

Findings from the S.C. Lifespan Respite Summit – June 18, 2014

Organized by S.C. Respite Coalition (www.screspitecoalition.org)

Major funding from AARP-SC, Governor's Developmental Disabilities Council, ARCH National Respite Network and Resource Center, and the Center for Community Living at the Administration on Aging via S.C. Lt. Governor's Office on Aging.

Breakout Discussions - held in 5 work groups of 18-25 people Summary of reports and recommendations:

Morning Session

1. Please share your connection to respite services. Do you offer respite services in your area or are you a family caregiver who uses respite?

Attendees included family/primary caregivers (some who had and/or are using respite, some who are not currently using respite and some who have never used respite), respite providers, employers of record, fiscal agents and individuals and organizational respite advocates.

2. What systems or help already exist to assist families in accessing respite?

Councils on Aging, Alzheimer's Association, Lt. Governor's Office on Aging, referrals to programs from ER discharge planners, in home care companies, SC Respite Coalition, various voucher programs, education programs (such as Dementia Dialogues), Bright Start, United Way 211, Sci-Way, SC Access, networking with/through social workers, Adult Day Care Centers, Hospice (respite volunteers), lay volunteers from churches, faith-based education (Palmetto Project in the Upstate, Midlands Partnership in the Midlands), Careline (volunteers who assist caregivers), Family Connection, State & County based DDSN services, SC Thrive (formally the SC Benefit Bank), Continuum of Care, Spinal Cord Injury Association, School Districts, Veteran's Administration, Safe Alternatives for Family & Youth (SAFY), Duke Endowment (Providence Hospital – transitional care referral for home services), Home Share Program, Senior Companion Program, Veterans Administration (Aide & Attendants) Stephen Ministries and Parish Nurses, DDSN Autism Consultations, and Easter Seals.

3. What is missing? What are challenges, barriers and unmet needs?

Missing:

- The use of one, simple application which would allow a family to access multiple services, including, but not limited to, respite.
- Facility respite – not easily accessible especially for “end of life” care.
- Mental health services, education and screening.
- Caregivers for the mentally ill.
- Education for physicians about the need for respite care.
- Therapy services – especially counseling for caregivers and families.
- More accessible and user friendly places to access the internet.
- More non-computerized resources are also needed.
- Respite Education for first responders.
- Protection for families from workers compensation issues.
- Families do not understand what respite is – temporary, short breaks for the caregiver, not long term personal care for the care receiver.

Challenges, barriers, unmet needs:

- Lack of education for caregivers, what is respite (temporary, short breaks) and how do you access it.
- Caregivers don't recognize need to care for self in order to be there for loved one(s).
- Respite funding needs to be ongoing, not one time.
- Changes in systems are difficult for caregivers to cope with and understand.
- Systems need to be more flexible and consumer driven – funding rules can be restrictive.
- The cost of background checks on private providers can be a deterrent.
- Lack of funding to provide respite to everyone who needs it.
- Providers need to be more flexible in terms of the hours during which respite is provided.
- The volume and different types of providers can be overwhelming to families.
- There needs to be a single entry point for families wishing to access services.
- Rates of pay for individual providers (current average of \$9.30-\$10.37) are too low. It's difficult to find and retain employees at that payment rate.
- Difficulties in getting physicians to fill out forms to qualify for services.
- Caregivers with loved ones who fall through the cracks because of their age; caregivers of loved ones who are not Medicaid eligible yet the family cannot afford private pay respite.
- Changing the image of Adult Day Cares – eliminating the stigma.

Afternoon Session

1. Strengthening Collaboration – Who else needs to be a part of or partner with the Respite Coalition to ensure all family caregivers are served regardless of age or disability? (Please be as specific as possible).

- Open the lines of communication between the SC Respite Coalition, the Area Agencies on Aging / Aging & Disability Resource Centers and other organizations working to provide respite to families. A free flow of information benefits both the organization and helps get the families what they need.
- Increase collaboration with other entities such as public safety, Meals on Wheels programs, US Postal Service, Meter Readers – those folks often know who is in the house and the status of caregivers and care receivers.
- Communication needs to be increased between Hospital Care Managers and Voucher Providers – if a referral is being made by the hospital, giving the voucher program information and a heads up would get help to families more quickly.
- Doctor's offices need more education on respite and are vital to increasing awareness and making referrals within their patient base.
- More collaboration is needed with Rural Health Clinics and Federally Qualified Health Centers / Community Health Centers. These businesses are community based, serve a large percentage of low-income individuals and are a good way to reach rural populations.
- Increased communication with care managers regarding Medicare/Medicaid dual eligible individuals and their caregivers.

