



# NC CAREGIVING POLICY SUMMIT

*CHANGING THE CARE CONVERSATION*

**Wednesday, May 10 and Thursday, May 11, 2023**

**12:00 – 1:30 pm**

*Organized and led by caregivers with diverse experiences,  
addressing issues of caregiving across the lifespan.*



NC CAREGIVING  
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# Project Overview

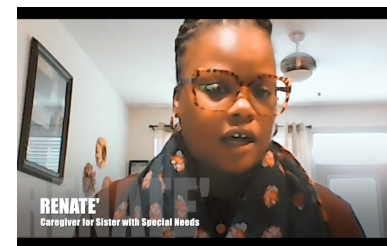
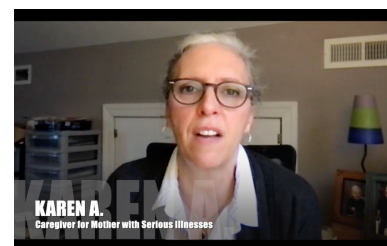
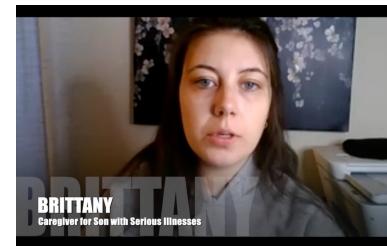
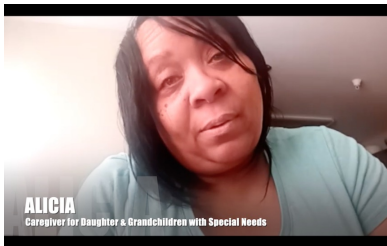
- North Carolina was one of 10 states selected to participate in Changing the Care Conversation -- a year-long grant project coordinated in partnership with the NC Serious Illness Coalition, NC Coalition on Aging, and the Children's Complex Care Coalition of NC. The project was funded by Grantmakers in Aging and facilitated by Community Catalyst. Project goals included:
  - Building the coalition and grassroots power of a diverse group of family caregivers to advance state and federal policy solutions that improve support for family caregivers.
  - Providing training, technical assistance and an online learning community and funding.
- 10 Caregiver Champions attended workshops and completed training to help use their lived experience for advocacy efforts to improve policies supporting caregivers in NC. This Summit is the culmination of the grant project.



## NC CAREGIVING POLICY SUMMIT

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# NC CAREGIVER CHAMPIONS



- Alicia
- Amy
- Brittany
- Heather
- Joe
- Karen A.
- Karen S.
- Nancy
- Renate
- ... AND Denise!

<https://www.ncscoalition.org/ctcc/>



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# DAY 1

## WEDNESDAY, MAY 10

- Project and Summit Overview
- NC Caregiver Champions video
- **Invited Speaker:** Greg Link, Director, Office of Supportive and Caregiver Services, Administration for Community Living
- **Topic 1** – Stronger Together: Caregiving Across the Lifespan
- **Topic 2** – Barriers to Support Services
- Q&A / Wrap Up



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## **DAY 2**

### **THURSDAY, MAY 11**

- Welcome and Day 1 Recap
- NC Caregiver Champions video clip
- **Topic 3** – Employment Issues Related to Caregiving
- **Topic 4** – Financial Issues Related to Caregiving
- Q&A / Wrap Up
- Next Steps



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**DAY 1**  
**WEDNESDAY, MAY 10**

## **Greg Link, Director**

*Office of Supportive and Caregiver Services  
Administration for Community Living*

- The RAISE Act & The National Strategy to Support Family Caregivers: A Roadmap for Change





# The RAISE Act & The National Strategy to Support Family Caregivers: A Roadmap for Change

North Carolina Caregiving Policy Summit

Greg Link, MA

Director, Office of Supportive and Caregiver Services

Administration on Aging, Administration for Community Living

May 10, 2023



## Family Caregivers: In their own words...

- “When you’re starting the journey, you don’t have enough knowledge to know what you need.”
- “It would have been immensely helpful to just hear other people and know that I’m not alone in this.”
- “Nobody ever taught me how to do the medical portion of taking care of my son . . . It can be scary. I wish someone like a nurse . . . could have spent more time teaching me how to use his medical equipment.”



