs.**

An added challenge for employers' support for caregivers is **making is ensuring caregiving support is available in the community where the employee lives.** Employers provide support and sometimes find that the **caregiver could not access that support in their area** – leaving both the employer and the employee disappointed.

RECOGNIZE, ASSIST, INCLUDE, SUPPORT AND ENGAGE (RAISE) FAMILY CAREGIVERS ACT REPORT TO CONGRESS presented by Beth Wiggins, MSW, LISW, Director of Caregiving and Aging Services, FamilyMeans.

The RAISE family caregiver act was enacted in 2018 to develop a national strategy around caregiving in the United States.

The United Kingdom developed their national strategy for caregivers in 1999, New Zealand in 2008, Australia in 2011, and Ireland in 2019.

The RAISE family caregiving advisory council did a lot of research, focus groups, and conducted interviews. **From the information gained, they developed recommendations and submitted their initial report to Congress.**

The recommendations coalesced into five goals / areas:

- Awareness and outreach.
- Engagement of caregivers as partners in healthcare and long-term supports and services.
- Supports and services.
- Financial and workplace security.
- Research, data, and evidence-informed practices.

These five areas were the focus of the two break-out sessions during the forum.

Awareness and outreach include:

- Increasing awareness of family caregiving.
- Identifying caregivers whether they self-identify with the term 'caregiver' or not, ensuring they get the support they need.
- Making recommendations about catching caregivers earlier in the caregiving trajectory.

FamilyMeans found it makes a dramatic difference to help people anticipate what may be coming around the corner, identify contingencies to alleviate today and reduce stress in the future.

Engagement of caregivers as partners in healthcare and long-term supports and services includes:

- Ensuring caregivers are included in their care recipient's health care team as a partner, not as an afterthought.
- Ensuring the family caregiving lens is engaged during change to healthcare policy and practices.
- Taking time to discern caregiver's ability and willingness to provide caregiving rather than just assuming it is going to happen somehow.
- Ensuring culturally sensitive approaches and tools are used during the assessment.
- Ensuring various professionals, practitioners, and caregivers encounter have the training needed to actively engage caregivers with services and supports that are useful for the caregiver.

Supports and services includes:

- Ensuring long-term supports and services are accessible, flexible, and tailored to diverse and ever-changing needs.
- Ensuring a personal preconceived notion of what something is – *which may not be accurate or appropriate* – does not influence decisions made regarding care given, e.g., respite care.
- Ensuring high-quality options are available in ways that caregivers define as meaningful breaks for them, e.g., being able to take a weekend away, use of professional home health care, or an activity they can enjoy with the person they care for.

- Broadening the definition of support to include counseling, training, peer support, education, and technology solutions.

Family and friend caregiving is intertwined with paid professional care provisions. Each benefits from the effectiveness and availability of the other.

Financial and workplace security includes:

- Protecting and enhancing a caregiver's lifetime financial and employment security by:
 - Increasing workforce flexibility.
 - Facilitating financial education and planning.
 - Improving the affordability of long-term supports and services in ways that reduce out of pocket costs to the caregiver.

Many Minnesota caregivers do not have access to paid leave. Caregivers who reduce their hours or quit their job bear the burden of their own reduced financial well-being over the remainder of their lives.

Research, data, and evidence-informed practices includes:

- Standardizing definitions of caregiver across surveys allowing statistics to be aggregated, e.g., is caregiver only defined as spousal; are caregivers of younger children included?
- Conducting research to document caregivers real lived experiences.

When we know better, we have a chance of doing better. Knowing better is about collecting data, developing and testing new approaches, measuring progress, and measuring results.

PANEL: CAREGIVER SERVICES AND SUPPORTS

DAWN SIMONSON, PRESIDENT AND CEO, TRELIS, formerly the Metropolitan Area Agency on Aging [trellisconnects.org]

Trellis is a non-profit organization that provides direct services through Senior LinkAge Line® in partnership with the Minnesota Board on Aging. Trellis also administers federal Older Americans Act funding for services that help older adults and caregivers live safely and independently in their community. Trellis may not always be the entity providing the direct service but is the gateway to finding the best services for the family caregiver.

SHERYL FAIRBANKS, CO-CREATOR, DEMENTIA CAREGIVER RE-ENTRY INITIATIVE

Sheryl is a co-founder of Dementia Caregiver Re-Entry Initiative (DCRI). Sheryl left a highly skilled Information Technology career to become an unpaid caregiver for both her aging parents and in-laws during their last days in hospice to their death. Two of the four were diagnosed with dementia.

Sheryl was invisible as a caregiver, and upon the loss of the parents, became ultra-invisible – no longer employed, no longer a caregiver, and without direction in her life.

Sheryl and her husband, Warren Wolfe, are writing a workbook, “When Caregiving Ends, Who Am I Now?” The workbook is intended to be a doorway for people to gain a new purpose and direction in life. Their workbook should be available early 2022.

DOROTHEA HARRIS, DIRECTOR, CULTURALLY RESPONSIVE CAREGIVER SUPPORT AND DEMENTIA SERVICES AT VOLUNTEERS OF AMERICA

The goal of Culturally Responsive Caregiver Support and Dementia Services is to bridge the gap of health inequities by expanding culturally diverse and relevant services, and providing community health care workers that help older people and their caregivers, primarily in the African American and East African communities.

The Culturally Responsive Caregiver Support and Dementia Services organization also provides an aging and memory mobile clinic focused on the needs of the African American and East African communities and values. The highlight of the mobile clinic is the memory screening where the model allows the team to support the care recipient, the caregiver, and their family as a unit.

