Caregiver Research Strategy Meeting

Thursday January 8, 2026 in Chapel Hill, NC
Hosted by the Jordan Institute for Families, UNC School of Social Work, the NC Serious Illness Coalition and the NC Caregiving Collaborative

Purpose: Create an opportunity for connection related to caregiving research, explore building a caregiver research network, vision about how we can amplify existing research and expand our collective work to improve the health and wellbeing of North Carolina's caregivers across the life course.

Participants: The 26 individuals attending the meeting included caregiver coalition leaders, researchers from 6 universities and multiple disciplines, policy experts, and graduate students. Participants represented a variety of populations of caregivers including aging, cancer, veterans, serious illness, children and youth with special health care needs, people with Intellectual and Developmental Disabilities, postpartum and NICU parents, palliative care, youth caregivers, and kinship care.

Some of the reasons participants offered for attending the meeting ranged from their respect for the people who invited them and the people on the attendee list to an interest in building connections, increasing understanding of what work is already happening and excited about what could be accomplished collaboratively. Others mentioned that they value being in a space with others who feel the same energy and passion for caregiving and caregiving research.

Agenda Highlights:

After a welcome from Karen Appert and introductions, Erin Kent provided an overview of the possibilities that could emerge from increased research partnership and well as opportunities in North Carolina that could support research collaboration. She noted that **several key national reports** have been published (e.g. Family Caregiving for People with Cancer and Other Serious Illnesses) that have helped set the stage for caregiving research and show that caregiving is receiving national attention. The National Strategy to Support Family Caregivers has perhaps the most relevance to our collective work (https://acl.gov/CaregiverStrategy). Other groups have created follow up strategies such as one report focused on county level support ([Natl-Strategy-Support-Fam-Caregivers.pdf).](Natl-Strategy-Support-Fam-Caregivers.pdf)

She highlighted **data such as Caregiving in the US 2025 (data opens for larger use in a few months), Behavioral Risk Factors Surveillance System, Health and Retirement Study, National Health and Aging Trends Study & National Study of Caregiving, the**

2022 National Strategy to Support Family Caregivers

2 Councils + 5 Shared Goals = 1 Vision for Holistic Support

GOAL 1 — Increase awareness and outreach

GOAL 2 — Advance partnership and engagement

GOAL 3 — Strengthen services and supports

GOAL 4 — Ensure financial and workplace security

GOAL 5 — Expand data, research, and evidence-based practices

Health Information National Trends Study, National Longitudinal Survey of Youth, American Time Use Survey and the Panel Study of Income Dynamics data set – all with caveats and challenges. Erin also highlighted North Carolina specific plans such as the **NC DHHS All Ages, All Stages** strategic plan and work by the Serious Illness Coalition that offer ready-made synergy and ideas. The **North Carolina Caregiving Portal** (by Trualta) is another example of a platform with great potential and opportunity for data and evaluation. She also highlighted that North Carolina has **many community-led groups focused on caregiving i**ncluding but not limited to the Family Support Network of NC, the NC Serious Illness Coalition, The Center for Volunteer Caregiving, Advocates for Medically Fragile Kids NC, NC Coalition on Aging, Friends of Residents in Long Term Care, Children's Complex Care Coalition of NC, and the NC Caregiving Collaborative. These groups along with a potentially new Caregiver Advisory Group (via the NC Institute of Medicine) offer rich opportunities for genuinely connecting researchers with caregivers and a conduit for caregivers to guide research focus. Finally, there are several gatherings coming up including the **Legacy Series on Aging, the Duke Caregivers Conference and the upcoming 4th Biennial Conference on Caregiving Research** (Sept 23-25, 2026 – the 2028 conference will be in North Carolina). While not a complete list, Erin made a clear case that there are many foundational building blocks in place upon which a NC Caregiving Research Network could be laid.

