

Lifespan Respite Report

“My personal oxygen. Without respite, I feel like I can’t breathe and right now I don’t have it and I am gasping.”

“A light at the end of the tunnel. And right now, I am in a very dark tunnel with NO other lighting.”

-Definitions of Respite by Commonwealth Roundtable Participants

Introduction

This report provides summary, analysis, and evaluation on the Lifespan Respite Care program implemented by the PA Department on Aging (PDA). Included are a succinct examination of data gained from the two roundtables facilitated by PDA and the results from the three rounds of community surveys administered by The Institute on Disabilities at Temple University. The report also includes a secondary data analysis of the “State of respite in Pennsylvania” and an evaluation of the lifespan respite programs in nine other federal lifespan grantee states. The report concludes with recommendations for sustainable respite services in Pennsylvania as well as recommendations for the method and development of lifespan respite policy.

Background

Respite care, defined as planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to a family caregiver, was expanded with the passage of the Lifespan Respite Care Act of 2006 (govtrack.us, 2006). The Lifespan Respite Care Act amends the Public Health Service Act to authorize the Secretary of Health and Human Services (HHS) to award matching grants or cooperative agreements to eligible state agencies in order to enhance and expand respite care services to family caregivers, improve statewide dissemination and coordination of respite care, and provide, supplement, or improve access and quality of respite care services to family caregivers in order to reduce caregiver strain. Funds provided by this act must be used at the state and local level to develop or enhance lifespan respite care services, provide respite care services for family caregivers caring for children or adults, train and recruit respite care workers, provide information about available respite and support services, and assist caregivers in getting access to services. Funds are provided to eligible state agencies that demonstrate the ability to implement and enhance lifespan respite statewide, and give preference to agencies that build or enhance the capacity of their care systems to respond to the needs of their residents. The Lifespan Respite Care Act also created a grant to maintain a national database on respite care, provided training and assistance, provide information, referral, and educational programs to the public on lifespan respite care. The Administration on Aging (AoA) has been implementing aspects of the Lifespan Respite Care Act since 2009.

The AoA is responsible for ensuring that Lifespan Respite Care Programs (LRCP) meet the respite needs of children and adults with special needs and their caregivers. LRCP are designed to advance the following objectives: expand and enhance respite services in the states, improve coordination of dissemination of respite services, streamline access to programs, fill gaps in service where required, and improve the quality of respite care services.

The Commonwealth of Pennsylvania has respite programs that serve a variety of populations. The Pennsylvania Caregiver Support Program is the main respite providing governmental entity for the PDA (Pennsylvania Caregiver Support Program, 2014). Consumers who wish to receive respite services from this program must be the primary caregiver for an adult age 60 or older with chronic dementia, or the primary caregiver for an individual aged 19-59 with a disability. Eligibility for this respite program is income based and is determined based on a sliding scale. Other state offices that offer respite include:

- Office of Developmental Programs – for individuals with intellectual disability who have respite included in their care plan.
- Bureau of Autism Services – for individuals who care for an individual with autism.
- Office of Mental Health and Substance Abuse Services – for a limited number of families with children through the Bureau of Children’s Behavioral Health Services.
- The Office of Child Development and Early Learning – depending on individual need.

Private respite programs are available for a wide variety of individuals, and have a wide variety of eligibility requirements.

Analysis of PA Community Surveys

Two community roundtables were conducted in September 2013 and April 2014 in the Southwest and Northwest region of the Commonwealth. The result of the two community roundtables provide a glimpse into persons’ understanding of the concept of respite as well as their attitudes towards their respite knowledge and experiences. Participants were asked to define respite in their own terms and explain any barriers that they have experienced in finding or using respite. Participants were also asked to provide recommendations for short term and long term changes and/or improvements to the PA lifespan respite system. Summarized data from the two roundtables is attached in Appendix A. Unfortunately, roundtables were only held in the western part of the state; therefore these results may not be generalizable to the entire state.

Pre and post community surveys were conducted over three years by the Institute. Pre-and-post surveys asking individuals who were interested in respite services about their experience with respite were given to individuals in 2014. Nearly two-thirds of individuals who received respite services were male; the median age of the caregivers was 53. The pre-survey indicated that less than one-fifth of individuals had received respite services in the past two years. Three-quarters of individuals indicated that they were quite a bit or extremely stressed as a result of caring for their family member with special needs.

