Strategic Planning for Respite Sustainability: *Introduction to Logic Model and PATH leading to current recommendations*

The first effort to create a statewide plan to promote respite sustainability dates back to 1999. A reference back to this point is critical towards identifying future steps as it can be observed that the needs, objectives and anticipated outcomes have not changed dramatically over the past 15 years. In 1999, with the support of the Statewide Special Kids Network, a statewide committee (and subsequent regional subcommittees) formed to address the unmet need for respite care in Pennsylvania. The group engaged in a PATH process. While the group's meeting was convened by an entity focused on resources for families of children with disabilities and preceded any Federal Respite Legislation, their efforts begin to reflect the need for available and accessible resources cross age and disability. Pennsylvania Community Respite Group PATH 1999 facilitated by MaryJo Alimena Caruso

In 2007 and 2009, the PA Respite Coalition in partnership with the Family Support Advisory Council and the Institute on Disabilities at Temple University hosted two respite summits. The purpose of the summits was to address the Lifespan Respite Legislation and prepare Pennsylvania to create a system of sustainable respite cross age and cross disability. A summary of those summits, facilitated by Jill Kagan of the National Respite Resource Center / ARCH and MaryJo Alimena Caruso yielded the following information:
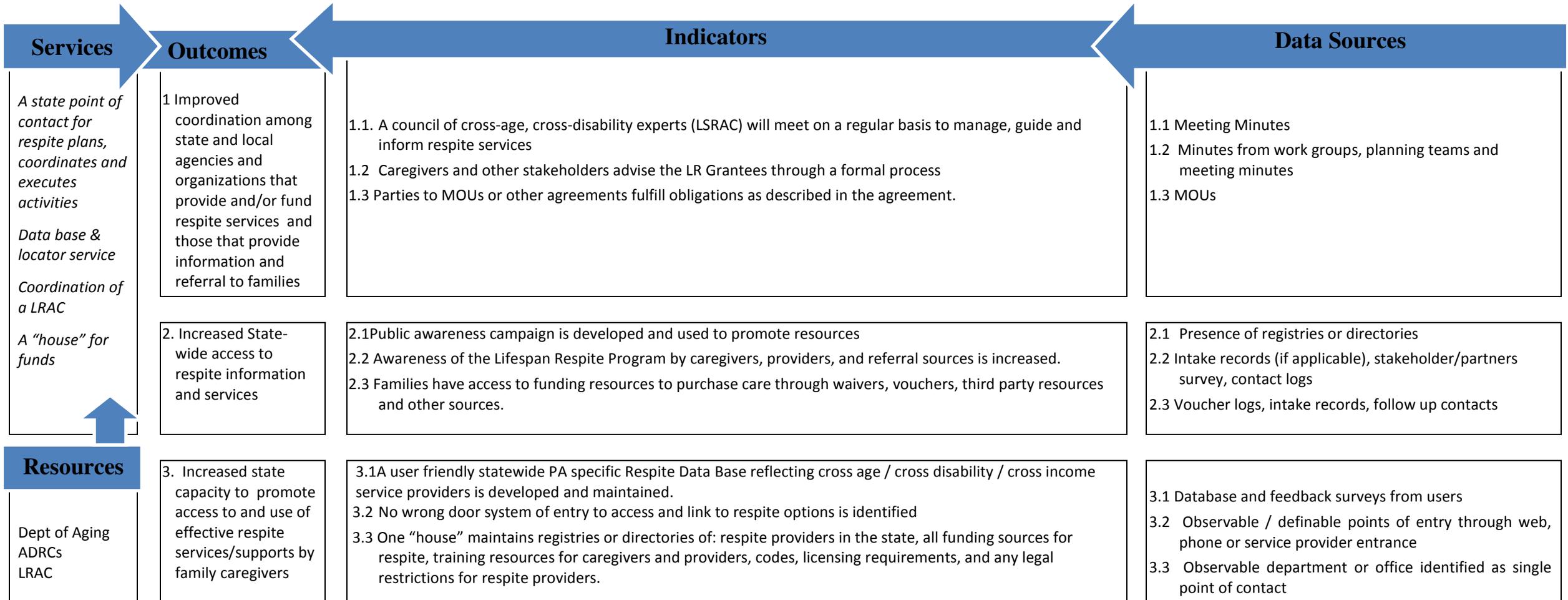
Issue	Strategy	
Strengthening Collaboration. **Who else needs to be part of or to collaborate/partner with the State Respite Coalition and a State Lead entity to ensure that all family caregivers are served regardless of age or disability?**	- Parents - Business Community for funding and universal awareness of respite as a public health issue - Children's Trust fund - Provider Associations for Aging- Homecare Assoc. - Foundation Communities/Association - Office of child development and Early Learning - Office of Long Term Living - Professional organizations - Governors' office - PAR-PA Assoc. of Resources, PARF, PCPA (here) - Department of Health - Department of Aging- family caregiver support staff, - Universities	- Employers/Employee assist. Programs - Behavioral Health 2-1-1- system - United Way - All counties represented: one contact per county - PA academy of Pediatrics - PA Academy of Family Physicians - Insurance/Managed care - Legislators (Senator Vance, Senator Orie, and others)
Building the Lifespan Respite System. **Which overall infrastructure would be best for our state's Lifespan Respite program? What is the best possible structure we can develop in Pennsylvania at**	"House" in state government - One place to go for services (vouchers) - emergency vouchers for those who are not currently receiving respite care - Someone needs to manage the house. - Set up Regional Lifespan Offices - Must connect information with what actually happens - must have gap-filling services	- Information sharing across the silos - Ensure that the information shared includes training of people who will be answering the phone, directing the calls for respite, etc. - Training (on respite awareness) - State advisory Group inclusive of family members) - Website (one source for respite information)

