



# Sustaining Lifespan Respite Programs: Successful Strategies in Economically Challenging Times

15<sup>th</sup> National Respite Conference

October 17, 2013



# Overview

- Program implementation update
- What is sustainability? Why is it necessary?
- North Carolina
- Texas
- Virginia
- Discussion



# Presenters

## **Greg Link, MA**

Administration for Community Living/Administration on Aging

## **Alicia Blater, M.S., APR**

NC Division of Aging and Adult Services

## **Joyce Pohlman**

Texas Department of Aging and Disability Services

## **Ellen Nau**

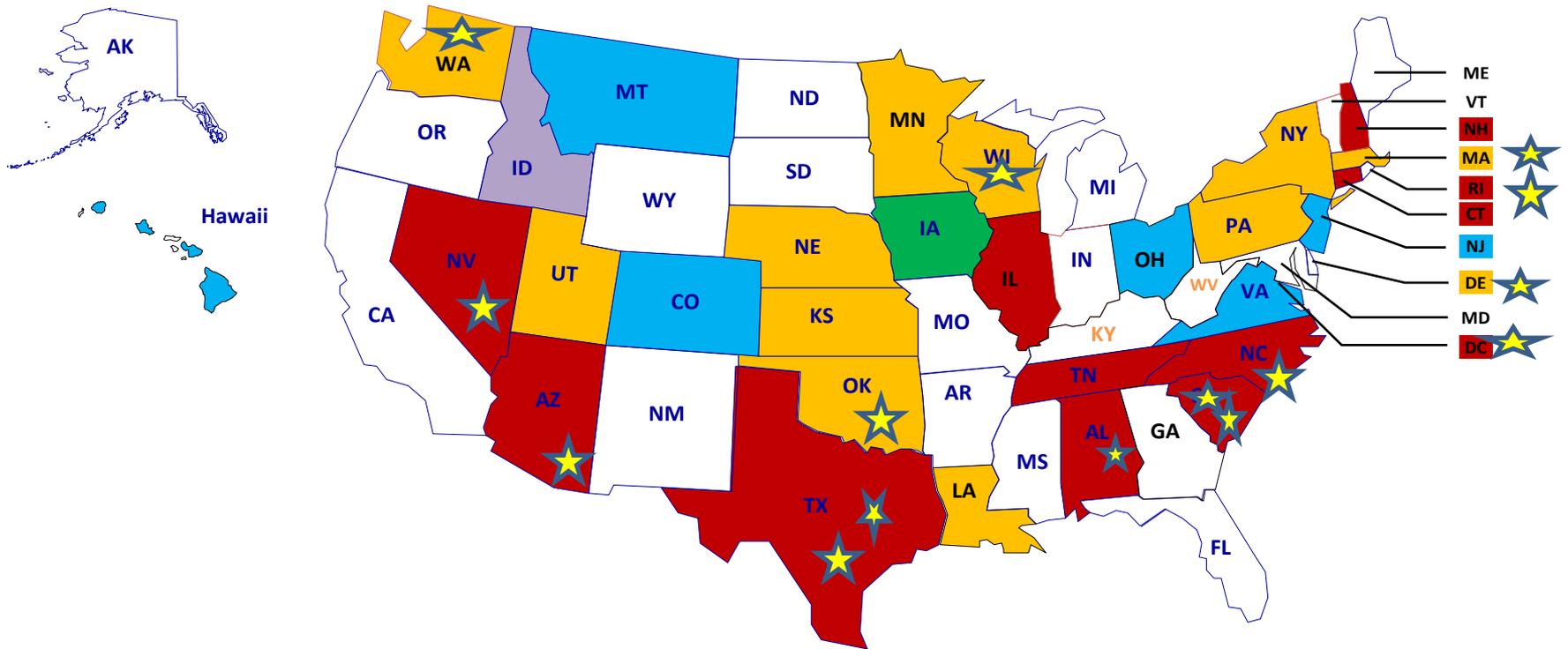
Virginia Department for Aging and Rehabilitative Services



