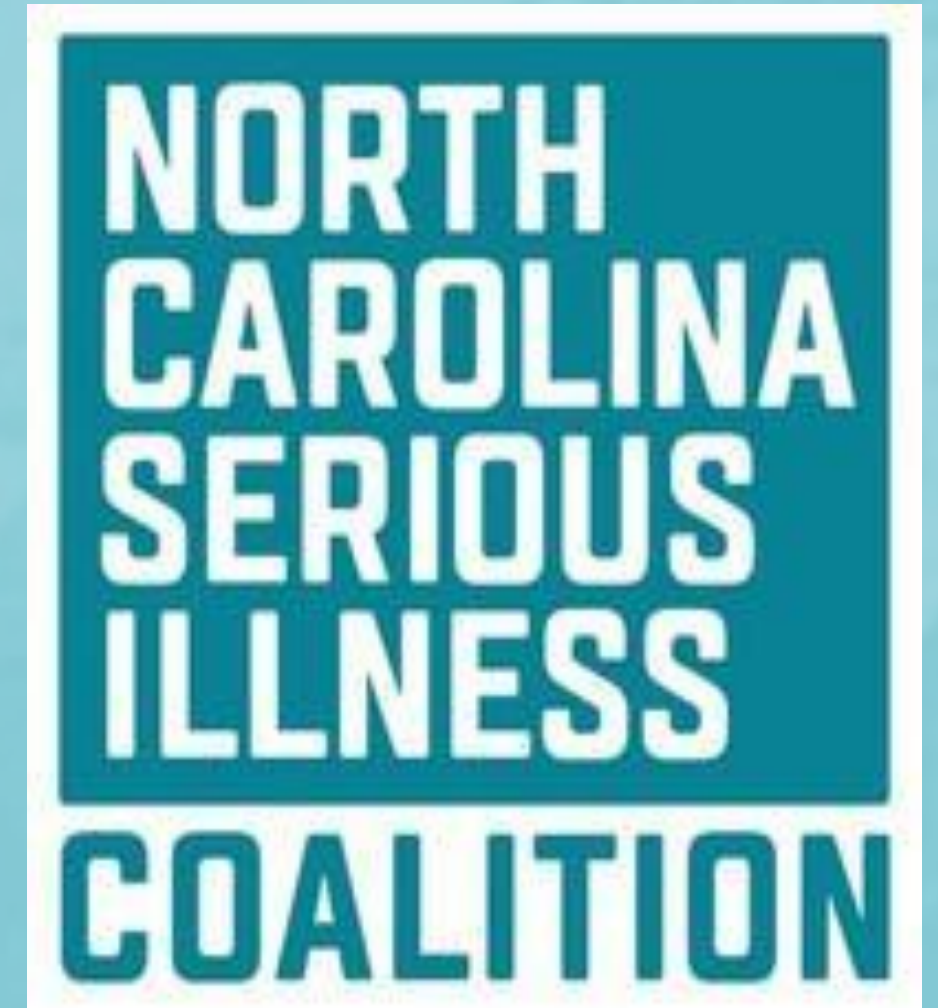


**North Carolina
Serious Illness Coalition
2025 Year in Review**



2020

30 Members

2021

80 Members

2022

180 Members
from 98 Organizations

2023

200+ Members
from 100+ Organizations

2024

330+ Members
from 120+ Organizations

2025

370+ Members
from 150+ Organizations

Coalition Membership & Participation

Gratitude to our New Sponsors & Supporters!

Operated by:



Thank you to our generous sponsors and supporters:

Sponsors:



CaroNova



Supporters:



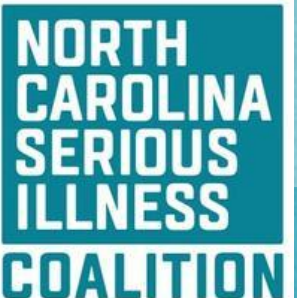
**NC CAREGIVING
COLLABORATIVE**



SCHOOL OF SOCIAL WORK
Jordan Institute for Families



LOWER CAPE FEAR
LifeCare



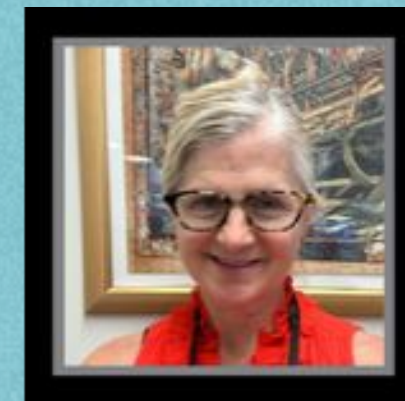
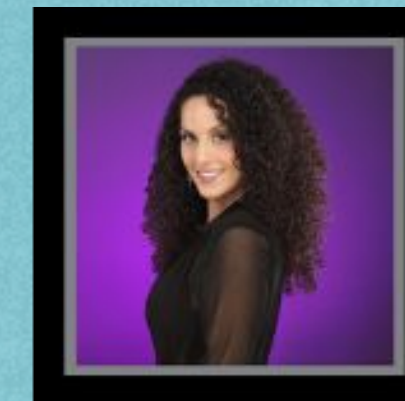
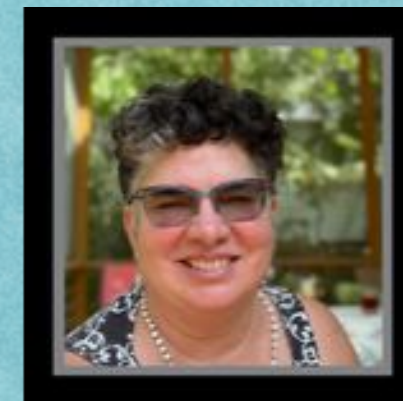
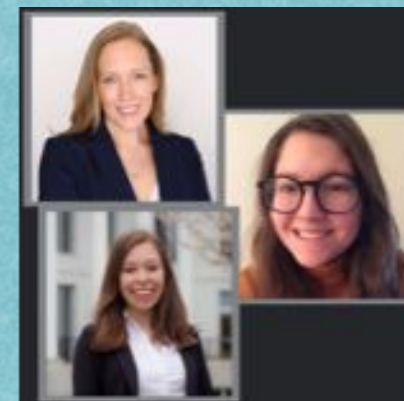
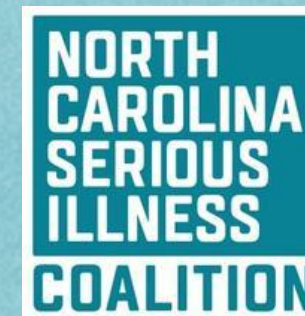


2025

Friday Facts & Presenters

Yocasta Bianconi (Caregiver Coach)
 Laura Foy (Medicare GUIDE program)
 Jacqueline Zanders (NCSI Intern)
 Mike Tramber (Miracles in Sight)
 Heather Boykin (Lower Cape Fear LifeCare)
 Stacie Sinclair (CAPC Palliative Care)
 Sangita Ramani (Novant)

Elaine Whitford (NC Respite Consortium)
 Tiffany Fountain (American Cancer Society)
 David & Catherine Sevier (NCSI Founders)
 Jamie Hunter, Katalia Alexander &
 Iris Greenspan (NCSI Interns)
 Betsy Barton (Transitions LifeCare)
 An Act of Love Video (Transitions LifeCare)
 Karen Seagraves (Ceribell)
 Lisa Toole (NC Secretary of State)



2025 Monthly Meeting Topics

January
GUIDE
Dementia
Program

February
Disparities in
Organ
Donation

March
Palliative
Care State
Scorecard

April
ACP @
NC Secretary
of State

May
Age Friendly
Communities

June
AI & Brain
Health

July
No
Meeting

August
2020-2025
NCSI Report

September
100th FF
Celebration
with Seviars

October
American
Cancer
Society

November
NC Volunteer
Respite
Consortium

December
No
Meeting



NCSI Coalition Interns



Sabita Markose
UNC CH



Bernadette Moss
UNC CH



Steven Nordstrom
UNC CH



Disha Patel
UNC CH



Maria Rivera
UNC CH



Aviti Dombasi
UNCC



Megan Reid
UNCC

2023



Lauren Stalzer
UNC CH



Carrie Poole
UNC CH



English Bonds
UNC CH



Hannah Dodge
App State



Manasi Somkuwar
UNCC



Mannah Patel
UNC CH



Brooke Middleton
UNCC



Essence Turner
UNC CH



Sucharitha Tiyyagura
UNCC



Shravan Durga
UNCC

2024

Focus Areas:

Clinical Training & Palliative Care
End of Life / Advance Care Planning
Health Equity & Health Disparities
Caregiving Supports & Policy
Coalition Evaluation & Planning
Social Media & Content Creation



Jacqueline Zanders
UNC CH



Iris Greenspan
UNC CH



Jamie Hunter
UNC CH



Katalia Alexander
UNC CH



Destiny Coe
UNC CH

2025



State of North Carolina

JOSH STEIN
GOVERNOR

NORTH CAROLINA HEALTH CARE DECISIONS MONTH

2025

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

A PROCLAMATION

WHEREAS, Health Care Decisions Month is designed to raise public awareness of the need to plan ahead for health care decisions, especially related to end-of-life care and medical decision-making when patients are unable to speak for themselves, and to encourage the specific use of written documents that explain individual preferences in health care decisions, such as advance directives for end of life; and