# Family Caregiving: The Numbers

- Nearly one in five (53 million) adults provide care to a family member or friend
  - Twenty-four percent care for more than one person
  - Twenty-six percent have difficulty coordinating care\*
- Nearly 2.5 million grandparents are raising grandchildren
  - 56% of grandparents are age 30-59
  - More prevalent in ethnic/culturally diverse population†

Sources: \* [2020 Caregiving in the U.S. NAC/AARP](#)  
† 2019 American Community Survey Data

# Legislative Milestones in Family Caregiver Support

- Legislative actions
  - National Family Caregiver Support Program/Native American Caregiver Support Program (2000)
  - VA Caregiver Support Program
  - Lifespan Respite Program (2006)
  - RAISE Family Caregivers Act of 2017
  - 2018 Family First Prevention Services Act
  - Supporting Grandparents Raising Grandchildren Act (2018)
  - National Technical Assistance Center on Kinship and Grandfamilies (2021)



# The RAISE Act: Nuts & Bolts

- Became law: Jan 22, 2018
- Three key components:
  - Family Caregiving Advisory Council
  - Initial Report to Congress
  - National Family Caregiving Strategy

## Public/Private Partnership at its Best!

- The John A. Hartford Foundation
  - History of supporting ACL's efforts
  - Projects of national scope
  - Collaborated with ACL to develop concept for the RAISE Resource and Dissemination Center at NASHP
- National Academy for State Health Policy (NASHP)
  - National Alliance for Caregiving
  - UMass Boston
  - Community Catalyst
- [The RAISE Family Caregiver Resource and Dissemination Center](#)

# Public Engagement at Every Step

## For Starters:

- ACL RFI (2019)
  - 1613 responses
  - 75% from caregivers
- Caregiver Focus Groups
  - 13 sessions/80 individuals
  - All populations, including teens
  - Delved into RFI findings
- Stakeholder Listening Sessions
  - Aging and disability organizations
  - 60 invited/42 participated
  - 6 sessions focused on operationalizing the recommendations
- Council meetings

## From 12/2020 - 12/2021:

- Interviews & Listening Sessions
  - 17 key informant interviews
  - 22 listening sessions
  - 145 stakeholder organizations
- Stakeholders included
  - State entities
  - Counties
  - Employers (large and small)
  - LTSS and healthcare providers
  - Respite providers
  - CBOs/faith-based organizations

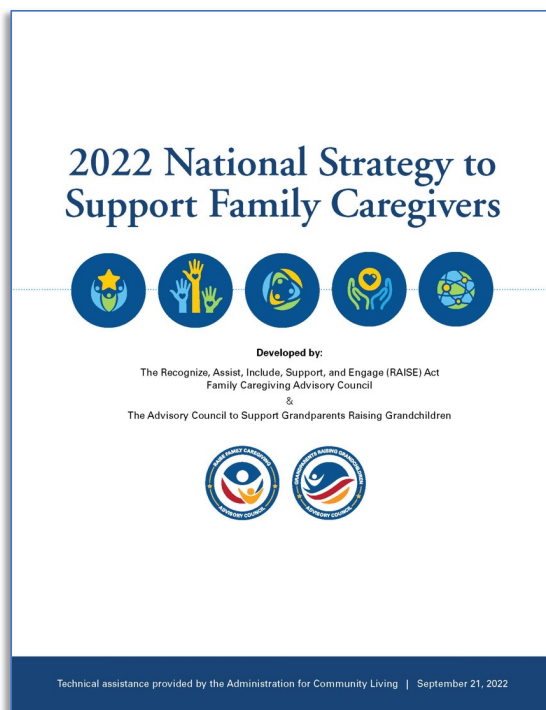
# The National Family Caregiving Strategy

Grounded in five priority areas for action:\*

- 1) Awareness and outreach
- 2) Engagement of family caregivers as partners in healthcare and long-term services and supports
- 3) Services and supports for family caregivers
- 4) Financial and workplace security
- 5) Research, data, and evidence-informed practices

\* RAISE and Grandparent Advisory Councils

# One Strategy | Four Components



[2022 National Strategy to Support Family Caregivers](#) - An overview and description of the strategy's goals and intended outcomes

[First Principles: Cross-Cutting Considerations for Family Caregiver Support](#) - Describes the four key principles that must be reflected in all efforts to improve support to family caregivers

[Federal Actions](#) - Nearly 350 actions that 15 federal agencies will take in the near term to begin to implement the strategy.