Next, participants broke into small groups to begin discussing common issues for caregivers that need to be addressed and supports that caregiver researchers and caregivers alike wish they had. Each group then had a chance to share back some highlights from their conversation with the larger group. Information shared during these groups is incorporated in the content below.

Prior to lunch, Dean Ramona Denby Brinson from the UNC School of Social Work welcomed the group, thanked them for the gift of their time, offered her enthusiastic support and issued a call to 'dream big' during the afternoon discussion. After lunch,

participants had some quiet time to write down their ideas towards a larger dream/vision and more immediate next steps followed by a robust full group discussion. Participants expressed an interest in reconvening virtually sometime in February/March for an hour around noon to continue the conversation about specific action steps for the next several months and a strong consensus that they wanted to see this work continue to advance Nine individuals completed post-meeting follow up evaluation surveys. The majority found the meeting to have been valuable and expressed excitement at what is to come.

Key Considerations from Small Group Discussions (not already captured below)

- There was strong energy for taking a life course approach to caregiving research with an opportunity to go further together and given there are many common concerns and needs across caregivers.
- There is a real need to gap the bring between what the community is doing to support and engage caregivers (and their lack of money) and researchers and others in the health care space that are accessing resources but not doing the work that is really needed to be done.
- The health care system focuses only on the individual patient, which ignores that the person – particularly if they have a serious health issue – is part of a family. How can we reshape a care system that includes the caregiver fully as a partner? For example, family members / caregivers may have important information that pertains to the patient's health/diagnosis, but that is never sought or heard. It is very hard for families to get relevant information to a provider.
- Health policy assumes there is a person to take on the patient's / family member's care! YET caregivers are not included and ignored.
- We cannot overlook the financial aspects of caregiving.
- When people are in times of crisis, this is when they need support the most but have the least capacity to access it. How might we find ways to a) get people services and supports before they are in crisis, b) get people what they need when they need it?
- We need to remember that providers and families work in a time and resource-consuming space as we consider interventions.
- It would be interesting to look at various settings that have different types of caregiver support and compare outcomes for patients. This came up a second time in the context of counties where there is a seamless connection between hospital and community palliative care and where certificate of need issues/competition or whatever keeps that connection from happening.

- We want to create and adapt research that can make caregivers' lives easier. How can we collaborate and amplify each other's work if we collectively come up with interventions in a way that is mutually beneficial.
- How do we think across systems? Focusing on specific research populations is necessary and this has been a hindrance to research because we are not sharing common study instruments or tools.
- Time constraint is a major issue for caregivers. They can be overwhelmed by resources and at the same time do not have time to find and navigate the resources that exist.
- We need to be inclusive of non-traditional relationships between care givers and care recipients.
- We need to consider the nuances of care situations, medical information and communication about the recipient's care.
- How can we revise measures to capture relationship complexities.
- Emphasize practices of care rather than care giver as a way to identify more people who are caregivers but don't see themselves as such.

Dreams for the Future (Big Vision)

The group had a wealth of ideas about what they would like to see emerge from a caregiver Research Network over time. Below is a list sorted into general categories.

<u>Improved service delivery for caregivers/care recipients</u>

- Apply a family perspective to medical care shifting from a focus only on the individual patient to the people who support that patient's care. Caregivers / caregiving recognized as the center of person-centered care. Identifying and considering caregiver needs is integrated into routine clinical care across primary, specialty, and hospital care.
- Research and share findings that demonstrate the impact of family caregivers on concrete health and quality outcomes (e.g. cost benefit of supporting caregivers)
- Integrate medical-social practices across systems that identify and supports family caregiver needs along with the individual care recipient's needs. We need to develop, evaluate, and implement interventions that bridge clinical and social care for families and caregivers.
- Develop comprehensive interdisciplinary palliative care for Medicare and Medicaid populations. Learn from the successes of this care model. Study the impact of disjointed palliative care models.