WHEREAS, decisions concerning health care should be made by individuals in consultation with their health care provider and their families; and

WHEREAS, many North Carolinians do not make adequate preparation for health care decisions in times of crisis or at end-of-life; and

WHEREAS, Health Care Decisions Month helps raise awareness of the need to provide clear and consistent information to the public about advance directives and encourages medical professionals and lawyers to volunteer their time and effort to improve public knowledge and increase the number of North Carolina citizens with advance directives;

NOW, THEREFORE, I, JOSH STEIN, Governor of the State of North Carolina, do hereby proclaim April 2025, as “**NORTH CAROLINA HEALTH CARE DECISIONS MONTH**” in North Carolina, and commend its observance to all citizens.



Josh Stein
JOSH STEIN
Governor

IN WITNESS WHEREOF, I have hereunto set my hand and affixed the Great Seal of the State of North Carolina at the Capitol in Raleigh this nineteenth day of March in the year of our Lord two thousand and twenty-fifth and of the Independence of the United States of America the two hundred and forty-ninth.

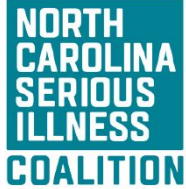


Governor's Proclamation:

North Carolina Healthcare Decisions Month April 2025



NCSI Coalition 5 Year Report



NCSI Coalition: 5 Years of Impact, Growth, and Vision (2020–2025)

August 2025

1

NORTH CAROLINA SERIOUS ILLNESS COALITION

THE VOICE OF SERIOUS ILLNESS CARE IN NORTH CAROLINA

WHO WE ARE

Established in February 2020 as a directive of the North Carolina Institute of Medicine's Task Force on Serious Illness Care. The North Carolina Serious Illness Coalition is a volunteer-led group of health professionals, providers, consumers, and advocates dedicated to **improving the lives of individuals with serious illnesses and their caregivers.**

IMPACT SNAPSHOT:


- Monthly meetings, newsletters & presentations, **Friday Facts highlighting NC Thought leaders**, "Advocacy 101" videos
- **Annual "Joining Our Voices" Symposium** & special events
- Active workgroups to focus member interest & expertise
- **350+ participants from 125+ organizations**
- 20+ interns hosted from NC universities to support training
- **Statewide partnerships** and national representation on advance care planning, clinical practice, family caregiving, serious illness care, and advocacy

STRATEGIC PRIORITIES:

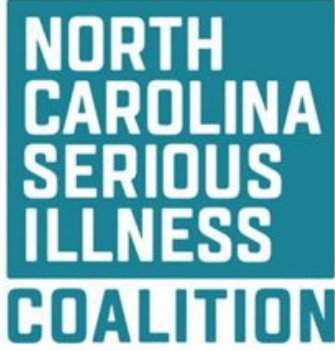
- **Connect** diverse stakeholders and strengthen partnerships to strengthen awareness, advocacy, and collaboration.
- **Create** educational content to promote advance care planning, and serious illness care that aligns with personal goals
- **Convene** thought leaders to collaborate on innovative models and initiatives
- **Champion** policies that increase access and reduce disparities for patients, providers and caregivers

HOW YOU CAN GET INVOLVED

- Join the Coalition & attend monthly meetings
- Share Coalition resources with your networks
- Present at an educational session
- Attend the "Joining Our Voices" annual symposium and other special events
- Help us advocate for policies to support patients, families and communities
- Support the Coalition as an organizational sponsor or individual donor
- Fuel the infrastructure needed for equitable, person-centered care in every community



admin@ncsicoalition.org
www.ncsicoalition.org/







THE COALITION'S MEMBERS AND PARTNERS ARE WORKING TO IMPROVE THE QUALITY OF LIFE FOR MILLIONS OF NORTH CAROLINIANS LIVING WITH OR CARING FOR SOMEONE WITH A SERIOUS ILLNESS.

Join us in our vision of equitable, person-centered care for all:

- **Patients** will have the information they need to make informed decisions and ensure their care reflects their values.
- **Caregivers** will have their voices heard and gain access to the training and support they urgently need.
- **Providers** will be equipped with the training, tools, and standards to deliver high-quality, consistent, evidence-based care.
- **Policymakers** will be guided by data and real stories to shape legislation that improves serious illness care.