# Lifespan Respite Program Status

- 31 states and DC funded since 2009
  - Up to \$200,000 for initial three year projects
  - Expansion supplements to 10 states
- Technical Assistance Resource Center (FY 09 & 12)
- FY 2012 & 2013– Integration and Sustainability Grants (I&S)
  - 15 states funded to date
  - Up to \$250,000 each
  - Builds on the initial three-year grant
  - Additional requirements for second I&S grants
  - Focus on integrating respite/caregiver supports and sustainable approaches

# Lifespan Respite States (as of 2013)



- 2009 Lifespan Respite States
- 2010 Lifespan Respite States
- 2011 Lifespan Respite States
- 2012 Lifespan Respite States

- 2013 Lifespan Respite States
- ★
 Integration & Sustainability Grants

# Example Grantee Activities

- Environmental scans & needs assessments
- Marketing and outreach campaigns
- Mini-grant programs – local level work
- Voucher respite programs
- Web sites, databases, access points
- Faith-based programs and initiatives
- Volunteer recruitment, training and placement
- Training programs and curricula
- Performance measures
- Service delivery and outcome data

# Lessons Learned

- It takes time....
- Partnership, partnership, partnership
- Look to model approaches
- Stay flexible
- Performance measurement from day one
- Sustainability focus from the beginning

# Emerging Themes in Sustainability

- Engage grassroots/community
- Embed grant activities into ongoing state efforts
- Forge state agency fiscal partnerships
- Grow and support State Respite Coalition to focus on sustainability
- Plan long-term

# Program Sustainability: Why?

- Focus of ACL/AoA discretionary grant activities
- Required in application narratives
- Keeps activities going post-funding
- Greater focus moving forward

# Supporting Grantee Sustainability Activities

- ARCH Technical Assistance and Resource Center for Lifespan Respite Programs & The Finance Project
  - Webinars
  - Sustainability Toolkit
- Work with “Exemplar States”
  - Phone coaching and consultation
  - Interactive webinar
  - Information sharing and lessons learned
  - Conference presentations

# Contact Information

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**For more information about ACL**

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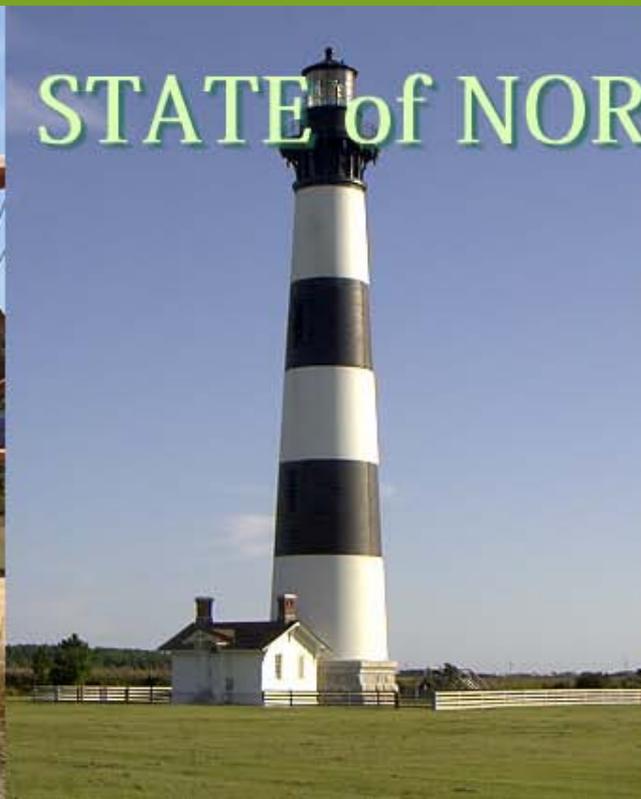
Email: [greg.link@acl.hhs.gov](mailto:greg.link@acl.hhs.gov) Web: [www.acl.gov](http://www.acl.gov)



# Awareness to Action: Strategies for Sustainability in NC



*HCBS Conference, September 12, 2013*



STATE of NORTH CAROLINA

# From the Beginning ...

## Putting the team together

- Volunteer advisory team, less than part-time project specialist, leadership at SUA added to Family Caregiver Support Program role

