North Carolina Lifespan Respite Strategic Plan: 2015 - 2020

Family Caregiving in North Carolina

<table>
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<th>20% of all adults are providing care</th>
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<td>80% of those needing long-term services and supports are living at home</td>
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About one-fifth (20%) of the 7.6 million adults over 18 years of age in North Carolina (more than 1.5 million people) reported providing care or assistance in the previous month to a family member or friend with a long-term illness or disability, and 70% of these caregivers were women.

2011 Behavioral Risk Factor Surveillance Survey (BRFSS), U.S. Centers for Disease Control

What is Respite Care?

Respite is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

Lifespan Respite Care Act definition PL 109-442

Research shows that temporary relief (i.e., respite) from the ongoing care of a child or adult with special needs:

1. Improves family caregiver stress levels, which can enhance physical and emotional health;
2. Improves overall family well-being, family relationships and stability; and
3. Reduces hospital costs and helps avoid or delay more costly foster care, nursing home or other out-of-home placements.

Faces of Respite in North Carolina

I have been caring for my 95-year-old mother for six and a half years. Caregiving is very stressful! I am grateful for friends and volunteers who provide me a break from this responsibility. ~ Joanna Stallard, caregiver to an elder parent

From 2009 through 2012, my husband and I adopted three children with complex medical and behavioral needs. We wish we could care for them entirely on our own, but that is simply not possible. I find that I feel less overwhelmed and frustrated when respite care is present in our life. Respite provides the gift of family and home for us. ~ Aimee Henderson, mother of three children with special needs

My 23 year old son was a resident of a skilled nursing facility for 2 years and I just had to bring him back home. I am very grateful and thankful for the wonderful caregivers who allow my husband and me a few hours to ourselves and other family to recharge our batteries.
~ Marianne Collins, mother of an adult with special needs

My wife and I have been married for 54 years and in 2011, she was diagnosed with Alzheimer’s Disease. Respite through a day program allows me to fulfill my commitment to my wife to care for her. With respite, I can do this. Without it, I could not.
~ Al Vissers, husband of a wife with dementia
Aim of the Lifespan Respite Project:

Create a coordinated system of accessible, community-based respite for all family caregivers, regardless of age or special need.

- Expand and enhance respite services
- Improve coordination and dissemination of services
- Streamline access to programs
- Fill gaps in service where necessary
- Improve overall quality of respite services

Top Barriers to Respite in North Carolina

1. Funding Limitations
2. Lack of Awareness
3. Policy and Practice Barriers

These barriers were identified during the 2015 Lifespan Respite Survey and Strategic Planning Summit.

Participants identified a need for a standard respite definition and brainstormed ideas for building awareness of respite with families, funders, legislators and the general public.

Moving Forward Together - 2015 - 2020

Recommendations and Action Steps

1. Create a sustainable, collaborative Lifespan Respite organizational structure.

2. Secure ongoing staffing for the North Carolina Respite Care Coalition.

3. Develop and implement an awareness and advocacy agenda.

4. Diversify funding for the North Carolina Respite Coalition and respite vouchers, using Lifespan Respite Grant funds as a base.

5. Work with key state agencies to systematically analyze and improve respite policies and processes.

For a copy of the full strategic plan and information about respite services in North Carolina, contact:

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NC Respite Care Coalition:
www.northcarolinarespitecarecoalition.org