NCSI COALITION WORK GROUPS

-  **ADVANCE CARE PLANNING & CLINICAL PRACTICE**
Promotes consistency in serious illness care and champion advance care planning so that everyone receives care aligned with their personal goals and wishes
-  **CAREGIVER & PATIENT ENGAGEMENT**
Engages with organizations, agencies, and individuals to elevate community voices, promote awareness and expansion of supportive policies, practices and resources for patients and caregivers
-  **COMMUNICATIONS, ADVOCACY & EDUCATION**
Fosters collaboration and cooperation, develops educational and outreach activities to raise awareness, promote education, and support advocacy efforts



350+ Members
125+ Organizations

- Highlights from the past 5 years
- Reflection on Coalition strengths, opportunities, and challenges
- Priorities for the next phase

NC Serious Illness Coalition

2025-2026 Public Policy & Legislative Priorities

The following are the 2025-2026 public policy and legislative priorities for the NC Serious Illness Coalition. These priorities do not represent the entirety of the issues which the Coalition supports and on which it takes a position. The Coalition leverages collective advocacy through its members and partner organizations.

SUPPORT THOSE LIVING WITH SERIOUS ILLNESS & THEIR FAMILY CAREGIVERS

UPDATE REQUIREMENTS FOR ADVANCE HEALTH CARE DIRECTIVES

Support legislation to expand the ability for individuals to identify who will speak for them when they cannot speak for themselves, make their healthcare preferences known, and share their Advance Directives electronically. Align NC with the 46 other states who have updated signature and notary requirements for health care powers of attorney and advance health care directives, as well as electronic access to these documents.

STRENGTHEN PALLIATIVE CARE ACCESS

Support legislative efforts to strengthen access to palliative care services, including implementing new palliative care payment models, approve Medicaid coverage for comprehensive adult and pediatric palliative care, and explore development of a NC Palliative Care Advisory Council.

SUPPORT FAMILY CAREGIVERS

Support programs and services to lessen the caregiver burden, such as those providing respite care. Strengthen family leave policies and provisions, including paid and unpaid leave, and provide resources to employers to adopt workplace policies to help employed caregivers. Establish a state tax credit for family caregivers to help offset out-of-pocket costs for expenses incurred in caregiving, such as home modifications, assistive devices, and personal care items.

EXPAND ACCESS TO CARE

STABILIZE THE DIRECT CARE WORKFORCE CRISIS

Help stabilize the health care workforce crisis by building on existing initiatives already ongoing in the state and by expanding financial incentives such as loan repayment programs, tuition reimbursements, and stipends to attract and retain health care workers.

AUTHORIZE FULL PRACTICE AUTHORITY FOR ADVANCED PRACTICE REGISTERED NURSES

Support The SAVE Act. Bring North Carolina in line with long-established national standards by modernizing regulations to allow Advanced Practice Registered Nurses (APRNs) to work to the full extent of their training and education; thus improving North Carolina's healthcare system to deliver better care, faster access, and lower costs.

PROVIDE ADEQUATE RECURRING FUNDING FOR HOME & COMMUNITY BASED SERVICES

Provide adequate recurring funding for home and community-based services (HCBS) to address access to services for seniors, and for adults and children living with disabilities, medical complexities, or serious illness. Funding is needed to address waitlists and staffing across the HCBS continuum.

SUPPORT INDIVIDUALS TO SAVE FOR FUTURE SERIOUS ILLNESS CARE COSTS

Promote legislation to establish private-public partnerships to help individuals save and to empower families to take control of their financial future to help face the costs of serious illness care.

Advocacy Efforts

VOTE "YES!" HOUSE BILL 349

Help Our Citizens Take Charge Of Their Health, Ease The Burden Of Advance Care Planning



BACKGROUND

- NC is one of **only three states** that requires a notary **AND** witnesses to complete Advance Care Planning (ACP) Documents.^{7,9}
- **HB 349** would align NC with the rest of the country and allow residents to use a notary **OR** two qualified witnesses.^{7,9,12}
- In 2024, there were **1,993,441 people over 65** years old in NC. This population is projected to **increase 52%** by 2050.¹¹
- 70% of US adults express **preferences for less aggressive treatments** near the end of life, but **only 37% have fully executed** ACP documents.^{3,6,10}
- In the **absence of ACP** documents, medical professionals may perform major and costly interventions unknowingly **against a patient's preferences**.^{1,10}
- Completing ACP documents was associated with less in-patient time at the end of life, and an overall adjusted **cost savings** of \$9,500.^{2,13}
- An ACP **reduces the decision burden on caregivers**, and reduces guilt, conflict, distress, and regret when caring for a critically ill loved one.^{4,5}

WHAT IS AN ADVANCE CARE PLAN?