this time and what services should we make sure are included?	• Income tax credit, or reimbursement system	• 1-800-single phone hot line
State Respite Coalition and ADRC Role and Collaboration in State Implementation: **What should be the role of the State Respite Coalition in state implementation? Which tasks or responsibilities would you include for the coalition in the mandated "memorandum of agreement"? (e.g., coalition can be I&R portal for families; train and recruit providers; conduct needs assessment; or be advocacy focused). What will be the role of the other networks and community-based or state based partners?**	• No wrong door ~ whatever portal you enter will direct you to respite, a point of contact, etc. • Statewide: one stop, not regional • Customer focused/user friendly statewide partnership of public and private agencies • Sharing training resources (Website) • Recruitment and marketing-Getting the word out- Be a Respite worker!) • Have a statewide adoption network model and Disability Employment model • Using existing agencies (AAAs) to do some of the program management. • Identify best practices • Vehicle to provide input from families • Accountability • Website specific to respite care in PA with links to it on other sites • Information gathering days (awareness activity): could utilize Link sites • Advisory committee membership-Rotational membership • Information gathering and sharing • Marketing of respite resources, one stop shop / website / number • Outlining what people are eligible for-to pay for the need • Eliminate duplication by working together • Links can provide cross training	• Toll-free# • Resource guide: educating families about what respite care is, welcoming them to ask for it and giving them options about where to go • Formal Structure- Sign on to membership • Information gathering for evaluation- In partnership with ADRCs/University • Training House • Identify local organizations to be resources • Develop provider profiles across system • Identify what factors determine a quality respite program. What should families be looking for, what should providers strive to do? • facilitate community forums • assist with provider training • serve as a single point of contact • connect with other training programs • be aware of different needs of different populations • Streamline information. • Coalition, ADRC and State Agency can work together to "close the loop" so people are directed in ways that aren't helpful

In 2014 a group of stakeholders from the Lifespan Respite Advisory Council agreed to serve as a workgroup to address sustainability issues. The workgroup was facilitated by the Finance Project in Washington, DC. Pennsylvania was able to apply for sustainability technical assistance from the Finance Project as a result of their Federal Lifespan Respite Grant Award. Pennsylvania applied, was identified as an exemplar state and received technical assistance from the Finance Project to further guide the sustainability effort. As a part of the technical assistance the workgroup created a Logic Model to guide the sustainability efforts from this point forward.

Pennsylvania Lifespan Respite Systems Change Logic Model

Vision: A community in which family caregivers for people of all ages and disabilities have easy access to quality respite information, services and supports.