Additional partner suggestions:

- Medical Provider Associations,
- Employment Agencies,
- Funeral Directors,
- Rehab Facilities,
- Pharmaceutical Companies,
- Long Term Care entities,
- Local Women's Groups,
- Faith Based Organizations,
- SHRM – Human Resource Management,
- DSS/Protective Services,

- Veterinary / Animal Care Providers,
- Department of Mental Health,
- Mental Health Providers and non profits,
- Social Work Degree Programs,
- Chambers of Commerce,
- Cancer Association,
- Library Community Education Resources,
- Industry Groups,
- Legislators and Staff,
- Rotary Clubs,
- FMLA Extension,
- Transportation Association,
- Barbers and Beauty Shops,
- Collaborate with other states,
- Eldercare Attorneys,
- Long Term Care Insurance Providers,
- Department of Parks, Recreation and Tourism,

2. What should the role of the Respite Coalition be in the Lifespan Respite program or in helping to sustain coordinated respite services in the state once federal funds are expended? What should the leadership and the structure of the Coalition be in order to fulfill this role?

- Serve to be the hub of respite information in the state and ensure that all parties involved know what the others are doing and that all are on the same page in regarding to respite talking points. I.e. Can we come up with an agreed upon statewide definition of respite?
- Maintain a current and user friendly website.
- Increase staffing in order to fulfill respite leadership role in state (paid staff as well as volunteers and interns).
- Actively utilize social media to get the word out about respite and disseminate information to families.
- In serving as a warehouse of respite information, have up to date information on the economic impact of respite provided by family caregivers on the state economy.
- The Coalition should serve to fill in the gaps to provide respite for the ages/families not served by other organizations.
- Serve as a warehouse of respite information and maintain a current fact sheet of THE RULES: what are the current eligibility standards for various voucher programs and service agencies statewide and how do the programs and/or waivers operate?
- The Coalition, in order to establish a stronger statewide presence, should establish strong regional councils across South Carolina.
- Educating and training families: COACHING families about respite – what is it, how do you access it, creating circles of support, should be a primary role of the Coalition.
- Create a provider list and/or collaborate with SC Access to create a provider list which would create a code for the cost of care, identifies profit versus non-profit providers, gives detail on providers to help educate families and provides a rating system; all of which would help families, overwhelmed by choices in different providers, make more educated choices.
- Offer grant writing support to others wishing to provide/promote respite.
- Offer Lobbying Support to groups advocating for respite.
- Expand the group of respite stakeholders – serve as a leader in bringing groups to the respite table.
- Develop a “Decision Tree” which shows best path through agencies and organizations for families in different circumstances in need of respite.
- Revitalize the State Respite Advisory Committee.
- Establish a task force for dual diagnosis.

- Question was raised in one group: *Will it be difficult for the Coalition to be a central point of contact for respite (which involves a lot of state agencies) when the Coalition itself is a non-profit?*
- 3. Enhancing the Lifespan Respite System – What should a Lifespan Respite system look like in our state? Based on what you know and learned today, which overall infrastructure (underlying foundation or basic framework) would be best for the state’s Lifespan Respite Program? *What would a “dream” system look like?***
- A dream system would be a No Wrong Door System in which various points of entry would lead to eligibility for various services. This would include ONE APPLICATION which, when completed, would be used to determine eligibility for all social services. *Question: Could the SC Thrive (formerly the Benefit Bank) be used for this purpose?*
 - An ideal system would also include availability and accessibility to emergency respite.
 - More training for caregivers – a mobile training which travels to different areas of the state.
 - More state funding would be available for vouchers to include a realistic reimbursement rate for providers.
 - Pertinent agency officials would be strongly encouraged to maintain an association with the Respite Coalition so that agencies stay current with respite opportunities / services.
 - Churches/Faith Communities would include respite training for all care teams, parish nurses & so on.
 - There would be a centralized pooling of respite funds administered by one agency.
 - Respite would have long-term, recurring state funding.
 - 1915I (new waiver for Medicaid); SC needs to get in on the ground floor.
 - Guarantee 1 voucher per family in need.
 - All disease specific groups should receive information for special events.
 - Hold service fairs to educate families about service provision.
- 4. Building the Services and Ensuring the Program’s Future – Based on identified strengths, barriers and unmet needs, what services should the Lifespan Respite Program provide to overcome obstacles or build on strengths? What needs to be done to find and sustain funding for the program or for respite services generally when the federal grant expires? Brainstorm major goals or next steps for the program.**
- Diversify funding streams such that services can be continued – do not rely on government alone, look to foundations, corporations and other funders.
 - A standard for distribution of federal and state funds is needed
 - Seek to obtain some percentage of lottery funds dedicated to respite
 - Develop an alliance with the Veteran’s Administration for more support, funding & services.
 - Consider a shared funding approach among key agencies.
 - Ensuring the program’s future will require thorough Quality Assurance / Evaluation of functioning voucher programs.
 - Goal for 2020 – establish a uniform definition of respite across agencies/ groups statewide and make that a word commonly understood by the public.
 - Initiate a high profile statewide campaign promoting and educating the public about respite; include well-known ambassadors in PSAs.
 - The Coalition could increase its funding by becoming a membership organization.
 - The Lifespan Respite Program needs to truly be LIFESPAN and ensure that respite is accessible to all caregivers of loved ones with a significant disability of ANY AGE, whether that be through the Respite Coalition, a AAA/ADRC or any other agency/organization.