Results in the post-survey indicated that slightly more than three-fifths of individuals received respite services from an individual; the remainder received services from a respite agency. 93% of individuals who received respite responded that they were quite a bit (13%) or extremely (80%) satisfied with the care they received. 94% of individuals indicated that the services provided by the respite caregiver met their needs quite a bit (17%) or extremely (77%). 90% of individuals responded that they were somewhat likely (3%) or highly likely (87%) to use that respite caregiver again; however, 10% indicated that they were highly unlikely to use the respite caregiver again. 93% of individuals felt that the respite was provided in a way that kept their individual or family member healthy and safe. All individuals who responded to the post-survey responded that they were able to use the time offered in the way they intended. The mean amount of hours received for respite care was 32.5. Nearly two-fifths of individuals responded that they were still quite a bit or extremely stressed after receiving respite, down from three-quarters in the pre-survey. 90% of respondents said that receiving respite made a difference in their physical or emotional health. Nearly three-fifths of individuals reported that respite improved their relationship with their family member with special needs quite a bit (27%) or extremely (30%); relationships with other family members also improved quite a bit (31%) or extremely (35%). Individuals overwhelmingly responded that they would continue to need respite care monthly (97%), over the next three months (90%), over the next six months (90%), and over the next year (93%). All individuals responded that they were either somewhat likely (7%) or highly likely (93%) to use respite care in the future. The data and multi-year summary of these surveys are highlighted more specifically in an additional report from the Institute.

State Reports

Many Lifespan Respite federal grantee states operate various types of program while utilizing different respite tools. Below are examples of the most popular and evidence based types of program with examples of how they work in different states (Arch, 2012).

Child Health Insurance Program

The Child Health Insurance Program (CHIP) was enacted into law in 1996, reauthorized by Congress in 2009 and strengthened in the Affordable Care Act in 2010. The purpose of the program is to provide health care coverage for low-income children who do not qualify for Medicaid and would otherwise be uninsured. States may elect to provide coverage to qualifying children by expanding their Medicaid programs or through a state-designed program separate from Medicaid.

Example: North Carolina CHIP, known as Health Choice, has a separate component for children with special health care needs. Services under this additional coverage include emergency respite for “unplanned situations in which family members temporarily do not have the capacity to safely care for their child or when changes in their child’s health, behavior, or development require in-home or out-of-home temporary support.”

Community Development Block Grant

The purpose of the Community Development Block Grant (CDBG) administered by the Department of Housing and Urban Development (HUD) is to enable local governments to undertake a range of activities intended to create suitable living environments, provide affordable housing, and create economic opportunities, primarily for persons with low and moderate income.

Example: Give Me a Break (GAB) Community Respite, Inc., GAB provides respite care provider training, a 24-hour statewide respite information toll-free line, community respite program days, community service, and technical assistance and outreach in the State of Nevada. Until recently, GAB received annual funding from the City of Las Vegas CDBG program to support its respite services.

Social Services Block Grant

The purpose of the Title XX Social Services Block Grant (SSBG) is to furnish social services best suited for meeting the needs of the individuals residing within each state. States have wide latitude in how they use the funds. Services provided may include, but are not limited to: daycare for children or adults, protective services for children or adults, special services for persons with disabilities, adoption, case management, health-related services, transportation, foster care for children or adults, or any other social services found necessary by the state for its population.

Example: In Delaware, the Community Companion Respite Program is funded with SSBG funds and provides respite outside the home. The goal is to provide opportunities to adults with physical disabilities for personal, social, and/or educational enrichment through access to community resources while simultaneously reducing stress and exhaustion for caregivers.

Example: The Mississippi Department of Human Services provides SSBG funds to the Division of Aging and Adult Services, which in turn subcontracts with Area Agencies on Aging (AAAs) to provide SSBG supported respite services at the regional level. Most AAAs subcontract with respite vendors to provide the service locally.

Example: Respite services are provided at the Missouri Disability Resource Association (Center for Independent Living) using SSBG funding. Clients must be at least 60 years of age or at least 18 years of age with a disability. The respite is intended to offer caregiver relief for longer episodes than usually available. Those who are eligible have yet to complete the Medicaid eligibility process; have low income but don't qualify for Medicaid; or receive home and community-based services, but have a short-term need because of health complications or caregiver issues.

Senior Companion Program

The purpose of the Senior Companion Program (SCP) is to give older volunteers opportunities to provide critical support services, such as respite and companionship to adults at risk of institutionalization. The program is administered by the Corporation for National and Community Service (CNCS) and eligible entities are State and local government agencies and

nonprofit organizations. Programs use SCP funds to pay volunteer stipends and transportation costs and to oversee the program.

Example: In South Carolina, the Senior Companion Program of the Midlands is sponsored by Senior Resources, Inc., a Senior Corps grantee. The program is funded 90% through CNCS. The remainder of the funding is local. Adults over the age of 21 who have special needs are eligible for respite. Clients are primarily homebound senior citizens who require assistance with activities of daily living. There are no income guidelines for clients, but the majority is low income. Respite volunteers are over the age of 55 and have incomes under 200% of the Federal poverty level.

