

NC Lifespan Respite Planning Summit – 6/18/15

On Thursday, June 18, 2015, nearly sixty human service professionals and family caregivers gathered at the Wake County Commons Building in Raleigh, North Carolina to share information and ideas towards the goal of “*creating a unified and achievable vision for improving family access to quality Lifespan Respite services in North Carolina.*”

The Summit offered participants the opportunity to:

1. *Recognize the importance of respite services to families across the lifespan.*
2. *Describe the Lifespan initiatives underway at the state and national level.*
3. *Apply new information to the findings of the NC Lifespan Respite Strategic Planning Survey and develop preliminary strategies towards achieving an optimal Lifespan Respite system in North Carolina.*
4. *Discuss next steps for further development and implementation of strategies.*

The following notes were compiled through small and large group discussions during the Summit on June 18, 2015. These notes, along with findings from the survey referenced earlier will form the basis upon which a fully developed NC Lifespan Respite Strategic Plan, including a business plan for the North Carolina Respite Care Coalition, will be written in the fall of 2015.

Notes from Summit Breakout Sessions and Next Steps:

Question #1: Share your connection to respite services. What is the status of respite services in your community? (*A sample of who was in the room & respite status/comments*)

- NC BAM (faith-based community) – call center, 65+ in the home, need community connections
- DAAS – daycare/institutional/group respite
- NC Council on Developmental Disabilities
- Family Caregiver
- CAP-C
- CAP-DA
- Lost/don't know where to turn...
- Need basic necessities met
- Adult Day Care Center – 18+; Certified 16, August 10th
- Autism Society of NC – Innovations Waiver – 560 hrs. /yr.; paid agency provides service
- Respite through private provider
- Care.com – online service; pay privately
- Limited waiver services; waiting lists
- Lack of knowledge of respite
- Agency – Alzheimer's - Family Caregiver Support Program (FCSP); limited; 8000 wait list

- Uneducated about respite
- Lack of self identification
- Work with MS Society; refers clients to MS Foundation; refer clients to respite services; work with 100 counties in NC. 48 hours of care provided. Age varies – clients from age 11 – 89 years old. Certain amount of money goes towards respite services and they can choose their provider. Tries to find providers that don't charge over \$20/hr. No income limits. Always try to go through agencies
- AARP – services all ages as of recently. Doesn't provide direct services, but does research (e.g., Caregivers in the USA) – 1.1 million in NC; avg. age of members is 57. Tries to provide resources, information for caregivers. Want to make sure that people can age safely and are empowered.
- Social worker for school. Innovative Approaches grant through health department. Helps approve respite vouchers through NCRCC; runs a support group for parents of special needs children. Part of Innovative Approaches is education parents on resources.
- Duke Family Support Program – Caregiver Alternatives to Running on Empty (a.k.a Project C.A.R.E). Originally a gov't. grant for people with mental disorders. Covers several counties in NC. Does not have respite funds. Originally had \$2,500 to offer to families of people with Alzheimer's, only for Western North Carolina, but lost that funding. Now offers family consulting services; to see if families are using available respite services. Had a grant in the 80s to do study about Alzheimer's respite care, funded by AARP.
- CAP-DA; institutional respite – hard to find nursing home that does this; non-institutional respite 30 days
- PACE – contracted with nursing home little as 2 or 3 days to 2 weeks
- ARC of NC – not enough services; not individualized enough; guilt about having respite; respect and understand cultural differences; qualified providers.
- Monarch – respite outside of home
- Non-flexibility in funding sources; respect generational differences; non person first

Question 2: Discuss and name possible solutions to the following respite care barriers in NC by 2020 (*These were the top three identified in the May 2015 NC Lifespan Respite Strategic Planning Survey*):

A. Funding limitations

B. Lack of Awareness – families, public, legislators/funders

C. Policy/Process/Respite Definitions (consult list of specific policy/practice barriers & challenge participants to think of how they can address these in their own spheres)

Make specific suggestions: i.e., for each named barrier, what is the recommended solution? What does it require? Who needs to do it?