## Determining the landscape

- GIS mapping of baseline respite resources, surveys, eligibility evaluation to determine funding gaps

## Executing contracts

- North Carolina Respite Care Coalition, respite database builders, direct services, oversight of leveraged funds

# Midway into our Plan ...

## Building awareness and moving to action

- Messages: Action oriented materials (what do you want audience to do?)
- “Just One More”

## Choosing where you can make most impact

- Where are caregivers already intersecting with others?  
People connecting with People
  - Medical offices
  - Health and Human Services workers (viewed very broadly)

# Project Advisory Team

- Chaired by Division of Aging and Adult Services
- Lifespan focus
- Includes 50+ members, average 30 at each meeting
- Team has caregivers, state divisions, associations, universities, faith communities, hospitals, and local government representatives

# Lessons from Advisory Team

- Keep people close, even if they can't attend every time
- Communicate updates and tell how it relates to current events
- Ask, and thank often
- Meetings focus on “good news”
- \* Include caregivers





# Sustainability Theme: Grow and support State Respite Coalition

- North Carolina Respite Care Coalition (NCRCC) long established, but now in transition
- Project staff assisting new volunteer leadership of NCRCC to determine strategies, conduct member survey, and update website
- Partnered with NCRCC to develop a volunteer respite guide; this year they established a respite caregiver directed voucher program. NCRCC used Lifespan funds to provide respite to 75 families with care recipients from age 2 to 110

# Sustainability Theme: Forge State agency fiscal partnerships

- Money Follows the Person (MFP) demonstration project determined two major barriers to people being able to come home from an institution were lack of housing and lack of caregiver supports
- MFP came to Advisory Team and asked for a plan to help in the area of caregiver supports to be paid for by MFP rebalancing dollars
- Result is two family caregiver to caregiver peer mentoring and respite volunteer projects underway, with one more to start later this fall



# Sustainability Themes: Engage grassroots/community

NC awarded 9 mini-grants to providers to reach out to targeted gaps (between \$5k and \$20k each)

- Provided 14,126 hours of respite to 235 new families
- Trained 86 volunteers
- 12 new or enhanced services have been sustained (summer camps, private pay options, volunteer teams)
- Gave providers a tool to help caregivers plan their respite time. Initial research leads us to hypothesize consultation by provider about planning respite time has a positive effect on reducing CG burden



# Sustainability Theme: Embed Lifespan Respite activities into ongoing state efforts

Central theme for NC's plan (look at where interactions are already occurring)

- Worked with Options Counseling certification team to include caregivers as recognized audience, action plan relevance, client registration
- Suggested medical intake forms include primary caregiver information, perform some level of assessment on caregiver & why



# Sustainability Theme: Embed Lifespan Respite activities into ongoing state efforts

## E-Learning Modules

- Target Audience: Professionals who offer Information and Referral, Options Counseling and Case Management to family caregivers who provide care to children and adults with disabilities, and frail older adults.



# Objectives of E-Learning Modules

Upon completion of the four-hour on-line training program, participants will be able to:

- Increase their ability to recognize the needs of family caregivers.
- Help family caregivers assess their abilities and circumstances, using a family-centered and multidimensional approach.
- Encourage family caregivers to seek and accept the help of respite services, as well as other supportive services.
- Provide suggestions to family caregivers to make respite most effective.

# E-Learning Modules (in draft form)



# E-Learning Modules (sample screens)



Personal Care

Work or School

Health

Behavior

While professionals are good at asking about the needs of the care receiver, some studies indicate they don't check to see how the caregiver is doing with managing those needs.