An Advance Care Plan includes:

- **Health Care Power of Attorney**
 - Designating someone to make healthcare decisions if you are unable to do so yourself.⁸
- **Advance Directives** i.e. "Living Will"
 - Treatments you would, or would not like to receive in an emergency, directives around life-sustaining care, organ donation preferences, etc.⁸

WHO NEEDS AN ACP?

Everyone! But especially...

- Older adults
- People living with serious illnesses, like cancer
- Those at risk for cognitive decline⁸

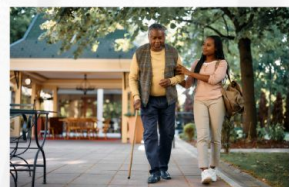


"WHEN AN ADVANCE DIRECTIVE IS NOT AVAILABLE IN CASES OF EMERGENCY, IT CREATES A COMPLEX SITUATION FOR THE CARE PROVIDERS AND SURROGATE DECISION MAKERS"

- ALEXIA TORKE, MD, MS

WHAT IS NC GA HOUSE BILL 349?

PART I. HEALTH CARE POWERS OF ATTORNEY SECTION 1.1. G.S. 32A-16(3) reads as rewritten: "(3) Health care power of attorney. - Except as provided in G.S. 32A-16.1, a written instrument that substantially meets the requirements of this Article, **that is signed in the presence of two qualified witnesses, and witnesses or acknowledged before a notary public,**"¹²



Easing the administrative burden required to fully execute a Health Care Powers of Attorney for those unable to access a notary, or those unable to easily find two witnesses who are not relatives, heirs, healthcare providers, or employees of healthcare facilities at the time of signing. This change will allow more North Carolinians to make their preferences known, ease the burden on their loved ones, and ensure they receive care that aligns with their values.

MEMBERS OF THE NORTH CAROLINA GENERAL ASSEMBLY

Please Vote "YES"

to ease administrative burden and give North Carolinians agency in their healthcare.

CITATIONS

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2. Bond, W. F., Kim, M., Franciskovich, C. M., Weinberg, J. S., Svendsen, J. D., Fehr, L. S., Funk, A., Sawicki, R., & Asche, C. (2018). Advance Care Planning in an Assisted Care Organization is Associated With Increased Advance Directive Documentation and Decreased Costs. *Journal of Palliative Medicine*, 21(6), 488-502. <https://doi.org/10.1089/jpm.2017.0544>
3. Brenner, A. B., Solovay, L. E., Palamitawan, C. K., & Burke, J. F. (2021). Understanding End-of-Life Preferences: Predicting Life-Prolonging Treatment Preferences Among Community-Dwelling Older Americans. *Journal of Pain and Symptom Management*, 61(3), 525-530. <https://doi.org/10.1016/j.jpainsymman.2020.04.012>
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12. North Carolina Department of Health and Human Services. (2024). *Advance Care Planning in an Online World*. State Law Library and Challenge to Care COVID-19. Patient Information Center. <https://patientinformationlibrary.org/advance-care-planning-online-covid/>
13. Zhu, Y., & Engstler, S. (2021). Advance directives completion and hospital out-of-pocket expenditures. *Journal of Hospital Medicine*, 17(6), 437-444. <https://doi.org/10.1002/jhm.12839>

Medicaid Matters in NC

Medicaid is the primary payor of essential long-term services and supports, ranging from home-based care to nursing facility care.

Cuts being proposed by Congress could severely impact access to these critical services in NC.



• Roughly **3.1 million** North Carolinians depend on Medicaid, including **older adults, people with disabilities, and people with serious illness**.¹



• Nearly **half** of older adults and people with disabilities who depend on NC Medicaid **live in rural counties**.²



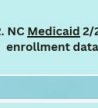
• Many people depend on Medicaid services for help with essential needs like bathing, eating and toileting. **These are services that help people stay in their own homes.**



• There is a **direct care workforce crisis**. **1 in 4** of these essential workers in NC use publicly-funded insurance, including Medicaid.³



• In NC, from 2024-2050 the **age 85+ population** will increase by **152%**. Older adults often depend on Medicaid for long-term services and supports, so it is important to protect NC Medicaid as our aging population grows.⁴



• There are approximately **1.3 million family caregivers in NC**. Medicaid cuts don't just hurt Medicaid recipients but **hurt the family caregivers who support them**.⁵

1. NC Medicaid 2/2025 enrollment data
2. PHI Workforce Data Center
3. NC Dept. of Health and Human Services, Insights into Aging
4. AARP

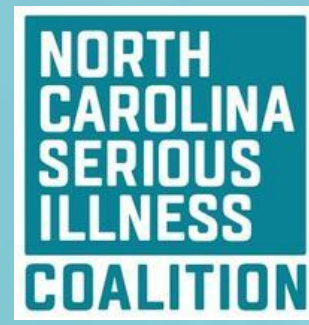
Medicaid Matters to ALL of Us. PROTECT IT!

