

Respite Care For Caregivers

The What, Why, and How for Family Caregivers



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The What, Why & How of Respite

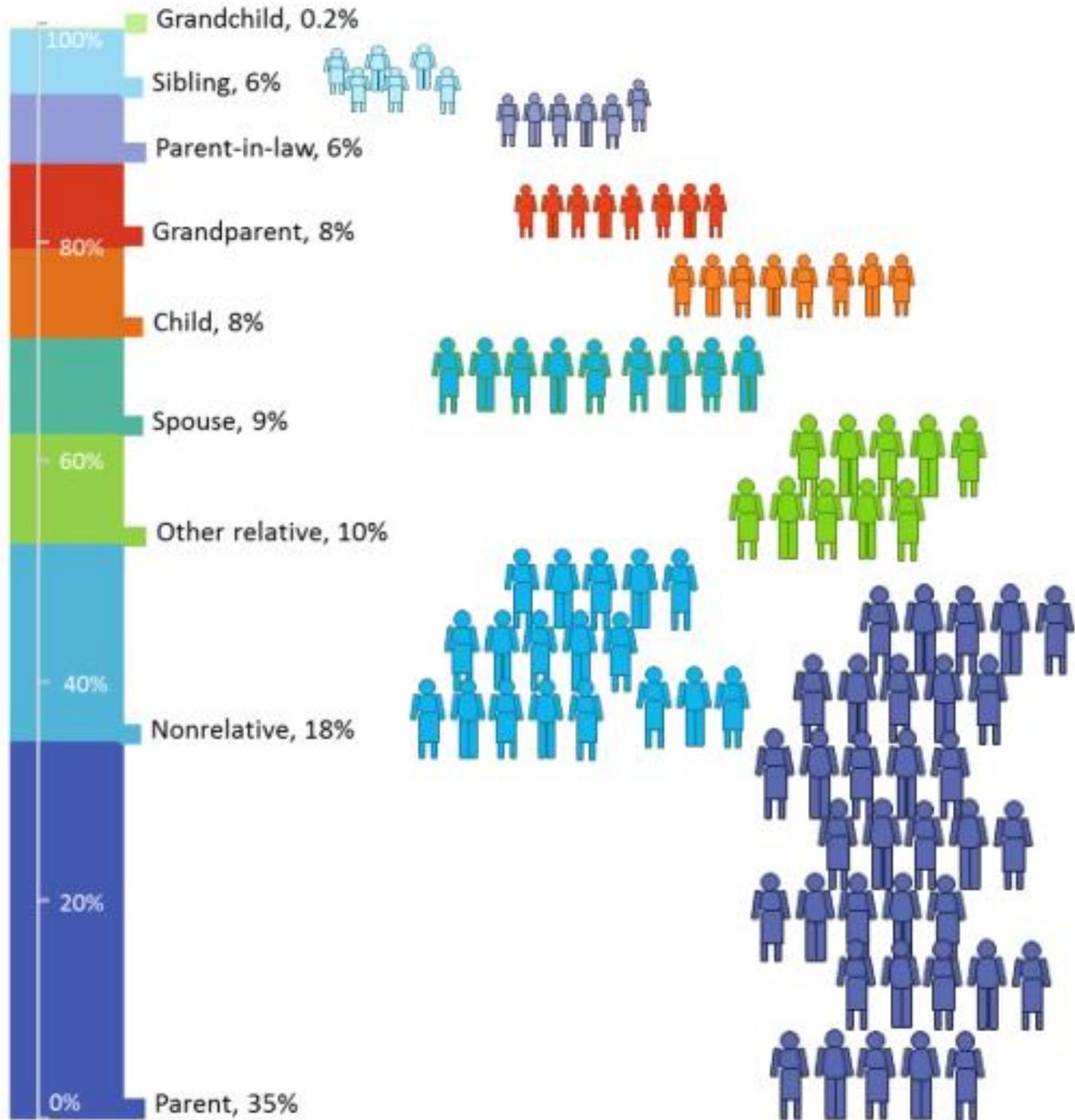
The North Carolina Lifespan Respite State Advisory Team recently endorsed the following definition:

Respite is a break for unpaid caregivers who provide ongoing care for an individual of any age who needs help, care or supervision due to disability, chronic condition or other special needs. Respite is intended to provide relief to the caregiver.