Personal Care

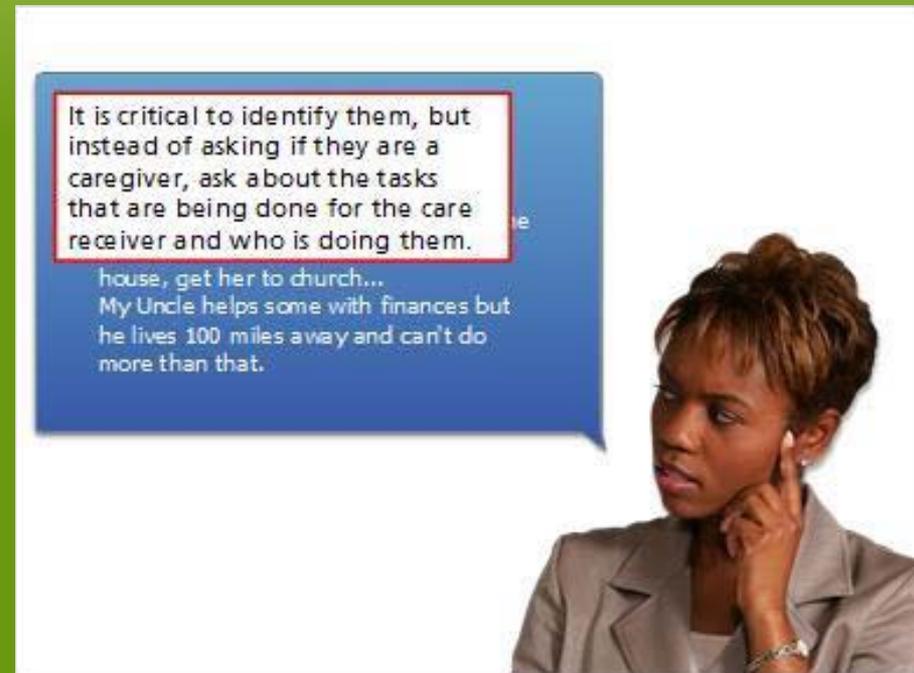
Work or School

Health

Behavior

If the caregiver doesn't identify herself and the professional fails to recognize her, supporting the care receiver can get to be too much and a crisis is more likely.

# E-Learning Modules (sample screens)



# E-Learning Modules (sample screens)

The point of this conversation is not to focus on the tasks themselves, but to understand how the caregiver appraises her ability to manage the multiple demands, her level of confidence with her skills, and the impact the caregiving has on her health. This can be done by asking these three questions as follow up.

- What is the impact of caring for your family member having on you physically and emotionally?
- From 1 to 10, how confident are you that you can provide the care your family needs? 1 is not at all confident and 10 is very confident.



Once you have asked these initial questions and gained some agreement with the caregiver that she is doing a lot, see if she is open to considering some supports and services to help her meet the increased demands. If she agrees, you can move on to assessing her situation in more detail.

But what if the initial questions hadn't indicated much stress in the caregiving role? Click on Angie to see how you might address this.

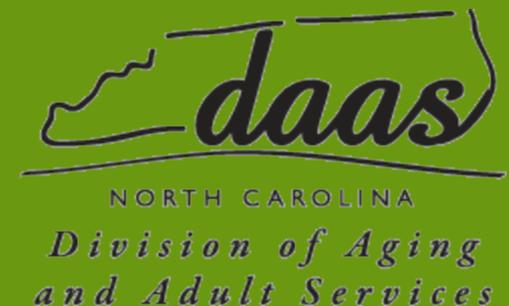


# NC's Next Steps

- Complete the e-learning modules, market these to Departments of Social Services, call center workers, medical practice workers, certified options counselors (counts as qualified training hours), aging and disability provider staffs, etc.
- Continue to share what we've learned about effective respite use planning
- Maintain the Advisory Team
- Continue efforts to strengthen NCRCC



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STATE of NORTH CAROLINA



# TEXAS

Department of Aging  
and Disability Services

# Texas Lifespan Respite Care Program

- Established by Texas Legislature in 2009
- Initial AoA grant awarded 2009
- AoA Continuation Grant 2011
- ACL Integration & Sustainability Grant 2012



# Major Accomplishments: State Funds



- Provided respite to nearly 1,400 caregivers
- Expanded partnerships with providers serving children and persons with disabilities
- Established system to regularly collect information on caregivers, and provide those caregivers with information on respite



# Major Accomplishments: Federal Funds

- Texas Respite Coalition
- Texas Respite Coordination Center
- Take Time Texas website
- Inventory of Respite Services



# Major Accomplishments: Federal Funds

- Extensive marketing campaign
- Marketing materials easily accessible and customizable
- Caregiver training
- Caregiver Teleconnection
- Best practice models & tools