Services	Outcomes	Indicators	Data Sources
A state point of contact for respite plans, coordinates and executes activities *Data base & locator service* *Coordination of a LRAC* *A "house" for funds*	1 Improved coordination among state and local agencies and organizations that provide and/or fund respite services and those that provide information and referral to families	1.1. A council of cross-age, cross-disability experts (LSRAC) will meet on a regular basis to manage, guide and inform respite services 1.2 Caregivers and other stakeholders advise the LR Grantees through a formal process 1.3 Parties to MOUs or other agreements fulfill obligations as described in the agreement.	1.1 Meeting Minutes 1.2 Minutes from work groups, planning teams and meeting minutes 1.3 MOUs
Resources Dept of Aging ADRCs LRAC	2. Increased State-wide access to respite information and services	2.1 Public awareness campaign is developed and used to promote resources 2.2 Awareness of the Lifespan Respite Program by caregivers, providers, and referral sources is increased. 2.3 Families have access to funding resources to purchase care through waivers, vouchers, third party resources and other sources.	2.1 Presence of registries or directories 2.2 Intake records (if applicable), stakeholder/partners survey, contact logs 2.3 Voucher logs, intake records, follow up contacts
	3. Increased state capacity to promote access to and use of effective respite services/supports by family caregivers	3.1 A user friendly statewide PA specific Respite Data Base reflecting cross age / cross disability / cross income service providers is developed and maintained. 3.2 No wrong door system of entry to access and link to respite options is identified 3.3 One "house" maintains registries or directories of: respite providers in the state, all funding sources for respite, training resources for caregivers and providers, codes, licensing requirements, and any legal restrictions for respite providers.	3.1 Database and feedback surveys from users 3.2 Observable / definable points of entry through web, phone or service provider entrance 3.3 Observable department or office identified as single point of contact

Family Caregivers IOD at Temple COSA DOH PA LRC DPW Stakeholders Legislators Training curricula Funding		3.4 Professionals are educated and provided resources about the benefits of respite and how to access it to help family caregivers and individuals connect with appropriate caregiver relief services 3.5 There is an increase in tangible contributions by policy makers, stakeholders and departments to the PA Lifespan Respite project such as other funding streams. 3.6 Key leaders and respite stakeholders report the PA Lifespan Respite Partnerships are resulting in increased caregiver access to respite across the lifespan and type of disabilities.	3.4 Survey of stakeholders (phone/email/face-to-face) 3.5 Meeting minutes, financial records, activity reports 3.6 Survey of stakeholders including caregivers and providers
	4. Increased State-wide capacity to provide effective respite service.	4.1 PA Lifespan Respite program identifies underserved / unmet populations not being served by current respite services/funding sources and provides access to respite care 4.2 There is an increase in resources (training, providers, funding sources, etc.) focused on service to the populations identified in 4.1. 4.3 PA Lifespan Respite follows administrative procedures to refer caregivers to available and accessible respite. 4.4 House for respite connect direct service providers to existing resources for improving recruitment, training and coaching of respite providers, when resources are available. 4.5 Providers define and evaluate their services for effectiveness 4.6 Caregivers have increased access to respite services. 4.7 Respite services available to caregivers are increased.	4.1 f/u from data from 3 rounds of vouchers / Needs assessment, stakeholder/partners survey & records of identified & implemented outreach strategies 4.2 Training curriculum, funding initiatives, data collection comparing baseline to current for number of volunteers / providers, individuals served / hours of care 4.3 Presence of forms, procedural guidelines, team. 4.4 Administrative records, phone /email/contact logs 4.5 Administrative records, summaries of quantitative and qualitative data collection, training rosters, provider report. 4.6 Stakeholder and partners survey 4.7 Registries/directories data collection reports reflect an increase in number of respite services.
	5. A sustainable, funded respite system for family caregivers	5.1 The Commonwealth enacts legislation to provide funding for actual respite services, outreach and education to community, training and education of volunteer providers, education for providers,	5.1 Drafted legislation, identified sponsors, identified list of advocates to educate about the legislation, a strategic process to pass legislation

Assumptions: The goal of the PA Lifespan Respite Care program is to improve the delivery and quality of respite services by supporting, expanding, and streamlining coordinated systems of community-based respite for family caregivers of individuals cross age regardless of special need. To meet this goal, partnerships across a broad range of systems must be in place and maintained and ideally legislated.

ADDITIONAL SUSTAINABILITY RECOMMENDATIONS:

Outcome One: Improved coordination among state and local agencies

Specific activities

- Continue meeting as a Lifespan Respite Advisory Council

- Schedule more presentations during our advisory council meetings. For example, we could listen to organizations that are running successful respite programs, or perhaps hear from recipients of services.
- Baseline data: It could make it easier to see success it we get regular data updates from the programs. The summary reports lists several state offices that offer respite, Office of Developmental Programs, Bureau of Autism Services, etc.
    - it would be helpful to collect data from them on the number of clients served, the number of hours of respite provided, etc. these numbers are not currently reported anywhere.
    - Identify other data sources from organizations not funded by state programs.