Example: In North Carolina, a joint effort of the Family Caregiver Support Program and the SCP provides respite in four of five counties served by the program. The care recipient's situation is assessed by the Family Caregiver Resource Specialist and the SCP Director to make sure the SCP is an appropriate service. The client service plan encourages outings not only for the caregiver but also for the care recipient to promote peer socialization and a sense of independence.

Community-based Child Abuse and Neglect Prevention Grants

States receive Community-based Child Abuse and Neglect Prevention Grants (CBCAP) funds via an annual formula grant and in turn fund community-based programs to provide abuse prevention services. Respite is considered a core prevention service that can be funded. States such as Illinois, Iowa, Alabama, Nevada, Wisconsin and others have received funding to support respite for children with disabilities, who are at higher risk of abuse, and for emergency respite for vulnerable families at risk of foster care placement.

The next section on state reports is continued below with a description of each requested state's current respite agenda and programs. As is expected, it was very difficult to ascertain certain information about state programs especially in relation to their programmatic challenges and limitations. Gaining more inclusive and holistic information about the programs of other federal grantees and making a more complete analysis would take a more comprehensive multi-sited program assessment or evaluation. Developing and maintaining the relationships in which participants would feel comfortable to share a greater breadth of information about the inner workings of their programs is indeed doable, but would take more time and relationship building to develop an authentic avenue for dialogue.

Alabama

Alabama was one of the first of 12 states to receive a Federal Lifespan Respite Grant in 2009. The primary goal of this grant is for the Alabama Department of Senior Services (ADSS) to work in partnership with a Coalition to provide a statewide, comprehensive, and coordinated approach to providing lifespan respite care to all Alabama family caregivers regardless of disability, illness, age, income, race, ethnicity, special needs, or situation. Alabama Respite then contracted with ADSS and partnered with the Coalition for a second Lifespan Respite grant that

allowed staff to create and post on their website the STC Toolkit and the Faith-based module training components; map current caregiver training resources in Alabama; certify staff to become volunteer respite provider trainers; build upon the existing STC entities and start up 12 new STCs; and update our website to begin building a strong training and education section. Alabama has three major respite initiatives happening in addition to maintaining their online respite network, offering a variety of respite themed trainings, organizing the Alabama Respite Coalition and participating as a representative to the National Respite Coalition.

In addition to the three major projects listed below, Alabama Respite is currently working on legislative outreach and building community and state-wide partnerships. They have two legislative events scheduled for August. Additionally, they are working on the development of new training protocols for their website and YouTube as well as coordinating presentations and trainings for caregivers and providers statewide. They are also beginning to focus on the development of new respite options in North Alabama using their Alabama Department of Child Abuse and Neglect grant for the Family Connections program. Alabama Respite is undergoing a change in leadership with the impending retirement of their current Director of Respite Services, yet have announced that their “Mission essential activities such as information and referral, maintaining the website’s database, hosting a toll free number, providing public awareness, and training will continue”.

- **HEARTS** Voucher Respite Program, first piloted in North Alabama by UCP in Huntsville in 1994, has successfully been replicated by all 5 UCP affiliates throughout the state. The program serves caregivers of children up to age 19 and is funded by the Department of Child Abuse and Neglect Prevention.

- **Sharing the Care** (STC) is a community-based initiative that creates an opportunity for key stakeholders living in a specific area of the state to collaborate and develop respite resources and address funding needs unique to their community. Piloted in 2005 in Limestone County, the project has been replicated in Madison, Cullman, Blount, Jefferson/Shelby, Tuscaloosa, Walker, Marengo, Dallas, Etowah, Houston, Lee, Montgomery/Elmore/Autauga, Mobile/Baldwin, and Colbert/Lauderdale Counties. Alabama Respite has created training materials to begin STC Projects in different communities. A training module is available on their website.

- **Faith-based Volunteer Respite** is a low-cost method of service delivery and many options for outreach ministries are available from which to choose. Alabama Respite has a special "module" included in the STC Toolkit that includes information and materials available for faith-based community leaders interested in learning more about this outreach ministry. Faith based respite programs are available in 12 counties throughout the state. A training module can be found on the website.

District of Colombia

Arizona was one of the first of 12 states to receive a Federal Lifespan Respite Grant in 2009. The DC Office of Aging operates the lifespan respite program. The program is initiating new programs designed to help connect caregivers with the necessary resources to assist them with regaining perspective and finding comfort in even the most difficult caregiving situations. The DC Lifespan Respite program includes:

- Lifespan Respite volunteer program
- Bi-weekly online chats
- Flex spending
- Referrals for respite care

We were unable to acquire any further information on the DC Flex account system despite many attempts to contact their program staff.