[Actions for States, Communities, and Others](#) - More than 150 actions others can take.

## Cross-Cutting Themes & Considerations

- Placing the person and family at the center of all interactions
- Addressing trauma and its impact on families
- Advancing racial equity and support for family caregivers in underserved communities
- Understanding the implications of the direct care workforce



## A “Whole of Society” Approach is Needed

- States, tribes, and communities – “the Aging Services Network”
- Community-based providers of long-term services and supports
- Child welfare agencies
- Health care systems
- Business leaders and employers
- Communities of faith/faith-based organizations
- National, state, regional and local philanthropic organizations and funders
- Academic institutions and researchers
- Advocates, family caregivers, care recipients, advocates, and the public



## Opportunities to Advance Policies & Programs

- Create pathways for better communication between family caregivers, care receivers and health care providers and systems
- Where appropriate and desired, include family caregivers early in the provision of care and planning
- Employ dedicated staff to engage with and include family caregivers
- Assess family caregiver needs along side those of the care receiver
- Partner with local community-based agencies to ensure caregiver needs are included in referrals for support

## Opportunities to Advance Policies & Programs

- Appoint family caregivers as board members to ensure their voices are included in all levels of policy planning.
- Ensure that policy-setting processes include documenting and responding to family, kin and grandparent caregiver needs.
- Pilot the use of caregiver assessments in a variety of care settings to improve identification of caregivers who need services and supports.
- Ensure that all intake forms adopt inclusive language to help family caregivers self-identify

## The Time is Now...

### **If family caregiving is...**

- Anxiety-producing
- Empowering
- Overwhelming
- Meaningful
- Exhausting
- Gratifying
- Lonely
- Hopeful

### **Then a National Strategy to Support Family Caregivers will...**

- Elevate the conversation
- Re-frame the narrative
- Drive change and innovation
- Promote greater recognition and inclusion of family caregivers
- Be a tool for advocacy
- Guide program planning & policy development,
- Shape research

## Family Caregivers: In Their Own Words...

“How do we create a world where caregiving is central to who we are, as opposed to something that diverts us or is a sideline of our real lives?”

Carol Zernial, M.A., caregiver & Family Caregiving Advisory Council member

# Resources for Engagement and Technical Support

- Support for State Implementation: [RAISE Resource and Dissemination Center](#)
- ACL Resources for Outreach and Engagement:
  - [Press Release](#)
  - National Strategy to Support Family Caregivers: [Infographic](#)
  - Spreading the word: [outreach and social media resources](#)

Thank You!



## NC CAREGIVING POLICY SUMMIT

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# DAY 1

## WEDNESDAY, MAY 10

### TOPIC 1 – CAREGIVING ACROSS THE LIFESPAN

*There are only four kinds of people in this world: those who have been a caregiver, those who are currently caregivers, those who will be caregivers, and those who will need a caregiver. - Rosalynn Carter*

- NC has an estimated 1.3 million informal caregivers, accounting for 1.1 billion care hours, *unrealized* economic value of \$13.1 billion per year.
- Increasing proportions in the population of older adults and of children and youth with complex health needs who often need in-home caregiving.
- NC ranks 9th nationally in total population and 8th in ages 65 and older.
- In next 20 years, 65+ population in NC projected to almost double (1.7 to 2.7 million).
  - Projected growth of 116% in 85 and older, when higher levels of care are often needed.
- NC has higher relative population proportion of children and youth with complex needs (22%) compared with the national average (20%).

Source: *Caregiving Across the Life Course: A Health Policy Priority for North Carolina*, NC Medical Journal, March 2023





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## **TOPIC 1 – CAREGIVING ACROSS THE LIFESPAN**

- *Application of a life course perspective to caregiving can help to mitigate health disparities by creating a system capable of identifying and addressing common challenges faced by caregivers and their care recipients across the age, race and ethnicity, geographic, and disability spectra.*
- *By integrating efforts that support specific populations with serious illness, disabilities, and functional impairment, we can share innovations and center caregiver experiences when designing solutions that address gaps in care and support.*