Call your US Representative at 202-224-3121 and ask them to protect Medicaid from budget cuts.

- Tell Them:
- Many older adults, people with disabilities and people with serious illness throughout our state depend on Medicaid.
 - As our population ages, the need for Medicaid-funded long-term services is rising fast.
 - If you have a personal story, share how Medicaid helps you and what it would mean if services and programs were reduced or eliminated.

Need to find your representative? Click here or go to this website: shorturl.at/TH4k5

- Thanks to the following groups for collaborating on this message:
- NC Coalition on Aging/Essential Jobs, Essential Care
 - National Domestic Workers Alliance
 - NC Serious Illness Coalition
 - NC Caregiving Collaborative
 - NC Council on Developmental Disabilities





The NC Caregiving Collaborative convenes organizations and individuals engaged in caregiving advocacy.

2025 State Activities

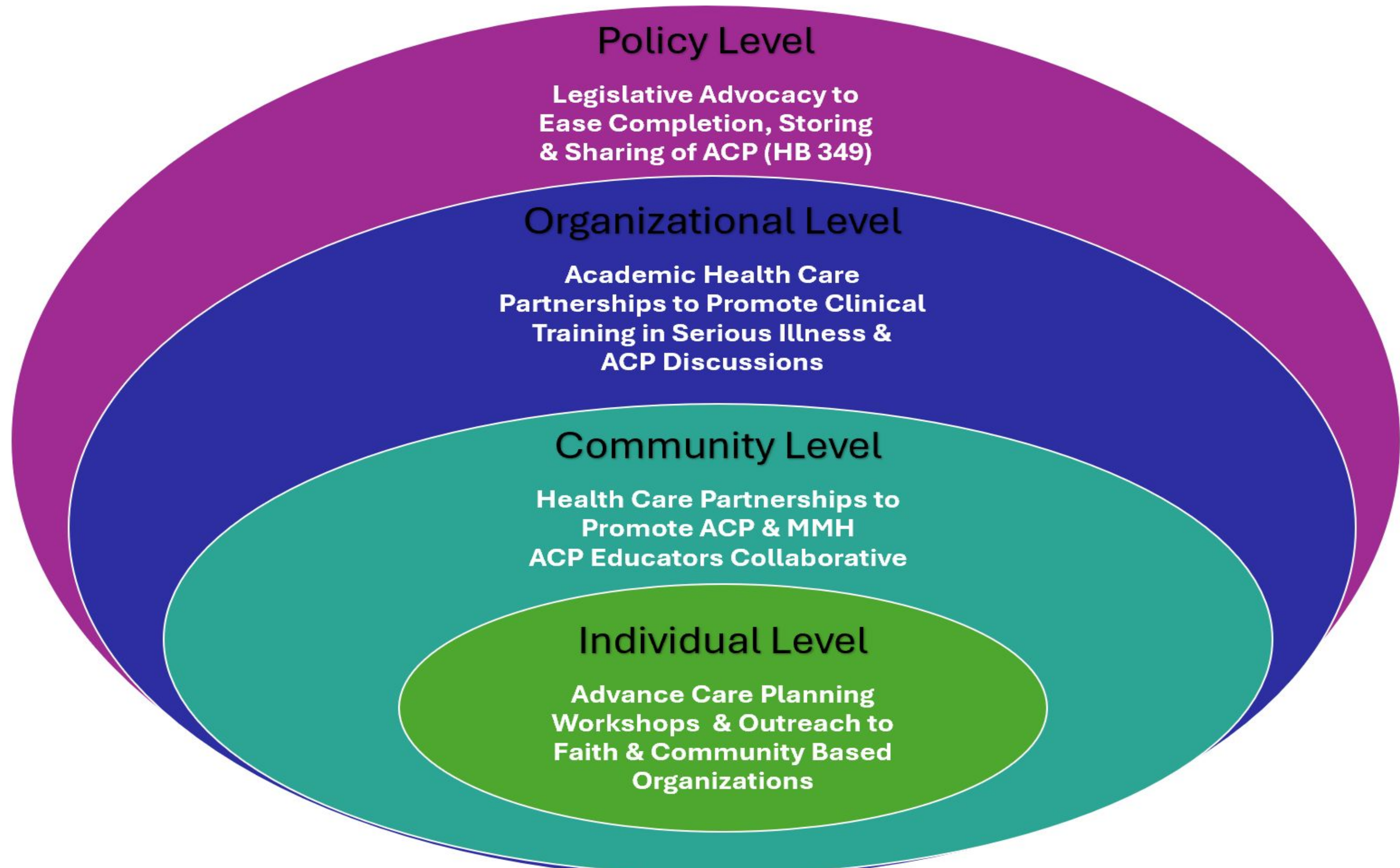
- Monthly virtual meetings
- Landscape analysis project of caregiver resources in NC
- *"Joining Our Voices"* symposium - Caregiving in the US 2025
- Advocacy
 - Medicaid - virtual federal legislative visits with Essential Jobs, Essential Care initiative before OBBB was passed
 - Paid leave/ paid sick days - virtual federal legislative visits with NC Families Care coalition and other organizations