Is Caregiving Prevalent?

- 1 in 5 NC adults reported in a recent Behavioral Risk Factor Surveillance Survey that they had been a caregiver to someone with special needs within the previous 12 months
- About 471,000 NC grandparents age 65+ have primary responsibility for their grandchildren
- 66% of older persons with chronic diseases are cared for by a family member
- 71% of adults with intellectual/developmental disabilities in NC live at home (First in Families of NC, 2014)
 - 25% of their caregivers are age 60+

Who receives the care?



Where is Respite, and Who Provides it?

- Respite care can be provided at home by:
 - a friend, neighbor, or another family member
 - a volunteer from a faith-based community or other community organization; or
 - a paid worker from an agency
- Respite may also be provided in a group care setting, such as a respite center, an adult day care/day health center or in a residential facility. Day or overnight camps and community caregivers' day out programs also provide group respite options.

How do you pay for respite services?



- Private pay
- Hospice
- Medicaid Waiver programs
- State adult day care fund
- Family Caregiver Support Program
- Project C.A.R.E.
- Donations/Awards from non-profit organizations

The Why of Respite: Caregivers are at Greater Risk

- Depression
- Guilt, anger, denial
- Declines in physical health
- Strained social & family relations
- Sleep disorders
- Anxiety about aging
- Neglect of self and others
- Less marital closeness
- Work absenteeism and job loss
- Exhaustion
- Loss of friendships

Caregivers,...

- Can experience profound grief, feelings of anger, guilt, fear and isolation
- Nearly half are clinically depressed at some point
- 53% of caregivers who said their health had gotten worse due to caregiving also said the decline has affected their ability to provide care

Caregivers, ...

- Almost half of family caregivers performed medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions*
- 3 out of 4 who provided this assistance were managing medications, including administering intravenous fluids and injections*

*Results from an online survey from the AARP Public Policy Institute and the United Hospital Fund

It's not all Bad, but its Sometimes the Only Choice

- Not many studies being done about positive impacts of caregiving
- Most family members are doing it out of love and report some sense of satisfaction and/or privilege
- They maybe made a promise to a loved one, saw a bad experience of someone in a facility, or have no other options
- Many people who need or would benefit from long-term care supports in and out of a facility cannot access it

What if you are the Caregiver and need help for You?



Types of Services for the Caregiver

- Home Care, Hospice (private pay & insurance)
- Veteran's Benefits
- Support Groups, Caregiver Training, Workshops
- Online support groups and caregiver training
- Financial Counseling, Legal Assistance, Mediation
- Friends & Family Supported "Caregiver Teams"
- Volunteer, Private Pay, or Covered Respite – things like "Caregiver day out," group respite, adult day programs

Services, continued

- SHIP counselors, ombudsman, certified options counselors
- *Powerful Tools for Caregivers* (6 week class)
- *Chronic Disease Self Management, Matter of Balance*, other Evidence-based programming
- Education and Trainings available through Area Agencies on Aging (AAA) and their network of providers with The Family Caregiver Support Program

Respite is
Most
Requested
Service on
Caregiver
Menu, Yet a
Very Small
Number of
People Use it

AARP surveys show approximately 85% of family caregivers have never used respite... Why?

- See caregiving as a family duty, not a role we share with others
- Hear about “caregiver services” or “respite” and don’t think they need it
- Report that my “fill in the blank” won’t let anyone else in the house to help
- Feel that no one else can do it right
- Can’t afford to pay for it and can’t find it at low or no cost
- Have tried it and it was still stressful to them
- Are saving it for an emergency
- Have been awarded it through a voucher or waiver program or can pay privately, but can’t find a worker that is adequately trained or available when they want them

The How of Respite

In the absence of increased funding, how can we raise the value of the respite that is provided?

How do we address the barriers to using respite?



Strategies to Help Caregivers Use Respite

- Talk about caregiving early. Generally, families are not prepared mentally and financially
- Don't wait for caregivers to self-identify. Reach out and tell them about the benefits of respite
- Suggest a trial plan to have other help in case something happened to the caregiver temporarily. Lack of crisis planning can lead to anxiety
- If awarded respite, many caregivers need frequent reminders and support

Possible Options

- Time Banks (give an hour, get an hour)
- Rearranging in-home aide/PCS hours to create a longer block of time
- Tandem respite – Are there appointments like hair care, grocery shopping, etc. where another person could take on the task, giving the caregiver those hours back?