A. Funding limitations & specific suggestions to overcome this limitation:

Flip chart notes:

- Inflexible funding - more flexibility needed in using funds

- Not individualized
- Money follows institutions/formal supports
- Respite doesn't help the (typically developing) siblings
- Use college students
- Cuts limiting to ADHC population and younger onset Alzheimer's & other
- Dichotomy between money provided to children/older adults – need awareness and change of attitude
- Public Health campaign – e.g. what is negative impact if no action?
- NCBAM (North Carolina Baptist Aging Ministries) funding ideas – going beyond churches – opening thrift/high-end antique store w/coffee shop.
- Knowing specific corporate interests (i.e., SAS, Cisco) – volunteer days could be used for respite
- Address fragmentation – still more to do on this
- What is definition of respite to use for funding?
- Increase awareness to get more funding beyond the Lifespan Respite Grant
- Tap into:
 - Faith based organizations
 - Insurance Companies (leverage \$)
 - Employers – Employee Assistance Programs (EAPs)
- Create new model of paying for respite
- Paid lobbyist
- The right information out to the right audience
- Model of evidence-based approach for child protection
- Make sure allocated funds are fully used
- Non-profits committing to respite services
- Cost/benefit shown to insurance companies
- Emphasize evidence –based practices
- Use store model (mentioned earlier) for funding

Small Group Facilitator notes re: suggestions to overcome funding limitations
(*more detail on comments captured on flip chart*):

- Society values children/milestones – adult funding is harder (“not cute”). Money harder to come by – perception – need societal shift
- NCBAM – repurpose store (Charlotte) – money for odd/uncommon supplies - paid community service hours – mass service opportunities for funding
- Funding is so fragmented – so many different eligibility criteria. People get overwhelmed.
- Trying to get different resources into 2-1-1 but that funding fell through, but now MS Society is not as fragmented now that 3 chapters are combined.
- May be best to establish a standard definition of respite care, standardization across the board. Funding dictates fragmentation, because it tells you what you can and cannot do.

- Not enough funding. National Caregiver Coalition in Washington. AARP is connecting with member of the Coalition to start educating them and allow them to hear more from their constituents.
- Need to find out who else is involved on the Hill and Ellmers and other members have taken up caregiving as a real issue.
- We need to inform people in general.
- More voucher system for more flexibility
- Internship for college students to get experience of caregiving
- Adult Day Care serves younger population and can not utilize HCCBG funding another age group
- Look to foundations; gatekeepers
- Leveraging resources in the community (faith-based, etc.)
- Billable hours vs. creating a new model

B. Lack of Awareness – families, public, legislators/funders (specific suggestions to overcome lack of awareness):

Flip Chart Notes:

- Connecting outside of formal organizations – schools – churches – parks and rec
- Make sure case managers know that respite is defined/distinct
- Don't lump respite with everything
- Public Service Announcements
- Keep it attractive and low key – get to “mom/daughter” side
- Staffing barriers – use retirees
- Younger population/staff not knowing “lingo”
- Public: Not enough information flowing between agency types – more collaboration
- Use drug reps business models to get in the door
- Tie CEUs to respite awareness
- Use Apps (e.g., AARP) and other media to meet people where they are
- More education – families planning ahead
- How to develop respite beyond government – empower families to plan for respite themselves
- Need champions
- Providers out in community
- Directory with eligibility criteria accessible – maintain with paid staff
- Media/information push
- Public Health – population language considerations; number for information
- Increase collaboration
- Translate English for other populations
- Cultural Competency – this can shut down the message
- Don't forget the “digital divide” – not just “go to the website”

Small Group Facilitator notes re: suggestions to overcome lack of awareness
(*more detail on comments captured on flip chart*):

- AARP is trying to get people to tell their stories because legislators hear these stories, and we can get to the heart and the brain.
- When vouchers are pending approval, knowing the stories of the caregivers/families will be very helpful in seeing the people behind the facts.
- Did a report on how well they're serving special needs youth – caregivers had no idea what respite services are available. Public Awareness is huge. Most social workers in the county don't even have the right information, so most parents don't know.
- Possible Medicaid solution – make one pathway for all services
- AARP app for caregiving with all services/resources at your fingertips
- Staffing barriers – RN required for ADC – must be there for 4 hours – Work with them individually as a group.
- Older individuals working with older people
- Disconnect with generations – young people working with older people not understanding the language barriers e.g., “washboard.”
- Lack of options
- Educating families to plan ahead – Changing the service from direct respite service to self-responsible.
- Policy change – Focus change
- Long term services
- Grassroots as champions
- Hospice services for Alzheimer's patients
- PSAs – e.g., smoking, milk. Public health concern – crisis (insurance funding wellness program).
- Info/call in center – live person
- Contact Directors of agencies – legislation for master registry
- Through drug reps; AHEC systems