Outcome Two: Increased statewide access to respite

Specific activities:
- develop an electronic newsletter. No printing costs, and if it's done in house, maybe no other costs either, other than staff time.
- create a youtube channel and develop short videos
- develop an awareness campaign and demonstrate the value of the unpaid family caregiver by utilizing statistics and research (statewide and nationally)
- We also need to consider all the possible avenues that people will come to learn about respite. Some will find out through informal family and friends…some through their employer…some through a health care system….some through church…..some through social workers or other helping organizations. Regardless of where they hear about it, they need to get the same message and get to the same core base of information that is correct and current.
    - outreach effort needs to focus on a very wide range of people and needs to think more broadly about who are stakeholders really are.
    - All of the avenues know how to properly and seamlessly refer someone to that core set of information on respite.
    - That leads to the question: who needs to be educated on what respite is and how to refer someone to that core set of information on respite services and supports?
- Continue to provide vouchers (also a part of outcome 4)
    - Fund through a state legislation
    - Fund through a penalty fee imposed by judges (a fee that would be assessed by a judge for certain nuisance crimes, etc. and put into a fund for respite)
- Completion and maintenance of the website
- When developing our plan for a better system of respite care we need to consider what core body of information will lead people to the set of services that are available. This information needs to be consistent across the board and should take into consideration language and cultural barriers. It needs to be current, up-to-date and user-friendly.

- Track utilization of the website

Outcome Three: Increased state capacity to promote access to and use of effective respite services/supports by family caregivers

Specific activities:

- Have a data base but ALSO a team or a paid staff person who is responsible for linking family caregivers to services and collecting information about effectiveness of the connection and / or unmet needs. Team could meet bi weekly or monthly to address caregiver issues
- Promote the ADRC site
- Continuously update the resource directory (online) funding and resource materials for family caregivers
- Strengthen the referral network with 211
- Address how those with limited internet use can have access to respite

- Create a map of need and lay over that a map of where resources are as well as a map of where the finances to fund resources are located. This will help show the areas that need the most attention or where there are resources that could be reused in other ways.

Outcome Four: Increased State-wide capacity to provide effective respite service

- Provide vouchers and offer families a reasonable time to identify a provider and use the voucher (other states provide 1 year) and continue to survey effectiveness
- Identify unmet respite needs either through minority, immigrant or rural families who may need, but not know how to access respite care
- Expand the capacity to provide service by training more volunteers:
    - Identify volunteer providers in the state and insure they are in the database
    - Expand the current initiative that is limited to children with special health care needs to other populations across age and disability
    - Make curriculums available for groups to train volunteers and provide some type of training and technical assistance to partner with them and promote safety
    - Create some guidelines around volunteer respite or organizations wanting to do respite with volunteers
- Identify at least one or two colleges / universities in the state willing to connect coursework to respite provision for college credit
    - Document how the activity is linked to the coursework and the benefit to students
    - Document the innovative volunteer respite that occurs: could be on campus or in community
    - Work with Penn State or Millersville since they have expressed interest or had experience in the past

Outcome Five: A sustainable, funded respite system for family caregivers

Specific activities:

- The LRAC should submit the principles of what respite care should be and its cost benefit to the Commission for its consideration. Deadline 8/14. Our message of the value of respite is completely consistent with the objective of the "right services at the right time in the right place" that drives the conversation.
- Find a legislative champion to spearhead some type of state legislation
- Pursue additional federal funding specifically designed for sustainability effort while legislation is being sought
- Long Term Care Commission is looking at the future of needs and services (including systems change), I think we are missing an opportunity if we do not include a strong recommendation that respite is assumed to be part of whatever changes are made. For example – the contract language of any new MLTSS managed care contracts should include it in the performance objectives.
- Continue meeting as a LRAC to further address these issues and work with legislators
    - Continue Respite Awareness week and a Proclamation from the Governor: More publicity and legislative awareness reinforces the foundation for lifespan respite.
    - A rally or celebration activities would allow for more families to come out and be heard and engage with legislators.
    - Possible champions could be identified.
    - The rally or celebration could highlight the plan or funding request submitted to the state.
- Create a lifespan respite toolkit:
    - The toolkit will provide additional information including real life stories about the benefits of respite, additional statistics, etc. (above that provided in the brochure) further increasing awareness of the issue.

- o This detailed information will keep all interested parties (agencies, non -profits, individuals) on the same page in terms of advocacy and understanding of the issues involved
- Identify a person or persons who will take responsibility for continuing the progress of this work