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History and Timeline of Effort to Make Respite Use More Rewarding



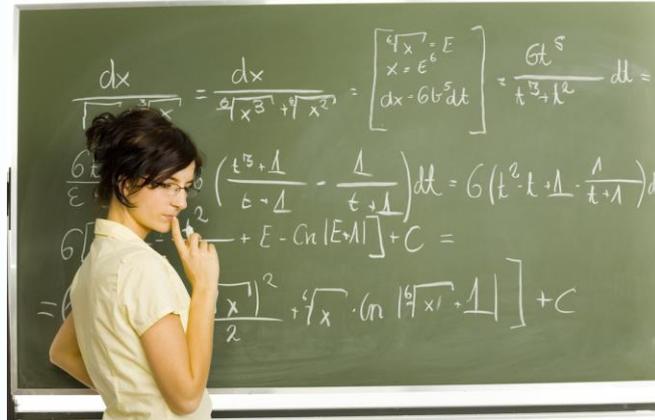
- NC one of eight states awarded Lifespan Respite Care Program Expansion Supplement grant in 2012
- 1 year effort focused on direct respite services for previously identified gap populations
- Request for Application process netted awards to nine local respite/caregiver service providers totaling \$135,657

Mini-Grant Recipients



- Alamance ElderCare
- Adult Center for Enrichment
- CarePartners Adult Day Services
- Community Adult Respite Experience, Inc.
- Montgomery County Council on Aging
- The Arc of Davidson County, Inc.
- First in Families of North Carolina
- Early Memory Loss Collaborative, Park Ridge Health
- Land of Sky AAA Senior Companion Program

Translating the Research



In addition to increasing respite service to underserved populations and challenging them to be sustainable, NC also wanted to add a respite planning exercise to the requirements for respite mini-grant recipients, and to measure its impact on caregiver burden.

Maximizing Respite Planning Tool

Basis of project stemmed from earlier research done by Dale A. Lund and colleagues at California State University at San Bernardino and the University of Utah. Findings supported that:

- Respite use does not automatically translate to lower burden/less stress for caregivers
- One study showed 46% of caregivers reported being only somewhat or not satisfied with how they spent their respite time
- Studies showed when a caregiver uses their respite time to do what they intended to do, he/she may feel less burden and more satisfaction with their caregiving role

Why Try to Impact What Caregivers do with their Respite Time?

- Next to payment for family caregiver duties (which is not provided), respite is most requested service in NC for caregivers of older adults and persons with dementia
- Average respite voucher/service awarded from OAA funds ranges from \$500 to \$2000 per year, per family
- Mini-Grant recipients would also have limited respite funding per caregiver (averaged \$577 per family)
- With flat funding, we looked at how to enhance the value of what we could provide family caregivers

Intervention

- Mini-grant recipients tested a respite planning tool we adapted from Lund and colleagues' published works, "Getting the Most Out of Respite" and "Time for Living and Caring"
- Mini-grant recipients were instructed to present the "Setting Goals to Maximize Your Respite Time" to caregivers at the intake or registration process. If not able to present in person, they were to telephone caregiver, instruct them about the possible benefits of planning their time, and mail caregiver the tool.

Setting Goals to Maximize Your Respite Time

“On this sheet of paper, please write down one to three specific goals of what you would like to accomplish during your respite time this week/month. Your goals can be anything (e.g., sleeping, cleaning, going to lunch with a friend), but they must be attainable during the respite time that is available to you. We recommend that you choose activities that:

you have always enjoyed doing;

you did before you became a caregiver but may not have been doing lately;

have religious or spiritual meaning to you;

may improve satisfaction with caregiving;

may reduce the stress you might feel from caregiving;

may increase your respite time;

encourage you to use your respite more regularly.”