**A Tool to Help Caregivers  
Refresh, Recharge and Return**

# Sustainability Strategies

- Integrate caregiver outreach into existing programs:
  - Caregiver Status Questionnaire
  - Options Counseling
  - LTSS Screen





# Sustainability Strategies

- Establish programs and procedures that continue beyond the grant period:
  - Caregiver Status Questionnaire
  - Take Time Texas Website
  - Texas Respite Coalition
  - Caregiver training using “Train the Trainer” model
  - Marketing materials



# Sustainability Strategies

- Advocacy to build state support:
  - Advocacy groups promoted state legislation to support caregivers:
    - Line item budget for lifespan respite
    - System for collecting information on caregivers
  - Integrate information on respite into other reports/ efforts of other Commissions
  - Respite summit will be used to build wider network of supporters



# Sustainability Strategies

- Establish partnerships that extend the reach of the grant:
  - Faith based organizations
  - Enhanced relationships with ADRCs
  - 2-1-1 Texas
  - Academic institutions



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# Lifespan Respite Care

## In the Commonwealth of Virginia

Ellen Nau, Program Coordinator

Virginia Department for Aging and Rehabilitative Services

Lifespan Respite Care Conference 2013

Boston, Massachusetts



# The Partners

## Virginia Department for Aging and Rehabilitative Services

2012



DARS, in collaboration with many community partners, provides and advocates for resources and services to improve employment, quality of life, security, and independence of older Virginians, Virginians with disabilities, and their families.

[www.dars.virginia.gov](http://www.dars.virginia.gov)

# The Virginia Caregiver Coalition

2004



The Virginia Caregiver Coalition (VCC) is a volunteer group composed of over 120 active and consulting members from public, private and non-profit organizations, as well as individual caregivers.



Commissioner Rothrock at the Launch of the Virginia Caregiver Lifespan Respite Voucher Program

DARS-VDA Conference Room - Launch of Virginia Family Caregiver Solution Center



Virtual Ribbon Cutting Ceremony for the Virginia Family Caregiver Solution Center



# VirginiaNavigator

2004



A 501(3C) non-profit that provides free health and community support information and guidance to seniors, people with disabilities, family caregivers, and health care professionals.

[www.virginianavigator.org](http://www.virginianavigator.org)

# Technical Assistance

Partnership for People with Disabilities, Virginia Commonwealth University  
Virginia Department of Health Video Conferencing Services



Williamsburg Health Department Video Conference Site 7/18/13

National Technical Assistance Center for Lifespan Respite





Jill Kagan from ARCH and Katie Benghauser from VirginiaNavigator (VN)

A typical meeting “beamed” to video conference sites throughout the Commonwealth!