Arizona

Arizona was one of the first of 12 states to receive a Federal Lifespan Respite Grant in 2009. The Arizona Lifespan Respite Program, enacted into law in 2007, was allocated \$500,000 annually for implementation. The Arizona Department of Economic Security is the lead state agency. Each local Area Agency on Aging (8) is functioning as the local Lifespan Respite Program. Primary caregivers of individuals who do not currently qualify for other publicly funded respite services are eligible, including family caregivers of: persons who are seriously or terminally ill, who do not currently qualify for hospice care; persons under 60 who have significant functional impairments, but are not eligible for disability services; persons with early cognitive deficit resulting in functional impairment, who have not yet received a “likely” diagnosis of dementia; Grandparents or relative caregivers less than 55 years of age caring for children 18 and younger; and veterans not qualified for respite services from the Veteran’s Administration. Although income is not a disqualifying factor, services will be targeted to those individuals in greatest economic and social need. Because funding is limited and in order to offer respite to the maximum number of caregivers, cost sharing will be required and is based on the care recipient’s household income, beginning at 250% of the Federal Poverty Guidelines.

Nevada

In 2009, Nevada’s Aging and Disability Services Division was one of the first 12 states in the country to receive a 3 year grant through the Lifespan Respite Act program. The mission of the Nevada Lifespan Respite Program is to expand statewide quality respite services throughout the age spectrum and to promote and assist in the development of respite services so caregivers can continue to provide long-term care for their loved ones. Nevada ADSD maintains a website that acts as a one stop resource for information on aging services, including lifespan respite. The respite component highlights training videos and documents in regard to: referral, caregiver

training and forums, models of respite, and respite tips and handbooks. The website also collects data from respite providers and those utilizing respite services.

North Carolina

North Carolina was one of 12 states to receive initial project funding and collaboration on the respite landscape in 2009. They received a 3 year grant through the Lifespan Respite Act program. North Carolina chose to create a request for applications and announced nine mini-grants to recipients focusing on direct service for their identified gap populations. They initiated contracts with nine community organizations and engaged in substantive development and reporting.

- Finalized materials for effective respite use effort
- Developed quarterly and end-of-grant reporting format
- Held conference call with all mini-grant recipients to train them on reporting and invoicing procedures and contract specifics.
- Created listserv of mini-grant recipients and their key contacts.
- Conducted summary interviews with each grantee at end of project.
- Wrote a comprehensive summary report.

North Carolina provided between \$5,000 and \$20,000 to each mini-grant awardee to reach out to targeting population gaps. The mini-grant outcomes are summarized as between March 2012- May 2013.

- 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.

Representatives from North Carolina presented on what they learned from their mini-grant initiative at the National Respite Conference in 2013.

- It was time consuming to manage nine grantees, but funding catalyzed nine communities across the state to create a lasting effect on peoples' lives.
- Timing and approach seem to be key elements in introducing and using the "Maximizing Respite Time" planning tool.
- In more than one setting, caregivers no longer receiving grant-funded services looked for informal/unpaid respite supports.
- Once experienced, respite was viewed as valuable.

Rhode Island

In 2009, Rhode Island was one of the first 12 states in the country to receive a 3 year grant through the Lifespan Respite Act program. The respite funds in Rhode Island go directly into service through the Diocese of Providence developing a very successful campaign into marketing and engaging caregivers. The Caregiver Alliance of Rhode Island is a state coalition of the National Lifespan Respite Care Coalition focus on the National Lifespan Respite Care Act who operates the New Hope Time Exchange website. The New Hope Time Exchange is a movement of individuals and groups dedicated to exchanging with each other, building community, and creating a healthy and sustainable world for future generations and our environment. The New Hope time exchange utilizes core values of time banking and sustainability to engage in respite exchange.

South Carolina

In 2009, South Carolina was one of the first 12 states in the country to receive a 3 year grant through the Lifespan Respite Act program. Awarded to the SC Lieutenant Governor's Office on Aging, in partnership with the SC Respite Coalition (SCRC) and Family Connection of SC, South Carolina's Lifespan Respite program has worked to increase public awareness and the understanding of what respite is and why it is so vital. The grant has provided outreach to family caregivers by encouraging the use of respite, by connecting those in need with respite options and working to improve information dissemination to caregivers through existing state resources such as SC Access, Aging and Disability Resource Centers and the Family-to-Family Health Care Information and Education Center. Over the past 3 years, partners have coordinated existing respite services, identified gaps in service provision and worked to build capacity at both state and local levels by cross training existing providers for all ages. This program has also worked to mobilize respite volunteers within community and faith based organizations across the state.