Goals:

Data Collection Method

- Caregivers who received a respite voucher were given a Pre-Respite Form which included a demographic questionnaire and a 16-item Caregiver Burden Assessment
- Post survey completed after respite was used and contained the Caregiver Burden Assessment and a 4-item satisfaction questionnaire regarding their use of the tool
- Pre and Post surveys were coded in pairs and submitted to NC DAAS once both pieces were complete
- 79 of 235 caregivers completed both pre and post questionnaires

Average Changes in Caregiver Burden by Caregiver-Care Recipient Relationship

Caregiver (CG) – Care Recipient (CR)	N	Pre-Respite Mean	Post-Respite Mean
Child (CG) – Parent (CR)	39	7.64	4.76
Parent (CG) – Child (CR)	19	4.47	2.77
Spouse (CG) – Spouse (CR)	15	8.67	5.20
Grandchild (CG) – Grandparent (CR)	5	9.00	7.00
Niece/Nephew (CG) – Aunt/Uncle (CR)	4	8.00	5.50
Sibling (CG) – Sibling (CR)	3	4.67	2.33
Friend (CG) – Friend (CR)	2	7.00	1.00*
Grandparent (CG) – Grandchild (CR)	1	0.00	-

Note: Scores on the 16-item form can range from 0 (no burden) – 16 (high burden), where a decrease in score equates to a decrease in caregiver burden

*Only one caregiver in this dyad completed the post-respite form therefore it could not be included in the Repeated Measures ANOVA analysis

Changes in Caregiver Burden as a Function of Respite Consultation

	Pre-Respite	Post-Respite
Consultation with Provider	7.61	4.54
No Consultation with Provider	5.10	4.50

Note: Scores on the 16-item form can range from 0 (no burden) – 16 (high burden), where a decrease in score equates to a decrease in caregiver burden

Effect of respite planning on caregiver burden scores

A Repeated Measures ANOVA was conducted to examine whether or not the provider discussing respite planning with the caregiver had an effect on the caregiver burden scores. An effect was found such that average caregiver burden scores significantly declined from pre- to post-respite only for those caregivers that talked to their provider about respite planning.

Burden scores did decline for those caregivers that did not receive consultation from their provider on respite planning, but the decline was not significant.

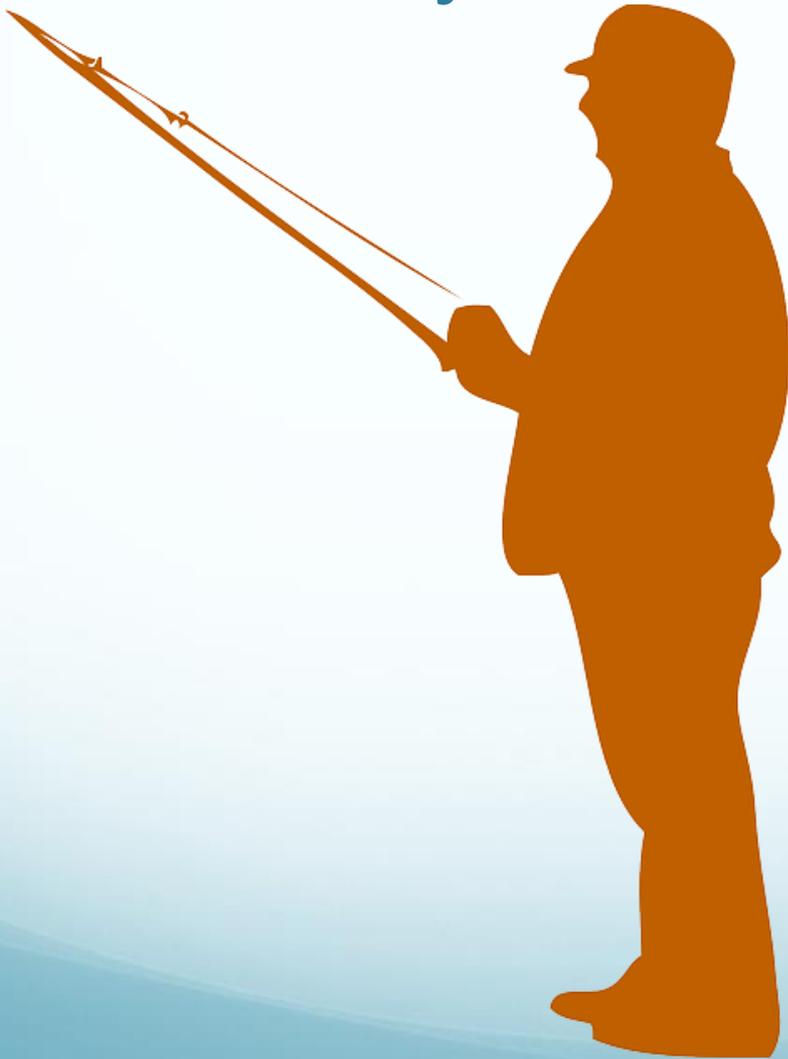
What we learned...