C. Policy/Process/Respite Definitions (specific suggestions to overcome these barriers to respite):

Flip Chart Notes:

- Look at waivers – what is allowed/not allowed – shouldn't always be at-home respite
- All waivers not “walking the talk” – i.e., person-centered practices – opportunities to follow
- Allow people to assume risk
- Quantify what respite will give back monetarily
- Build relationships with legislators – use stories and statistics.
- Do home work with funders – what have they funded?
- Listserv of help (e.g., retirees) – like homeschool networks
- More social media – blog, Facebook
- Absolutely common respite definitions

- Figure out a way to braid funding between groups
- “Temporary” – define this
- System to make sure more get service opposed to a few getting too much
- Differentiation between “care hours” vs. respite hours
- Where do 21 – 40 year olds go for adult day health care?
- Eliminate silos
- Leadership to create/define respite together
- Everyone advocate – bring Disability Rights, other organizations
- Decrease fragmentation
- Put in user-friendly language
- Collaborate so that different groups understand definitions
- Respite Care homes – develop these – how can model be sustained?
- Broad definition of respite and specific populations
- More transparent systems for easier access
- Policy change: FMLA (Family Medical Leave Act) – MS and AARP work group
- “Aging in Place” – caregiving – accessible home & resources
- Involvement in Caregiver Coalition (National - *Renee’ Ellmers and State)

Small Group Facilitator notes re: suggestions to overcome policy/practice/respite definition barriers (*more detail on comments captured on flip chart*):

- We need to inform people in the General Assembly/those making the decisions. Need to get Public Health directors together.
- Tax reform
- Legislation to see that caregivers have time off. Small Business Initiative to empower employers to have some sort of safety net for caregivers to have time off.
 - People in restaurant services, retail, etc....need a living wage, and flexibility for time off as caregivers. Parenting benefits for employers.
 - Trying to improve flexibility with leave.
 - SARE – 6 committees, active in Wake/Durham with 400 RTP companies.
- Have modification resources. Introduced tax credits for this, but state restructure of taxes killed that.
 - Tied into grant opportunities
 - States without income tax looking at using property tax.
 - Want to make living in place more affordable.
- AARP – Livability Index – shows scorecard on how well town (*ill.*) handles home modification, infrastructure, and amenities for the aging. Want to reach WHO aging goals:
 - Want homebuilders to be certified aging in place builders
 - Work with realtors to educate them about livability/home modifications.
 - Wake County has universal design group.

- VA has home modification tax credits for retrofitted homes, etc.
- Focus on caregivers instead of just looking at recipients for eligibility. No good way yet to define caregivers/scope out population. May not be a need for a respite definition because it varies so much.
 - Some definitions of respite say short term/intermittent and this causes a barrier for many.
 - The dependability, quality, and scheduling of respite services determines how often caregivers use it.
 - Work should be covered with respite, but some policy opposes that. Therefore, the respite definition should be broader.
 - REACT – Respecting Employers (employees?) Caregiving Time. Handbook that empowers caregivers – to provide flexibility in the workplace. On the docket on the Hill.
- If we had Dr. order statement that justified - therapeutic orders – different respite
- Allow waivers/policy – walking philosophical theories of person-first/community-based.
- Allow person centered plan to assume risk.
- Can we calculate in some way that value of 8 hours of respite?
- More retired individuals to assist who have more flexibility – AARP
- Hard to sustain volunteers within the need.
- Listserv to help with getting retired individuals e.g., homeschoolers are no longer just individuals but have groups to share information.
- Community Resource Connection through AAA
- NCRCC Blog
- Be more specific about volunteer opportunity – more time specific
- Review insurance industry – profits to invest in respite services
- Siloed agencies (state level) – to address respite across DHHS.
- Disability rights
- State leadership turnover.
- Grassroots – organizations/individuals
- Advocacy
- Suggestion: Double dipping – Standard definition across the boards part of PSA “temporary” – difference between regular care and respite
- Safeguard to stop abuse of the system.
- Hospice – provider definition? Across the board
- Explain how true respite hours are different from care hours
- Definition: Adult Day Care – Need to divide 21-40 & 41 – 100.