Texas

The Texas Lifespan Respite Care Program (LRCP) was created in 2009 by the 81st Texas Legislature. That same year Texas was one of the first 12 states in the country to receive a 3 year grant through the Lifespan Respite Act program. The program established a statewide respite care system to enhance and expand the coordination and availability of respite services for family caregivers caring for individuals of any age and with any chronic health condition or disability. The LRCP seeks to increase Texas caregiver's knowledge of the role of caregiving, and the options, services and resources existing in their communities. The goal of the Lifespan Respite Care Program (LRCP) is to establish a foundation for an effective, community-based system that builds capacity and increases Texas caregivers' knowledge about, and access to, a wider array of respite care options. Key program elements to help and support caregivers include:

- Development of a Statewide Respite Coalition.
- Creation of the Texas Respite Coordination Center.
- Enactment of Senate Bill (SB) 271 to increase public awareness activities and develop a statewide process to identify caregivers and assess their needs.
- Passing of House Bill (HB) 802 to appropriate funding through the Lifespan Respite Care Program to assist family caregivers.

The Texas LRCP has established two major projects in line with the mission of its original goals, the Center for Caregiver Excellence and the DADS services program. Established by the Central Texas Aging and Disability Resource Center in Belton, Texas, the Center for Caregiver Excellence offers education and training for:

- Family caregivers interested in gaining the skills, knowledge and abilities to meet the ongoing, changing roles and responsibilities of being a family caregiver.
- People interested in working in the home caregiver and respite business who desire paraprofessional training and certification.
- People currently employed as paraprofessionals working for nursing facilities, assisted living facilities, homecare agencies and home health care agencies.

DADS offers services designed to provide access, information, referral and assistance, care coordination, caregiver support and coordination, benefits counseling and awareness, and advocacy.

- referrals to respite providers,
- assistance in making long-range caregiving plans,
- information about services and supports to meet caregiving needs, and
- help arranging for services.

Virginia

In 2011, Virginia was in the third round of state grantees to receive a 3 year grant through the Lifespan Respite Act program. The Virginia Division for the Aging working together with the Virginia Caregivers Coalition maintain their original mission to build a statewide infrastructure of coordinated and accessible caregiver respite resources for families providing support to individuals of any age and/or with any disability or chronic condition. Virginia judiciously works to evaluate existing respite entities and develop a regional and local infrastructure for the use and delivery of respite services and a sustainable foundation for lifelong respite services.

Virginia has ran a successful centralized voucher program since they were awarded the grant in 2011. The merged money from their original 2011 grant, their 2012 expansion grant and a small \$25,000 state grant they were awarded to amass \$204,000 for their lifespan respite

voucher program. They created a statewide voucher program task force and after they investigated other state programs decided to run a centralized voucher program administered through the Virginia Department for Aging and Rehabilitative Services (DARS). The taskforce participated in many successful projects:

- Developed new and improved forms associated with: explanation, application, reimbursement requests and caregiver surveys.
- Developed and advertised a voucher launch ceremony and luncheon that included: DADS public relations team, television and radio news, statewide coverage, guest stakeholders, Virginia Care Coalition, and the Virginia Navigator.
- Advertised voucher program through all media sources and public forums
- Formed a review committee that reviewed requests weekly

Virginia's voucher program successfully contributed to respite vouchers for 517 applicants giving care to individuals ranging from 2-102 years old. Each approved applicant received the ability to utilize up to \$400 in a calendar year. The majority of individuals served were diagnosed with Alzheimer's or Autism Spectrum Disorders. Families were given the choice to utilize a family caregiver or a registered respite organization. Ellen Nau reported six lessons learned with their first round of respite vouchers:

- Not all who applied for vouchers and were awarded them actually utilized them.
- Because the program took some time to get up a running, they needed to apply for a no cost extension.
- Need to be more specific is asking for primary illness or disability on application.
- Many families utilized camps for their respite so they added a camp conformation form to help with paperwork.
- Respite provider charges need to be more formalized.
- Plan to add a caregiver burden survey to attempt to more accurately understand how respite effects families and caregivers.

Recommendations for Sustainable Respite Services in PA

Recommendations are still being drafted and should be completed in collaboration with the Pennsylvania Department of Aging. This section will be completed after feedback on the report and survey analysis is received.

- Across all ages
- Across all disabilities

Recommendations for Policy

Recommendations are still being drafted and should be completed in collaboration with the Pennsylvania Department of Aging. This section will be completed after feedback on the report and survey analysis is received.