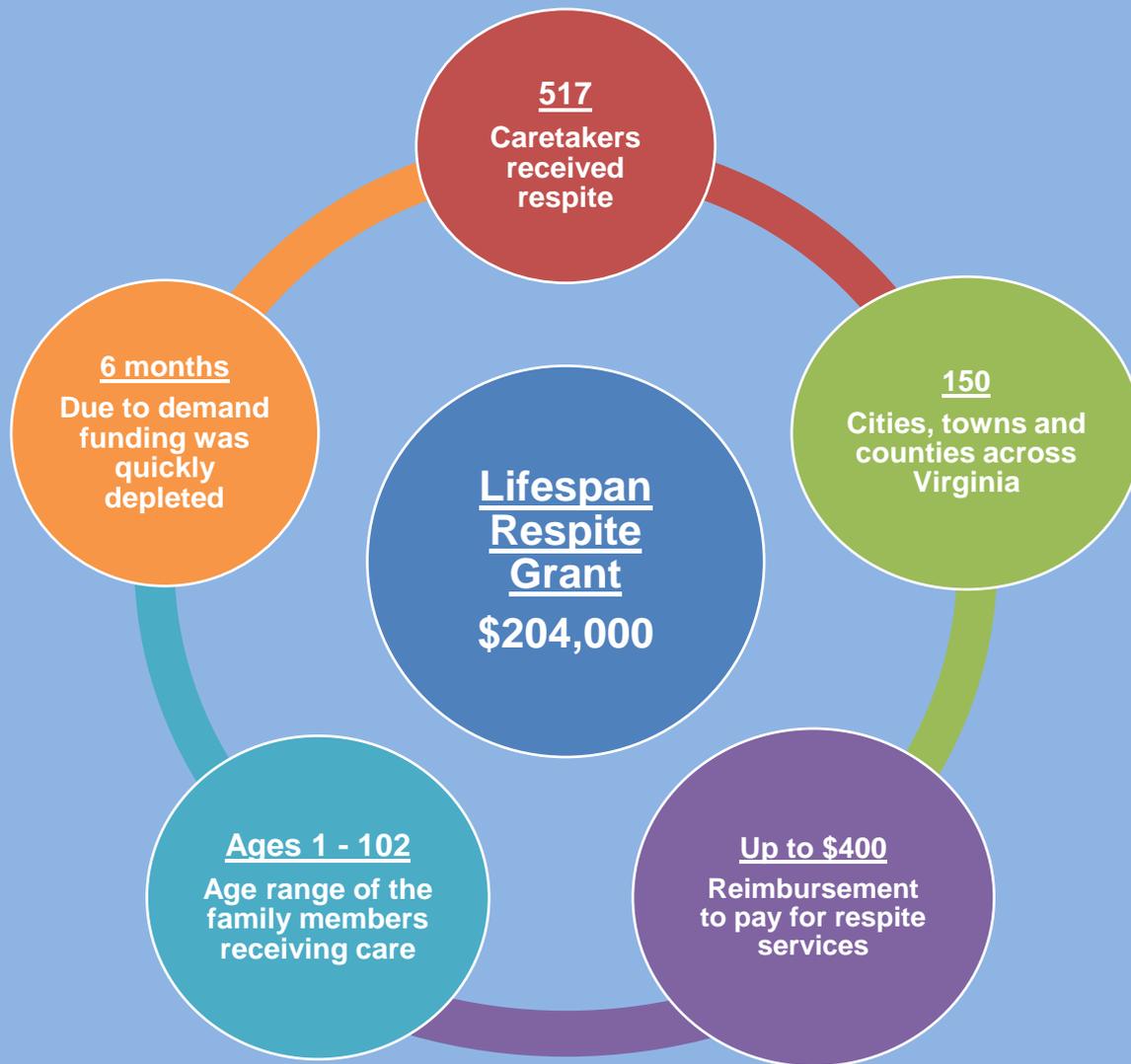


# Virginia's Lifespan Respite Care Program (2011-2014)

**Our goal:** Build a statewide coordinated caregiver respite system for families providing support to individuals with special needs of any age and/or any disability or chronic condition

**Major accomplishments completed to meet the goal:**

- Expansion of the Virginia Caregiver Coalition to include professional and family caregivers of individuals with special needs of any age and/or any disability or chronic condition
- Statewide survey of respite resources
- Link the ADRCs in Virginia with the Virginia Caregiver Coalition
- Online Family Caregiver Solution Center  
<http://www.virgininavigator.org/vf>
- One year pilot Virginia Caregiver Respite Voucher Program