- Timing and approach seem to be key elements in introducing and using the “Setting goals to Maximize Respite Time” planning tool. Not everyone responds to writing down goals, but for some the process was “life-changing”
- Given that there was not a comparison group in the study, we cannot say that the significant decrease in caregiver burden was a direct result of the intervention, but we can hypothesize that the respite service along with the “Consultation” has a positive effect on the caregiver.

How NC Using the Tool Today

- Planning Tool is part of respite voucher application packet whenever anyone applies for a \$500 Lifespan Respite Care Program voucher
- Original nine grantee providers and multiple other providers now using tool exactly as developed or as basis for caregiver consultation discussion during care planning
- Distribution through state's Family Caregiver Support Program, 16 Area Agencies on Aging, and within care planning tools used by Project C.A.R.E.
- Multiple presentations on Planning and Using Respite Time happening throughout state

One example of many...



A man moved out of the home he shared with his wife to stay at his parents' home to take care of them.

He was awarded a \$500 respite voucher from his local Area Agency on Aging using FCSP funds. He was given the "Setting Goals" planning tool and instructed to consider using it. He did, and planned a weekend fishing trip with his wife.

After the fishing trip he called the AAA and thanked them for the respite and fishing trip that "changed his life" and made him a new man.

He sought respite when needed and was able to continue caring for his parents until their passing. He and his wife are now living together again.