2025 National Activities

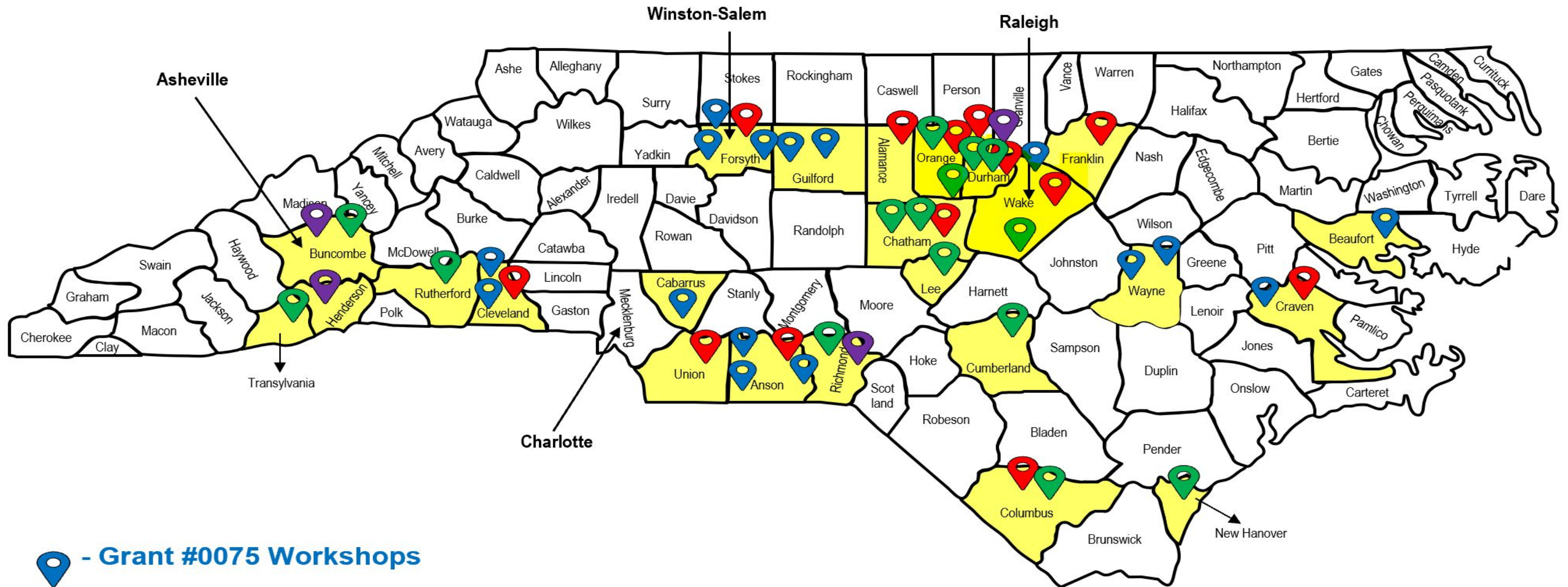
- Caregiver Nation Network - bi-monthly virtual meetings connecting with other states in Network
- Caregiver Nation Summit, Washington DC – workshops, speakers, and Hill Day advocacy visits to state legislators