517  
Caretakers  
received  
respite

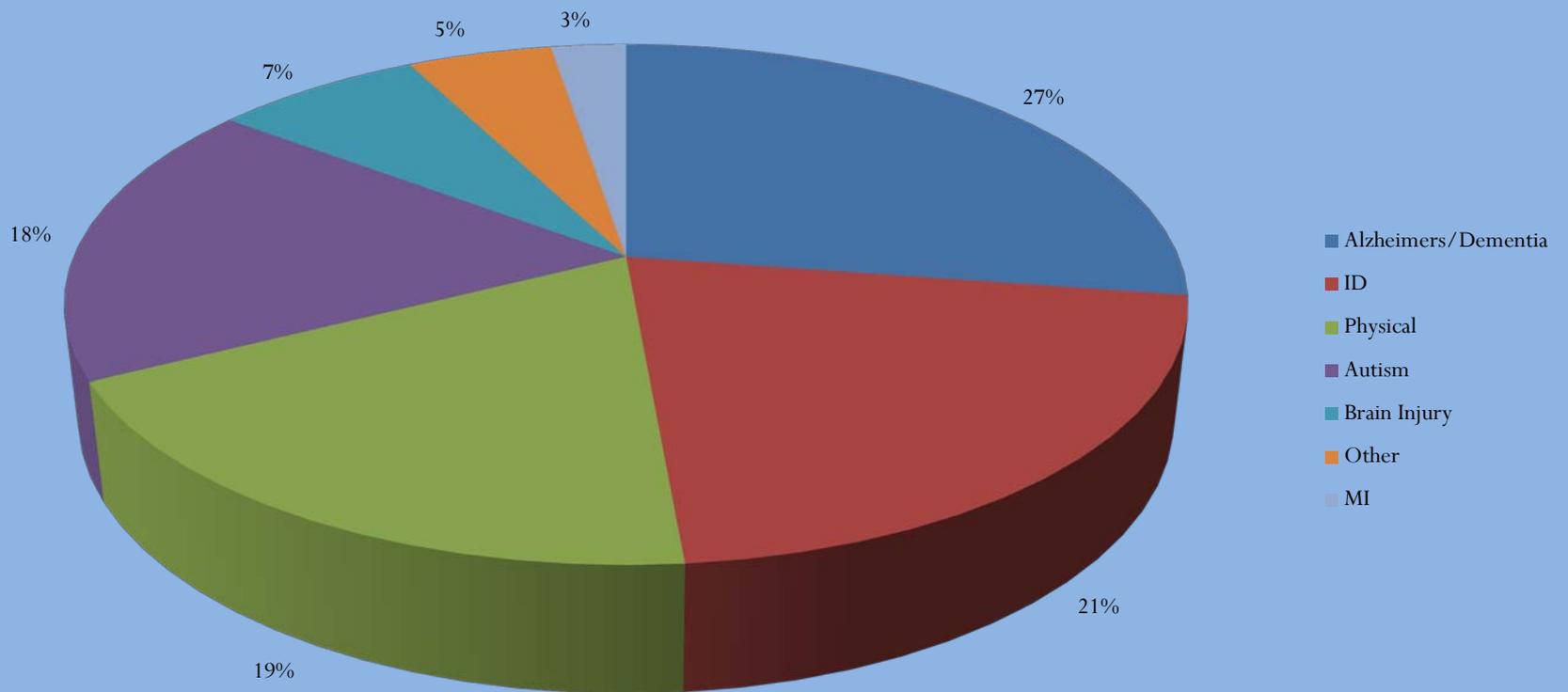
150  
Cities, towns and  
counties across  
Virginia

Up to \$400  
Reimbursement  
to pay for respite  
services

Ages 1 - 102  
Age range of the  
family members  
receiving care

6 months  
Due to demand  
funding was  
quickly  
depleted

Lifespan  
Respite  
Grant  
\$204,000



## Some responses from recipients:

- “It's been over 20 years since I have taken a fun trip on my own. It doesn't seem real...I'm tearing up as I write this. Thank you all very, very much!!”
- “Thank you so much, I so very, very badly need a break; he requires 24-hour care and I can't go shopping, Laundromat, or even take a bath much longer than I care to tell you. This is a Godsend.”
- “Thank you, this is awesome...This is the first vacation I have had in 21 years!”

## Some responses from recipients:

- “I can't tell you how much good it did for me to just submit the application and document my personal need for respite care. It will be so nice to take a few guilt-free days to spend with my family visiting colleges.”
- “Thank you so much for your consideration for me and my husband. I will cautiously and prayerfully use this opportunity.”

# Sustainability

## **Advocacy: national, state and local:**

- Reauthorization of National Lifespan Respite Care Act
- Virginia General Assembly
- Local partners

## **Formation of a Sustainability Committee**

## **Entities contributing to sustainability:**

- ADRCs
- Family Caregiver Solution Center
- Virginia Caregiver Respite Voucher Program
- Virginia Caregiver Coalition Programs
- Respite Volunteers

For further information on Virginia's Lifespan Respite Care Program, contact:

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