Source: *Caregiving Across the Life Course: A Health Policy Priority for North Carolina*, NC Medical Journal, March 2023



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**WEDNESDAY, MAY 10**

## **TOPIC 1 – CAREGIVING ACROSS THE LIFESPAN**

- **Caregiver Champions:** Karen Appert, Heather Altman, Brittany Cutshaw
- **Panelists:**
  - **Erin Kent**, PhD, Associate Professor & Associate Chair, Dept. of Health Policy and Management, Gillings School of Public Health, UNC-Chapel Hill
  - **Neal deJong**, MD, MPH, Assistant Professor, Division of General Pediatrics and Adolescent Medicine, UNC-Chapel Hill
  - **David Y. Ming**, MD, Associate Professor, Departments of Medicine, Pediatrics, and Population Health Sciences, Duke University Health System



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**DAY 1**  
**WEDNESDAY, MAY 10**

## **TOPIC 1 – CAREGIVING ACROSS THE LIFESPAN**

- **GAPS:** In your work, research, and personal experiences, what gaps related to this topic should be addressed? What steps can be taken to close the gaps?
- **POLICIES:** In considering a life course approach, what existing or potential policies might better support caregivers?
- **ADVOCACY:** Why should caregiving advocates consider this life course approach in working on solutions to supports for caregivers in NC? How can caregiver advocates use their lived experience to become involved in advocacy around this topic?
- **CAREGIVER CHAMPIONS:** *What does meaningful change look like?*



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## **TOPIC 1 – CAREGIVING ACROSS THE LIFESPAN**

Recommendations from *Caregiving Across the Life Course: A Health Policy Priority for North Carolina*

- **Establish a State Caregiver Task Force / Coalition**
- Analyze state data, legislative solutions, and financing options and promote best practices and strategies for supporting caregivers in NC.
- Study the availability of supports and services within the state and counties for caregivers of individuals with serious illness and develop mutual aid systems of caregiver support among counties.
- Assess the needs of care recipients and their informal caregivers, availability and sufficiency of caregiver training opportunities, and the frequency with which caregivers engage in those programs or opportunities.
- Identify costs and burdens associated with caregiving, incorporating input from diverse constituents and interest groups that reflect current patient and caregiver populations.
- Examine the impact of expanding resources provided directly to caregivers (e.g., direct pay/reimbursement to caregivers).
- Investigate disparities in availability of and access to caregiver services (geography, income, awareness, socio-cultural caregiving practices).
- Study ways that the state and private sector employers can enhance support for employees with significant caregiving responsibilities.
- Developing the serious illness care and special needs health sector workforce, including pre-service and in-service training, opportunities to develop the workforce pipeline, and methods of supporting wages and addressing provider burnout and compassion fatigue.
- Studying the feasibility, benefits, and challenges of establishing a state-based benefit for long-term caregiver supports and services.
- Prepare recommendations to the North Carolina General Assembly, the governor, and other constituents.



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## **TOPIC 2 – BARRIERS TO SUPPORT SERVICES**

- Caregivers who identify as racial or ethnic minorities, LGBTQ+, and others often face increased systemic barriers, including:
  - Distrust of providers from past experiences
  - Unaddressed cultural differences
  - Disparities faced by marginalized communities
- Other barriers include inability to meet eligibility criteria due to income, illness focus, age, location.

Source: Diverse Elders Coalition/National Alliance for Caregiving *Family Caregiving in Diverse Communities*, 2021



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**DAY 1**  
**WEDNESDAY, MAY 10**

## **TOPIC 2 – BARRIERS TO SUPPORT SERVICES**

- **Caregiver Champions:** Alicia Jones, Joseph Wheeler, Renaté Bender, Denise Pascarelli
- **Panelists:**
  - Sabrena Lea, Deputy Director, NC Medicaid, LTSS, Division of Health Benefits, NC Department of Health and Human Services
  - Jennifer Mahan, Director of Public Policy, Autism Society-NC
  - Scott Herrick, NC Director of Public Policy, Alzheimer's Association



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## **TOPIC 2 – BARRIERS TO SUPPORT SERVICES**

- **GAPS:** In your work, what gaps related to this topic should be addressed? What steps can be taken to close the gaps?
- **POLICIES:** What existing or potential policies might better support caregivers?
- **ADVOCACY:** How can caregiver advocates use their lived experience to become involved in advocacy around this topic? Where can they play a role to make a difference?
- **CAREGIVER CHAMPIONS:** *What does meaningful change look like?*