- Increased application of trauma and resilience-informed care for different caregiver populations.
- Engage caregivers in co-designing the Caregiving Portal or apps or other means to help identify resources – particularly when under acute stress.
- Studies and interventions need to focus on removing burdens to caregiving, especially administrative burdens.

Defining and identifying caregivers

- Agree upon a common definition(s) of caregiver.
- Engage with caregiver coalitions to build understanding of how caregivers identify themselves and the language that could be used to better identify individuals providing care for research and practice studies.
- Revamp healthcare system to focus on the family system. Document caregivers on EMR using self-identification plus functional activities guidelines.
- Get caregiver status included in all EPIC charts and/or part of the medical history questionnaire.

Research priorities

- Increased recognition of intersections between caregiving and interpersonal violence and how to address them.
- Research that leads to the application of "right dosing" of education, support and respite for caregivers to prevent negative health consequences for them and those for whom they are giving care. Focus on timing to reach caregivers while they are interested / have needs but before they are in a caregiving crisis.
- Provide special attention to the caregiving experiences of immigrants, long distance caregivers, caregivers of color, caregivers in the LGBTQ+ community, and young caregivers. Focus on the unique experiences of these different groups, including trust. Consider the unique interests of caregivers for populations that have been overlooked such as kinship caregivers and their needs (often grandparents caring for grandchildren) and caring for individuals with severe and persistent mental illness and substance use.
- Increased research focused on the views, needs, and resources for ethnically diverse populations.
- Collect / review / share data on unpaid caregivers, direct care workforce, and the palliative care workforce – and how they intersect with each other.
- Support caregiver/partner panels to provide lived experience input and cross-sectional understanding of what supports are needed.

- Develop a new Caregiving Research Society that is headquartered in NC.
- Shape this research collaborative to understand the drivers of the complexity of the practices of care, including an acknowledgement of location, space and care transitions in the quality of care. Caregiving research that really examines the complexities of caregiving populations (e.g., experiences, ages, multiple care recipients, long-distance caregivers, transitions beyond just from hospital, and long-term care at home).
- Better understand available services and service needs of rural caregivers, including respite care.
- A statewide longitudinal study of caregivers that includes indicators related to the social determinants of health and financial wellbeing.
- Well-funded caregiving research to inform programs, policies and practices so they can better support caregivers.
- Establish a standing regional council of caregivers that researchers can tap into as needed.
- Research looking at paying family caregivers to see if it improves the lives of the care recipient and caregiver and evaluate the return on investment in health outcomes for both.
- Provide data and evidence to shift medical school and healthcare provider training to better integrate caregivers (support a paradigm shift).
- Remove administrative burden on caregivers (especially Medicaid work requirements).

Policy priorities
- Support universal paid family and medical leave to support family caregivers with a high rate of wage replacement and an expansive/inclusive definition of family.
- Identify funding to create caregiver resource centers in NC, as they have in California, potentially linked to the Caregiving Portal in some way.
- Advocate for policies that support paid care workers' pay increases and retention incentives. Likewise, advocate for policies that pay family care workers and offer care subsidies.
- Develop long-term care financial models and policies. The biggest help to unpaid caregivers is better access to paid care in the home and in facilities as needed
- Identify funding for a sustainable range of services for caregivers for people with cancer.
- Create a standing committee on caregiving at the NC General Assembly.
- Build an endowment devoted to caregiving research and practice innovation.

Caregiving Research Network

- Create a national hub for caregiving related research, intervention evidence and innovation.
- Develop a 5-year research action plan with concrete policy/investment steps.
- Improve capacity to translate research into accessible tools for families.
- Work harder at translating our work for lay audiences to give them hope and to see the results of studies in which they may have participated.
- Center marginalized populations' experiences, interests and needs in our collective research.
- Support movement away from age discrimination for caregiving supports (youth).
- Build a network that takes the time to understand complexity of caregiving particularly for those with minoritized identities; start with broad questions about experiences and then narrow.