- Methods to create policy
- Development of statewide respite program
- Other statewide programs that work and why

Works Cited

- Arch National Respite Network and Resource Center. 2012. http://archrespite.org/images/Webinars/Using_Federal_Funds_for_Respite.pdf. Retrieved 10 July 2014.
- United States Government. 2006. <https://www.govtrack.us/congress/bills/109/hr3248#summary> Introduced July 12, 2005, H.R. 3248 (109th): Lifespan Respite Care Act of 2006, Signed on December 21, 2006. Retrieved 24 June 2014.

References by State

Alabama

Hearts (Voucher Respite Program) <http://www.alabamarespite.org/about-us/31.html>

Sharing the Care (STC) info@alabamarespite.org

Faith Based Volunteer Respite

<http://www.alabamarespite.org/images/toolkits/providing%20breaks%20for%20family%20caregivers.pdf>

Respite Trainings <http://www.alabamarespite.org/index.php/training.html>

Alabama Respite Coalition <http://www.alabamarespite.org/index.php/about-us/alabama-respite-coalition.html>

District of Columbia

DC Office on Aging <http://dcoa.dc.gov/service/lifespan-respite-volunteer-program>

Nevada

Nevada ADRC http://www.nevadaadrc.com/images/lr/Respite%20Brochure_02.21.13.pdf

North Carolina

National Respite Conference 2012

http://www.arch.memberlodge.org/Resources/Documents/2013%20National%20Respite%20Conference/PPTs/Blater-Fields_1A.pdf

Rhode Island

New Hope Time Exchange <http://www.newhopetimeexchange.org/about/>

South Carolina

Strategic State Plan

http://www.lifespanrespite.memberlodge.org/Resources/Documents/State%20Tools/South%20Carolina/SC_StateRespitePlan_2013.pdf

Texas

Take Time Texas <http://www.dads.state.tx.us/taketimetexas/about/lrcp.html>

Virginia

Virginia Division for the Aging <http://www.vda.virginia.gov/index.asp>

Appendix A

Results from South West Roundtable

1. Definition of Respite

- Time away from daughter with my husband
- My child being able to continue with her life without relying on family
- Quality of care
- Someone familiar with my family member who is not a member of the family
- Those with increased medical needs need a safe medical environment
- Parents sense of peace and serenity; time for themselves (empowering)
- Self-reflection
- Something to help in time of crisis
- An ability to rejuvenate myself so that I can take care of my mother
- Something that feels more than a service ~ more of a necessity
- For caregiver and individual – not just babysitting, but based on interests the person has
- Individually driven (not just a body coming in)
- A resource that helps me feel better emotionally and physically.
- My personal oxygen. Without respite, I feel like I can't breathe and right now I don't have it and I am gasping.
- Emergency respite
- Time off for yourself
- Rest
- Break – short or long-term
- Relief
- Supportive, professional care
- Relief to families
- Mini vacation
- Quality care from someone you trust
- Ability to go to work
- My sanity insurance. I am embarrassed to say that I worry about what I will do if I can't get a break
- Take a break to do something special
- Survival for self-employed couple
- A "break" is different for everyone
- A light at the end of the tunnel. And right now, I am in a very dark tunnel with NO other lighting

- “Getting away from it all” emotionally and physically
- A regular step back. Even though I don’t feel like I deserve it.
- “A person needs to recharge themselves periodically and continually in order to provide effective and meaningful caregiving to others. In order to serve – you must serve from the saucer. Your cup must overflow. You cannot serve from an empty cup.”

2. Barriers

- Access to information (people don’t know they can get services)
- Thought it was only private pay – being unable to afford
- Legislators would rather put money into brick and mortar rather than services
- Respite is individualized
- Needs/stress
- Costs/funding
- More accessibility to more people rather than specific dollars for specific conditions or diagnoses
- Money
- Changing mindset of caregiver that a break is needed and deserved and loved one will be safe
- Awareness that respite is for caregiver
- Families are desperate to fit child into a category in order to get service
- Can’t find appropriate resources
- Limited resources for children under age 3
- Fear of leaving loved one with someone else
- Fear of trusting others
- Parent/child in same area to see they are safe - technology that allows parent to see child when they are out
- Funding
- Scarcity of facilities?
- Families resistant – no one can care for their special one
- Trust barriers (dependable)
- Caregivers – location and funding
- Sometimes not enough workers and funding
- Money
- Training
- Trust
- Handling behaviors
- Ratio of staff to client

- Bureaucracy (example: hopefully hire lay people, not health aides to care for a client with a feeding tube)
- Educating health care providers
- Sharing with service providers that putting me on a waiting list ISN'T respite
- Understanding that asking for help is hard. When I ask for it, I really need it
- No awareness that respite is a core service, not a privilege
- Availability does not = need and demand