The Culturally Responsive Caregiver Support and Dementia Services organization walks alongside the care recipient, caregiver, and family, for years as a cultural connection to equitable health services.

QUESTIONS FOR THE PANEL:

Questions #1: Given the framework we are using today, what do you think the greatest strengths and gaps are in the work you do and how does it align with the RAISE framework?

STRENGTHS identified by the panelists and speakers included:

- **Helping caregivers self-identify as caregivers.**
- **Providing access to financial linkages, including many kinds of public and private financial supports for older adults and their family caregiver.**
- **Providing new tools, such as a memory mind travel kit for care recipients with dementia, which can be used by a caregiver during appointments, when on local outings, or traveling longer distances.**
- **Ensuring community members from various ethnic backgrounds get regular checks ups, and are connected with a community health worker to ensure someone is going with them to keep them connected with the medical provider.**
- **Leveraging the heightened awareness of caregiving because of the pandemic. More and more individuals experienced caregiving in new and profound ways which can be leveraged in the coming months / years.**

GAPS identified by the panelists and speakers included:

- **Recognizing that communities are becoming more diverse at a pace faster than most organizations can support. Responses are generic resulting in missed nuances for cultural and community values frequently resulting in referrals for services that are not culturally acceptable.**

- **Finding enough culturally responsive volunteers**, those that can give back – family members, or others – who can work together in their communities, churches, or mosques.
- **Addressing the lack of resources and tools to help caregivers determine the next stage of their life**, either re-entry to the workforce or finding a new direction for their life.
- Ensuring research is capturing the voice of those living with dementia and their caregivers, **eliminating the disconnect between the lived experience versus what research is saying**.
- **Ensuring research aids us in identifying needs** in order to create programs, services, supports, and policies that have impact.
- Getting better at **capturing the caregiver's experience with caregiving**: “Is this the 1st time, or the 4th time, you’ve been a caregiver?”
- Doing a better job of **asking and identifying the caregiver's challenges and needs** – financial, workplace or mental health.
- Seeking clarification by **asking, “Is this for the caregiver, or does this help with caregiving?”** in order to provide the right resource for the right task.

Question #2: If you were meeting with the relevant committees in the Minnesota Legislature, what recommendations would you make to law makers as the most important policies to bring forward?

POLICY RECOMMENDATIONS:

- Find innovative ways to refinance long-term supports and services (LTSS) for Minnesota.
- Pursue the federal Program of All-Inclusive Care for the Elderly (PACE) in Minnesota.
- Build public health infrastructure for preparedness, response, and recovery for caregivers.
- Break down silos between the Medicaid system and the Older Americans Act systems.
- Provide paid leave for caregivers.
- Pay attention to the caregiver after caregiving (re-training, financial hardship, etc.).
- Look at matching caregiving respite care dollars.

BREAKOUT SESSION THEMES REGARDING THE FIVE RAISE GOALS

Through the lens of taking action, the breakout sessions focused on the question “**What can Minnesota do to better reduce gaps or leverage the strengths of family caregivers?**”

GROUP #1: INCREASE AWARENESS OF FAMILY CAREGIVING.

- Ensure employers provide flexibility for caregivers.

- *Support the shift from person-centered care to family centered care when the care recipient is diagnosed with a serious illness or condition, or their diagnosis becomes terminal.*
- *Develop and provide a list of known resources for family caregivers rather than telling them to ‘search the internet.’*
- *Recognize that grieving for both the care recipient and the family caregiver begins anew with every change the care recipient goes through during their journey.*

GROUP #2: INCREASE EMPHASIS ON INTEGRATING THE CAREGIVER.

- *Include patient representatives as part of the Interdisciplinary team (IDT)*
- *Shift from person-centered to family-centered at the time of a patient’s serious illness diagnosis, bringing the family caregivers into the conversations and the patient’s journey from the beginning*
- *Elicit the family caregiver’s needs during their caregiving journey. While caregiving is a social determinant of the care recipient’s health in a positive way, the caregiver frequently sees a decline in their personal health.*

GROUP #3: INCREASE ACCESS TO SERVICES AND SUPPORTS TO ASSIST FAMILY CAREGIVERS.

- *Pass legislation to support a former caregiver’s re-entry into the workforce.*
- *Involve caregivers in research whenever possible, either while actively caring for a care recipient or after their caregiving ends.*
- *Ensure more interagency collaboration for family caregivers.*
- *Ensure paid time off is defined not only for parents with children but for adult children with aging parents.*

GROUP #4: INCREASE FINANCIAL AND WORKPLACE PROTECTIONS FOR CAREGIVERS.

- *Pass legislation for family caregivers to receive paid leave.*
- *Pass legislation to provide unpaid leave without loss of job for family caregivers.*
- *Ensure employers have offerings for both parents caregiving for children with serious illness or conditions as well as adult children caring for aging parents with serious illness or condition.*
- *Extend length of bereavement for working family caregivers after their care recipient dies.*

GROUP #5: BETTER AND MORE CONSISTENT RESEARCH AND DATA COLLECTION.

- *Identify competencies around caregiving services and supports to better grown and train the workforce that assists and provides support to family caregivers.*
- *Expand insurance coverage, reimbursements that specifically support long-term services and support.*
- *Ensure the Medicare PACE program is available in Minnesota.*

- *Identify ways to integrate family caregivers more effectively into health care delivery and practice.*

REFERENCES:

¹ <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>

² <https://press.aarp.org/2019-11-14-Valuing-the-Invaluable-Series>

³ https://doi.org/10.1044/2015_JSLR-L-14-0305