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**DAY 1**  
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- **Questions**
- **Comments / Feedback**
- **Wrap Up**







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**DAY 1**  
**WEDNESDAY, MAY 10**

## **CONTACT INFORMATION**

- **HEATHER BURKHARDT:** [ExecutiveDirector@nccoalitiononaging.org](mailto:ExecutiveDirector@nccoalitiononaging.org)
- **KAREN APPERT:** [karen@appertgroup.com](mailto:karen@appertgroup.com)
- **CHANGING THE CARE CONVERSATION project page:**  
<https://www.ncsicoalition.org/ctcc/>
- **CAREGIVING COLLABORATIVE MEETINGS:** virtual, first Friday of each month, 12:00 – 1:00 pm.
  - Zoom link: <https://us02web.zoom.us/j/88073971189>



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**DAY 1**  
**WEDNESDAY, MAY 10**

- NC Caregiver Champions
- Speakers & Panelists
- Attendees
- Community Catalyst
- Grantmakers in Aging
- NC Coalition on Aging
- NC Serious Illness Coalition
- Children's Complex Care Coalition of NC
- Caregivers, Care Recipients, and Supporters

**THANK YOU!**



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## **DAY 2**

### **THURSDAY, MAY 11**

- Welcome and Day 1 Recap
- NC Caregiver Champions - additional video clip
- **Topic 3** – Employment Issues Related to Caregiving
- **Topic 4** – Financial Issues Related to Caregiving
- Q&A / Wrap Up
- Next Steps



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## **TOPIC 3 – EMPLOYMENT ISSUES FACED BY CAREGIVERS**

- It's difficult to perform caregiving duties while being employed; and it's difficult to be employed while performing caregiving duties.
- According to the *Caregiving in the US 2020* report,
  - 61% of caregivers report working while caregiving and the majority have experienced at least one work-related impact.
  - Lost income due to family caregiving is estimated to be \$522 billion each year



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**DAY 2**  
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## **TOPIC 3 – EMPLOYMENT ISSUES FACED BY CAREGIVERS**

- **Caregiver Champions:** Heather Altman, Brittany Cutshaw, Karen Summey
- **Panelists:**
  - Frances Hall, Founder & Executive Director, Adult Children of Aging Parents (ACAP)
  - Victoria Chibuogu Nneji, Founder, AKALAKA



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## **TOPIC 3 – EMPLOYMENT ISSUES FACED BY CAREGIVERS**

- **GAPS:** Many businesses currently have staff shortages, and supporting caregivers can help retain employees. How to best educate businesses on working caregiver needs?
- **POLICIES:** Given the nature of caregiving, what policies or practices can organizations establish for when caregiving responsibilities conflict with work responsibilities?
- **ADVOCACY:** How can caregiver advocates use their lived experience to become involved in advocacy around employment issues?
- **CAREGIVER CHAMPIONS:** *What does meaningful change look like?*



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## **TOPIC 4 – FINANCIAL ISSUES FACED BY CAREGIVERS**

- Out-of-pocket expenses
- Insufficient paid work leave / flexibility
- Need to leave the workforce either temporarily or permanently
  - Affects immediate and future financial needs, including SS credits
- As a result of providing care:
  - Approx. 1 in 5 caregivers report high financial strain.
  - 45% of caregivers have experienced at least one financial impact as a result of caregiving; 34% have experienced two or more financial impacts.
  - Lost income due to family caregiving is estimated to be a staggering \$522 billion each year

Sources: Caregiving in the US 2020, National Strategy to Support Family Caregivers





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## **TOPIC 4 – FINANCIAL ISSUES FACED BY CAREGIVERS**

- **Caregiver Champions:** Heather Altman, Karen Summey, Amy Vanwyk
- **Panelists:**
  - Lisa Riegel, Manager of Advocacy & Livable Communities, AARP NC
  - Beth Messersmith, MPA, Senior Director, NC Director, MomsRising Together & MomsRising Education Fund



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## **TOPIC 4 – FINANCIAL ISSUES FACED BY CAREGIVERS**

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- **Questions**
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# The National Family Caregiving Strategy

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