Returning to the Why of Respite

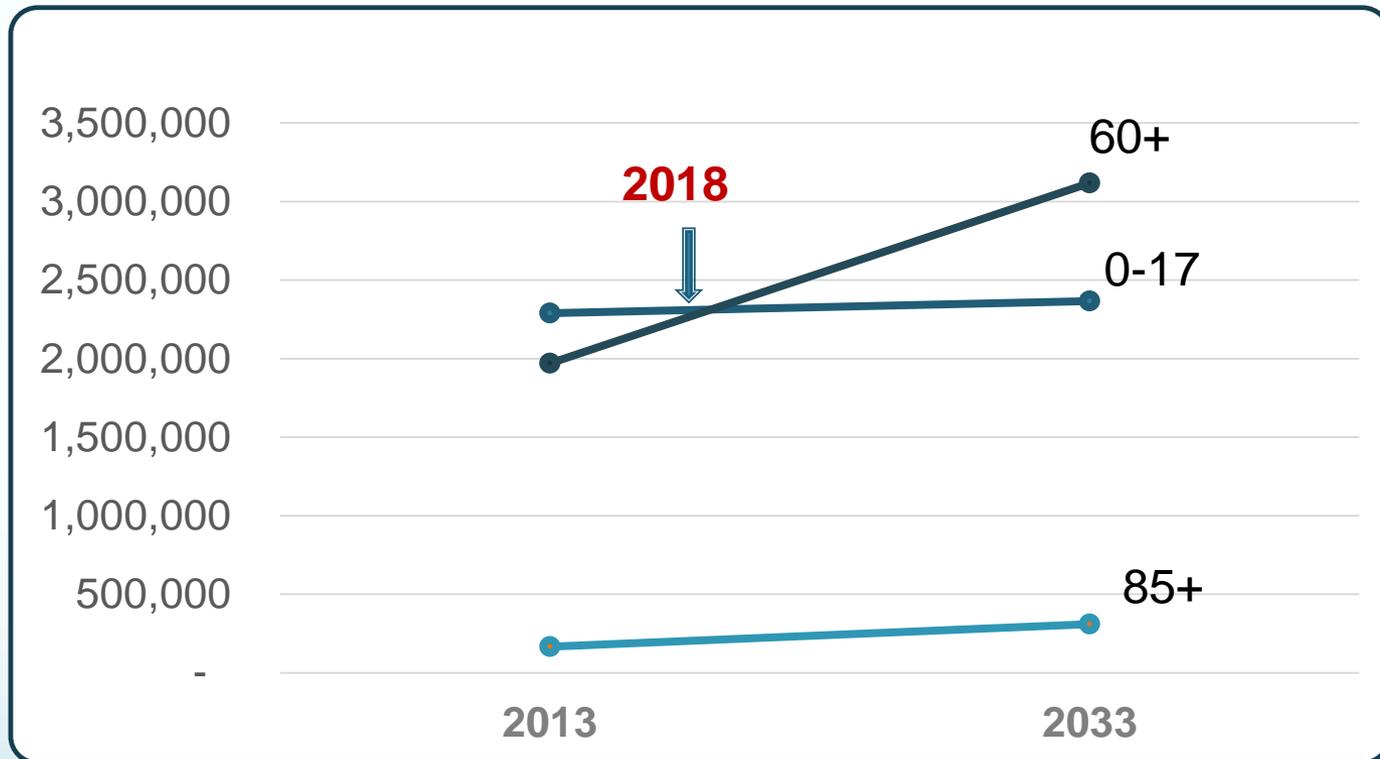


There are only four kinds of people in the world - those who have been caregivers, those who are caregivers, those who will be caregivers and those who will need caregivers.