3. Short term recommendations

- State should not take back money
- What is happening in Allegheny County should be replicated at the state level.
- An Alliance for Community respite care should be available to everyone
- It shouldn't matter what your age is ~ as a person needing care or the caregiver
- Disability (a specific one) shouldn't be the ticket to services
- Social media to get the word out
- One place to go ~ I keep checking different places and I am told different things
- Need better access to information
- Help finding appropriate services
- Respite shouldn't be categorized
- Government should have understanding of what respite does – prevent abuse/neglect
- Care should be available in home
- Respite saves money & out of home placements
- Respite is preventative care
- Medicaid providers pay for respite
- All roads leading to a primary respite information source. Who knows what is going on?
- Funding and caregivers
- Funding
- Educating every one of the benefits
- My company offers small periods of respite
- Celebrate caregivers – host TLC events (parties) that are free to caregivers, activities including pampering services, information, and a sense of community
- “As a life coach, formally trained social worker, and music therapist, we offer a “for free” coach on call program. When someone is “stressed,” they can call us and we can calm them down.”
- Inform the general community about Family burnout/effects including friends, co-workers, etc.
- Address loss of identity for caregiver

- Help people understand WHAT respite is. I didn't even know what it was and now I understand, but I have needed it for far longer.
- A language to express it ~ so if you are a new parent, an experienced caregiver or an aging person, you understand what this break is AND how to get it.
- Someone to talk to about my respite needs. Sometimes I just feel better knowing that someone appreciates how hard it is for me to be a caregiver
- A website. I can't be on hold waiting on the phone all day
- Legislators who are informed and on board
- Some respite events (respite day for families, resource fairs, etc.) to get families information AND services

4. Long term recommendations

- Federal level – should receive benefit on tax return if you are a caregiver - Caregivers have to quit work to care for a loved one or they work all day and come home and do the caregiving without any breaks
- Government should recognize family caregiving is a job
- Put caregivers in the budget when grants are awarded
- Parents are often asked to volunteer and should instead be paid and appreciated
- Parents should be part of grants
- There should be paid respite providers
- Something to prevent caregiver burnout
- Reimbursement programs
- Saving money by keeping person at home rather than institutionalizing is really saving money to the government
- Look at providing health benefits to those who have to stay home to care for a loved one
- State wide initiatives including governmental leaders, cross all areas, ages and abilities
- Respite needs to have 'status' in the state
- Legislative caucus to study respite care, looking at dollars and cents
- Work with legislators
- Work with what family caregiver needs
- Networking opportunities for groups (parents, providers, government, employers, etc.)
- Community homes staffed with people to provide educated care
- Funding is not balanced for this type of program
- Raising awareness
- Advocacy initiatives

- Funding
- Funding for organizations to start up a program
- Make it a career path for HCA (Hospital Corporation of America?)
- Education for college students
- Communication/education/direct access to appropriate respite “solution”
- Caregivers need to learn that “team” is necessary for healthy caregiving
- Guilt should be removed and replaced by “accepted practice”
- Funds from judges who can impose fines for certain crimes (like a DUI) with that funding going to respite care
- Toolkits so that we can train volunteers in our community
- College campuses offering respite as a way to get college credit
- Respite for service learning through a global initiative
- A respite bank where someone can give time and then withdraw time for respite
- A prescription for respite care that insurance companies would have to fulfill
- An effort to educate churches
- College or student groups who can do respite as a part of their community service
- Partnerships between child serving and adult agencies. To solve what happens when people age out
- Counseling resources for respite
- Access to comprehensive training
- A tool kit to help organizations get a program in place and run it ~ with training and technical assistance
- Public service / awareness activities

Results from North West Roundtable

1. Definition of Respite

- Time to spend having fun.
- Renewal, relaxation, worry free
- Being able to spend time sewing and working in my yard or home without having to hunt for him. He keeps disappearing and I spend most of my time looking for him.
- Reduces the stress and is such a relief from the daily grind. We look forward to this event every year.
- My wife was diagnosed in January 2009 and her progression has been slow. I am retired and able to be with her daily. I can still get away for a couple of hours occasionally.
- Freedom of constant responsibility. Relax and not worry about my loved one.
- Time off without interruption. The respite caregiver should be trained well enough to take over so time off truly is time off.