Next Steps for the Immediate Future (6 months)

The group identified several areas for moving forward. There was a clear desire to continue along this path of collaboration. The Jordan Institute for Families offered to provide ongoing convening and coordination support as the work moves forward.

Continued conversation and collaboration

- Develop and share a resource/asset map of this network of people.
- Convene this group on a regular basis (e.g., bi-monthly) to figure out next steps, collaborate, and continue discussing opportunities for working together.
- Continue to support opportunities for researchers and advocates / community/coalition leaders to learn from each other and build strong, mutually beneficial relationships.
- Continue to meet and collaborate with other caregiving researchers and policy makers to discuss the problems and potential solutions.
- Stay connected with the work of the NCIOM as they learn about funding and build a Family Caregiver Task Force.
- Coordinate this group so they can support the 2028 Caregiving Research Conference. Consider attending the 2026 Conference in Salt Lake City (abstracts open now).
- Continue to proactively connect to and engage additional groups, associations and researchers in this network.

- o Consider identifying researchers interested in caregiving issues for people who care for individuals with substance use disorder and severe and persistent mental health conditions.
  - o Consider identifying researchers who work in family systems and relationships given the way that family relationships influence caregiving – and wellbeing and finances and everything else. What skills do families need?
  - o Consider reaching out to family medicine to find someone there interested in caregiver support or family systems care and research to engage.
- Continue to build the partnership between the Jordan Institute for Families and the NC Caregiving Collaborative to build sustainable and stable opportunities for research / community advising and reciprocity.
- Explore having the 2027 UNC School of Social Work Legacy Series focus on Caregiving.
- Create a central online location for sharing resources, networking, plans etc. The Jordan Institute for Families has offered to support this development. Establish a directory for the Caregiver Research Group
- Identify a subgroup of individuals interested in collaborating to work with and enhance the NC Caregiving Portal.

Research-related activities
- Facilitate deliberate connection between researchers and community-engaged programs like CARES on funded projects focused on caregivers (Community Boards).
- Build from this first meeting to develop a 5-year research roadmap. Publish a paper on the roadmap to increase visibility for collective work.
- Hold an event that connects research with policy and advocacy needs in NC.
- Create a hub for research sharing within this group (research and funding opportunities, sharing resources, etc.)
- Identify some of the throughlines that connect our diverse research and practice interests. Transitions was one potential thread that could be explored from a life course perspective. This could be done by hosting a full day in person meeting to map this out.
- Develop an intentional strategy/plan to connect caregiving practice and research more closely.
- Develop a process paper based on this and/or future meetings to help encourage other caregiving researchers to come together and provide a roadmap for how to make that happen.

- Engage research "clusters" by topic to connect, work together and present their work. Megan Shepherd-Banigan's work with the VA was suggested as a first potential webinar/conversation.
- Look into the feasibility of research coordination for this group.

<u>Caregiver service-related activities</u>
- Integrate more implementation science principles into the design, study, and roll out of caregiver services to increase likelihood of success, sustainability and replication.
- Continue to support cross-collaboration of different approaches related to caregiving across the lifecourse to inform future funding and policies.
- Establish a standing Care Partner Advisory Council (or regional councils) which researchers can engage to inform their work – from study conception to implementation and dissemination of findings.
- Pursue policy opportunities to have caregivers integrated into medical records – this is foundational for research and family support.

Participants:
Tess Thompson, Brystana Kaufman, Elizabeth (Betsy) Olson, Cassandra Germain, Shelley Gist, Sandi Lane, Karen Appert, Jenny Hobbs, Megan Shepherd-Banigan, Michelle Ries, Patrick Tang, Ayana Simon, Nathan Boucher, Christine Lathren, Christina Hugenschmidt, Sheryl Zimmerman, Linda Kendall Fields, Kathy Colville, Tyreasa Washington, Erin Kent, Sarah Verbiest, Jenna Muller, Robert Hawkins, Destiny Coe, Stephanie Sperry, Camille Murray