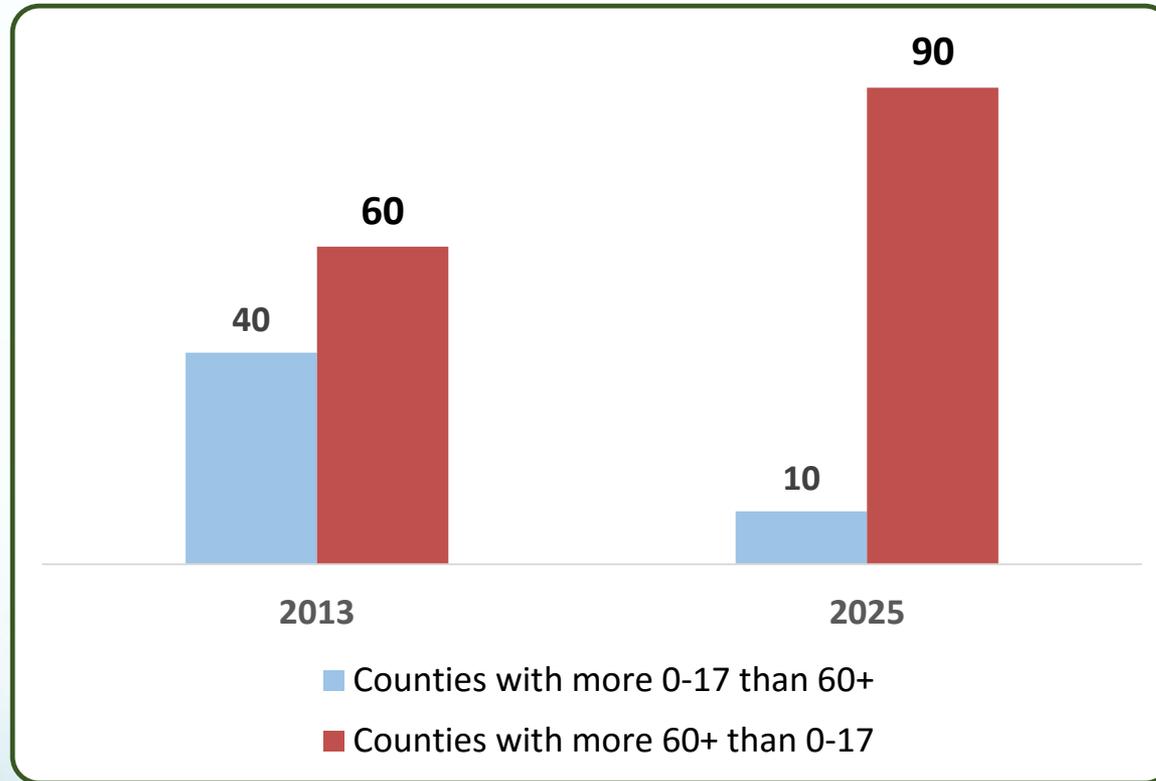
— *Rosalynn Carter* —

AZ QUOTES

By 2018, NC Will Have More People 60+ Than Ages 0-17

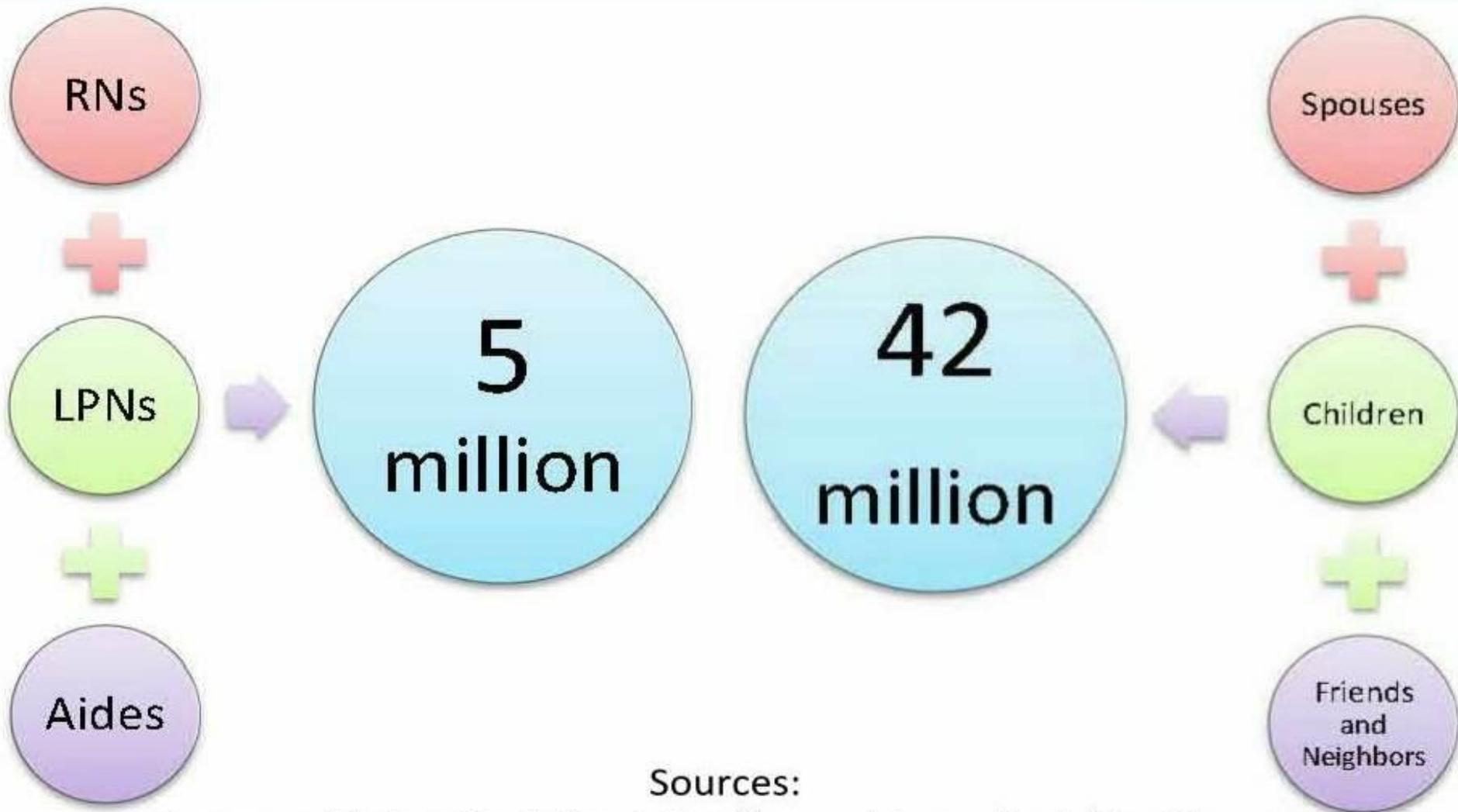


Number of Counties with People 60+ Than Ages 0-17 Will Increase



*By 2033, 96 counties will have more people 60+ than 0-17. The four counties with more people 0-17 are projected to be Cumberland, Harnett, Hoke, Onslow

Impact of Family Caregivers



Sources:

Bureau of Labor Statistics, <http://www.bls.gov/ooh/Healthcare>
AARP Public Policy Institute, Valuing the Invaluable: 2011 Update

“We can’t help everyone, but everyone can help someone.”

– Ronald Reagan