- To be able to have some "me time".
- Mental revitalization. We do not get respite
- Giving someone a chance to stop worrying and relax for a little bit.
- Time to regroup and rejuvenate.
- Being able to trust someone else to give care and understanding
- Having a special day to get away and laugh
- A vacation
- freedom, laughter, fun, a chance to breath
- A time to laugh, relax and rejuvenate. If I don't take care of myself I can't take care of others.
- Being able to do something you like alone.
- Sanity if just for more than a day
- Help from friends and family.
- Go on vacation so you can chill and relax regroup so you can continue your caregiving.
- An evening out. A vacation (week)
- Freedom
- It means so much it is so hard to find some time to relax.
- Being able to do what I want, when and with whom and however long. Something fun.
- Time to relax and release the daily ins and outs of helping those who need it.
- Gives me the energy and the endurance to keep going.
- Enjoy myself with friend
- Peace of mind.
- Relief
- Though not a caregiver myself as a professional and someone who speaks daily with caregivers the break or respite allows the caregiver to recharge, refresh and rejuvenate.
- A chance to leave the house and run errands.
- A break from stress, something as easy as a nap really helps. Letting someone else take over the responsibility for a while.
- Time to relax and regroup.
- It gives me a chance to get out for a break.
- To do things for my family and to have time away.
- Peaceful relaxation, chance for nerves to level out.
- Peace of mind.
- More time to visit my family and especially grandchildren
- Some time to relax.
- Less stress, pain perspective, self-directed activity.
- Relaxing, freedom.

2. Barriers

- Not knowing what is available to us. Lack of financial help.

- Our children don't realize the extent of their father's disease because I do all the work, when I try to tell them, I basically am told I am complaining.
- With relatives they are always too busy to help and caregivers we hire don't always do a good job or are not dependable.
- I can see that things will become more difficult, so I am ok for now, in the future, I'm not sure.
- The hardest thing is family members who live so far away.
- I find it difficult to ask people.
- The training required and the time required to do the training.
- unexpected illness
- we do not get respite
- Not being able to find someone to help out.
- Trustworthiness and money
- reliability, finance, trained personnel to provide care
- feeling emotional leaving a loved one with someone
- Finding someone to take over for me.
- Cost, trust
- someone to stay with him
- Limited vacation time.
- Finding someone reliable. Money, being able to pay for someone to stay with/take care of loved one.
- time from a friend/patient to care for family/friends
- No help from other caregivers.
- Expense, fear of stranger in my home, fear of someone not showing up.
- People don't realize you need a break.
- Taking care of my mother, we live on her income, so funds are low to do anything.
- Currently, 2 basic problems - both money and time.
- accessing the groups
- The primary barrier is knowing that the caregiver is safe or someone else know who to care for them properly.
- My mom doesn't want anyone but family taking care of her. My stepfather has been unable to afford to hire a nurse.
- In the beginning of an illness family are ready to help, but as time goes by so does the help.
- No one qualified for total care.
- family members
- Some people are hard to find to help you.
- Everything is new just learning to cope.
- Finances, family support, geographically far.
- None at this time - children and grandchildren are help and our problem is not that bad at this time.
- Money

3. Short Term Recommendations

- More local places available, help with healthier eating.
- I don't know who to call.
- Perhaps a "pool" of caregivers from which help can be requested.
- Call someone the day you need help.
- What we could have a plan for our grandson to go to so we could have respite.
- Education, have lists of numbers easily available.
- contact booklets with places/people to call and numbers
- financial assistance, more care placement facilities
- education
- social workers
- make it affordable
- A break from patient when you know they're getting at least the same care you give them.
- More attention from other caregivers.
- Adult day and evening care not in my home with trained volunteers or providers. Educate the caregiver.
- My mother's income is SSN and her husband's pension that we live on. It's not enough but just a little too much to qualify for any assistance.
- make the information more available
- Phone numbers of agencies in our area and the names.
- more education
- Get the word out, certified/licensed respite caregivers. Find a way to pay for the respite, rather than making people have to pay out of pocket.
- It's difficult to know where to start and who to call first.
- financial help
- List of names
- Expenses to take a short trip away from stress and a break from special care people.
- Learning more about the condition.
- short term health care
- A community center for Alzheimer's patients to be able to go for socialization and relief for caregivers.

4. Long Term Recommendations

- A dependable respite care if I need to go away for a few days.
- Help for grandparents raising grandchild.
- Education
- increased resources
- All age care facilities with trained personnel from all disability care.
- Education
- more counseling

- Educate public about funding and ways to get a financial break with quality care.
- more public funding for non-skilled care
- Make sure that people you send to relieve me do what they're supposed to do. Don't make me work harder when I return.
- Paying attention to the main caregiver.
- For nursing home to look more like a home.
- Need to raise the income level for qualifying.
- Senior Center and transportation in Wattsburg Area
- keep doing these events and let me know about the series
- More naturally occurring retirement communities or campus like settings so that skilled staff can be available for respite in one common location.
- I would think family doctors need to be better informed on who to contact and on how to get help.
- Making sure people know about the services that are available.
- Better info as to where you can get it.
- Being patient and learn.