Questions 3 & 4: What should the role of the Coalition be in helping to sustain respite services in the state? Survey answers:

- A. Increase Public Awareness**
- B. Increase Advocacy**
- C. Look for funding options**
- D. Collaborate with partners**

And what needs to be done to sustain funding for the Coalition and respite services (such as the vouchers) generally when the federal grant expires? Please be specific.

Flip chart notes:

- Increase awareness – social media, billboards
- Reach everyone even without computers
- Consistent message through NCRCC
- Connect with social workers, M.D.s, etc.
- Advocacy – paid lobbyist – partner with organizations
- A lot of outreach to membership – create a letter/template for legislators, etc.
- Connect with and use skills/passion of those receiving services for outreach
- On website, include option to donate
- Approach private donors/retailers (Belk's, Macy's, etc.)
- Triangle & Kate B. Reynolds
- Partners – Long Term Services and Supports events, senior centers, IDD Training Institute, NSAW
- Present at conferences – build relationships
- Suggested membership rate on the website to join
- PSAs – specific/high impact image/phrase
- Dialogue about pooling information with NCBAM and others
- Face-to-face events for information and funding
- Physical presence and sharing calendar/blog
- On-stop for all support – where?
- PSA – 1) What to do? 2) How to do it? Partner with a University as a project.
- Develop personal story – send to print media – write it so they will run it
- Establish relationship with legislators
- Private foundation (lower profile) – send to NCRCC for follow-up
- University students – respite volunteers (1-on-1 & other capacities)
- Corporate Partners/Insurance – sharing information between groups
- Corporate \$ for vouchers (e.g., IBM, SAS). Show data we saw today.
- Faith/Civic Groups – ideas for serving people with respite
- Transportation to services
- Planned Process: What is the message we want to convey? We need this! For public/for members. Create a platform.
- Create centralized hub/clearinghouse and devise ways to get it out
- Existing ways that organizations communicate (e.g. DHHS newsletter) – tap into it
- Partnering organizations within the Coalition – Adopt the message – heard across the board.
- Go after organizations to become members, not just individuals.
- Can these organizations/partners bring some funding to the table?

Small Group Facilitator notes re: suggestions for the role and funding of the Coalition
(*more detail on comments captured on flip chart*):

- Centralized hub/clearinghouse
- Challenge members to recruit
- Grassroots, social media, word-of-mouth
- MCOs to collaborate with NCRCC – contact directors; NC Council of Community Programs
- Messaging – uniform messaging platform
- Advocacy – leveraging our respite message into other platforms – AARP, Disability Rights, NAMI, ARC, NC Families United, etc.
- MCOs – savings from managed care (funding)
- Specific PSA
- One contact focus number
- Public Health Campaign
- Develop a “catch phrase”
- Social Media
- Direct Care Workers
- Caregiver tell their stories
- Oral Histories
- Contact your legislators
- Have kids write letters
- Marketing and advertising agency for “pro bona”
- Suggested dues
- Donate online
- NCBAM/faith based – intergenerational high school level – “community of volunteers”
- Physical presence in the community (face-to-face) – “special needs nights”
- Increase Public Awareness
 - Social media – expand appearance on social media, billboards
 - Coalition should maintain a consistent message and brand
 - Solicit from the membership
 - TV, commercials, reach people with limited access to computer, etc.
 - Should be all-inclusive – work to be appealing and culturally competent
 - Could advertise: Dr. office, insurance companies, on North Carolina Medical Society, Nurses’ Association, Social Workers (NASW)
- Increase Advocacy, (but buy-in is needed – educate, support and get buy-in)
 - City Council/mayors
 - Catch legislators while they are at home – create a relationship
 - Identify people to speak to audience.
 - Access recipients of the services who support it.
 - Create a template to become a letter and tweak
 - Increase membership
 - Hire a lobbyist – League of Women Voters; NASW
- Looking for funding options:

- Is there an option to donate?
- More private funders/retailers – Macy's /Belk
- Look at fundraising options – can we do it
- The Triangle Foundation/Kate B. Reynolds
- Collaboration with partners
 - Physician assistance
 - Long-term service support
 - Health fairs/maybe done in regions
 - Find out where the vendors are from
 - Senior Centers, aging parents, parents with children with disabilities
 - NASW Conference – partnering with other conferences
 - Developmental Disabilities Training Institute
 - Look at presenting at conferences that might be relevant
 - Ask membership what conferences they know about
 - Offer start-up training for volunteer respite programs