Community Engagement in Advance Care Planning Project

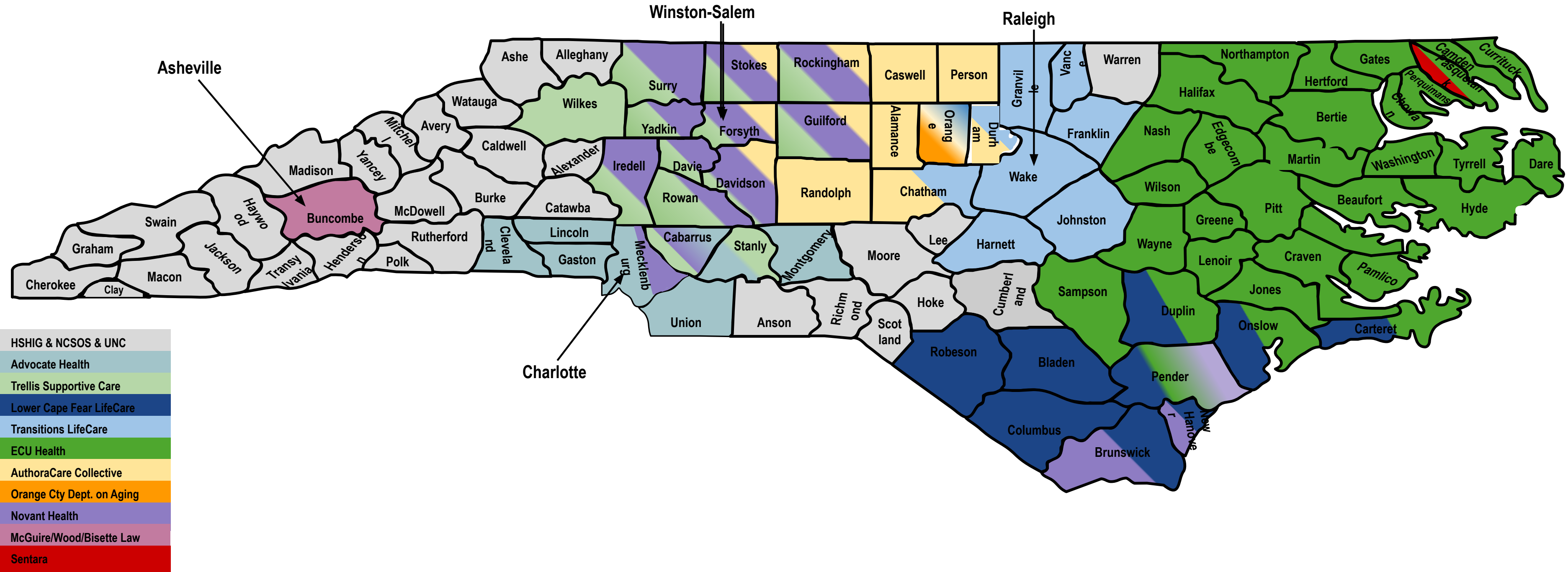


Advance Care Planning Workshop Locations



-  - Grant #0075 Workshops
-  - Grant #0081 Workshops
-  - Grant #0084 Workshops
-  - Grant #0091 Workshops

ACP Educators Collaborative - Coverage Map





2025 Joining Our Voices Symposium

Day 1

When Wishes Collide With Reality:
Navigating Dementia, Decision-Making, and
Disputes in Care Planning

Day 2

Conversations That Count:
Aligning Care with Goals for Every Patient

Day 3

We Are All In This Together:
Caregiving in the U.S. 2025

Symposium Participation: 140 Registrations
87 Unique Participants



ABOUT

Joining Our Voices: Envisioning the Future of Serious Illness Care is a virtual symposium that unites health professionals, providers, caregivers and advocates in conversation to share experiences, innovations, and opportunities for the future of North Carolina's serious illness care.

This event is produced by the North Carolina Serious Illness Coalition in collaboration with its membership and partner coalitions.

Learn more about the coalition at:
www.ncsicoalition.org.

EVENT LINEUP

TUESDAY, OCT 28, 12:00PM - 1:30PM ET
WHEN WISHES COLLIDE WITH REALITY:
NAVIGATING DEMENTIA, DECISION-MAKING,
AND DISPUTES IN CARE PLANNING

WEDNESDAY, OCT 29, 12:00PM - 1:30PM ET
CONVERSATIONS THAT COUNT: ALIGNING
CARE WITH GOALS FOR EVERY PATIENT

THURSDAY, OCT 30, 12:00PM - 1:30PM ET
WE ARE ALL IN THIS TOGETHER: CAREGIVING
IN THE U.S. 2025

[Click here or scan the QR code to learn more](#)

Operated by:



Thank you to our generous sponsors and supporters

Sponsors:



Supporters:



Looking Ahead to 2026

Maximizing YOUR time, engagement, interests
& organizing workgroup efforts around key initiatives...

★ Caregiving & Patient Engagement:

- * NC Caregiving Collaborative
 - NC Caregiving Landscape Analysis Project
 - NC Caregiving Research Roundtable

★ Clinical Practice & Advance Care Planning

- * NC Clinical Consortium on Serious Illness Conversations Training
- * NC ACP Educators Collaborative
- * Palliative Care Advisory Committee

★ Communications, Advocacy & Education

- * Legislative & Public Policy Activities
- * Monthly Meeting Topics & Friday Facts Speakers
- * Joining Our Voices Symposium & Special Events