

# Lifespan Respite Grantee and Partner Learning Symposium

Denver, CO

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## Roundtable Discussion: Sustainability: Lessons Learned from Exemplar States

### Summary of Groups 1-3

Facilitator: Susan Summers

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#### **Introduction to new ARCH Publication, [Sustaining Lifespan Respite Systems: Lessons Learned and Practical Applications with a Checklist for Success](#)**

Susan began with an introduction to the document by sharing her personal story of having a brother with a severe disability. She stated that although respite was of the highest priority to her parents and family, the topic of respite was not part of her professional training in special education, nor was it part of her work. She made the point that respite is often overlooked as central to person- and family-centered services. Defining and communicating the importance and relevance of respite presents a challenge to states taking on the task of coordinating systems of accessible, community-based respite care services for family caregivers.

As we coordinate and sustain services at a systems level, we must keep in mind that our work should seek to support quality services at the level of caregivers and families. The round tables discussed who to keep in mind when undertaking sustainability planning – caregivers, care recipients, policymakers, community. For the purpose of the Sustaining Lifespan Respite Systems document, Susan talked with states that had engaged in funding sustainability with The Finance Project. Susan noted that while she anticipated that project participants would talk about funding and finances during interviews, she was surprised that people, relationships and processes appeared to be the most salient issues to those interviewed.

Four key areas were identified as important in the Sustaining Lifespan Respite Systems document:

**People**

**Plans**

**Practical Options**

**Policy**

## People



The round tables discussed sustainability not just in monetary terms and bureaucratic contexts, but as it occurs through relationships and planning activities.

- Seek diversity among planning partners.
- Groups that work well address various group goals by including group members with different skills that complement those goals.
- Grassroots movement is important to make sure we include the perspectives of caregivers and families, (although we tend to think and work more often at systems levels).
- Grassroots movements and relationships with those in government can lead to change. Look for planning members with personal experience of respite and with government connections.
- To make respite more relatable, look for unique collaborations with known personalities, such as Elizabeth Dole and Tom Hanks to advocate for military caregivers.
- Attaching personal stories with data makes numbers more relatable and meaningful.
- Look for group members with expertise in research/evaluation field (such as university students looking for meaningful research/evaluation activities.)
- Universities – ARCH’s research respite agenda is available to upload – make friends with special education, gerontology, social work, and representatives of other related fields.
- Rather than lament gaps in personal or group skills, do what you are good at, and find and invite others to do the other pieces, e.g. University Centers on Disabilities exist in all states, easy to work with, and are mandated to conduct research and provide community service.
- Find or make friends in high places including decision makers.
- Have authentic and meaningful relationships with planning members and related others so that they look forward planning activities.
- Make meetings engaging. Include on your agenda topics to draw people to come, such as grassroots Autism Eats, Autism Housing Alliance. A speaker series can make meetings more enjoyable and meaningful and promote learning.
- Have a plan to deal with member attrition and lack of engagement.
- Look for ways to share leadership activities rather than top down leadership.
- As a group, identify concrete deliverables that define why you are meeting and that mark progress toward goals.
- Bureaucratic changes that inevitably occur when government leadership changes create the need to maintain group leadership that will continue in some form during times of change.
  - Succession Planning – Shared leadership – what to do when leader leaves
  - Be on the lookout for qualities of people with the leadership skills the group needs.
  - Rather than having one or few people doing all tasks, look for ways to share roles and responsibilities while increasing autonomy among group members and a sense of shared ownership.
  - “Shared Champions” when legislators/government supporters leave
  - Large group and functional group – need someone to track changes and history
- Diverse locations across the state
  - Functional exec committee

- Engaged regional activities
- VA Coalition Example
  - Regional leaders work with state level contact.
  - Statewide meetings every other month.
  - Agendas include both business and education.
  - Members across the state participate by video chat.
  - Local site leaders participate.

## ***Plans***

- Develop a finance model that works for your particular needs. Adapt existing forms (such as a logic model) to make it usable for your audience and purposes.
- Expect that external funding will support short-term services. Plan from the outset ways to continue successful short-term services in the long term.
- Start thinking about performance measures as you plan.
- Perseverance leads to sustainability. Don't let setbacks along the way deter you from longer-term goals. Use what you learn from setbacks to amend plans and activities.
- Distinguish between institutional time and human time.
  - Single funding and reporting cycle are not equivalent to long term plans. Make sure these are complementary, but keep the long game in mind.
  - Gaps frequently occur between approval time and actually having funding. Find ways to keep activities going before, during and after funding.
  - Bureaucratic deadlines may be discouraging, but as long as you are progressing, stick with your plan and forge ahead. Don't be deterred by deadlines from reaching your long-term goals.
- Find ways to exist as a group during funding gaps.
- Look for ways to build from existing groups and initiatives rather than repeatedly starting from scratch.
- Learn the art of collaboration.
- Reach across funding silos and look for commonalities in work in order to maximize resources and reduce duplications.
- Use qualitative as well as quantitative data.
  - Hear stories, then see data
  - Have evaluator on the coalition
- Some enjoy the planning process; others don't. Use a facilitator to maximize participation, investment in the product, and enjoyment of the process.
- Outside facilitation allows leaders to participate, hands off facilitation. If leaders are facilitating they cannot contribute their own (considerable) expertise.
- On sustainability plan, make sure that deliverables are concrete and measureable.



## ***Practical Options***



- Have a clear message with a plan to highlight the beauty and humanity of the work with storytelling.
  - Keep working to accomplish your goals while remaining flexible as you learn what is working, and what is not. Be willing to revise goals and strategies as it makes sense to do so.
- Interim reporting requirements may not allow time to achieve your long-term goals. Continue measuring progress, but give yourself grace period to allow time for change.
  - Take the long-view and be patient. Don't feel defeated because some tasks take longer than you anticipated.
  - Change mindset when grantee guidelines and processes seem restrictive compared to your overall plan. Look for ways that single grants fit into the larger plan.
  - Categorical thinking – increase trying to undo this
  - Connecting state funding to grassroots program (different culture)
  - How to sustain when aspects are divided, looking at different levels
  - Get “respite” and “caregiver” on the books with purpose and economic value

## ***Challenges to Sustainability***

- **Changes in agency leadership.** Have a clear, concise, compelling plan to share with new leaders so they understand what respite is, and why it is important.
- **Power concentrated in a single leader.** Seek and mentor leaders and share leadership.
- **Planning groups without clout.** Look for planning partners and advocates with authority and influence.
- **Groups lacking shared purpose and meaning.** Build consensus around a common mission and goals.
- **People unskilled at interpersonal relationships and collaborative work.** Choose members wisely.

## ***Overcoming Challenges to Sustainability (additional suggestions)***

- “Juicy conversations” that open and stimulate collaboration
  - Reframe ideas of “defeat”, and use set-backs to inform you on ways to remedy problems and progress.
- Caregiver partners will come with passion. Use them to recommend others in order to build strong caregiver participation.
- An example was shared about a high-level state meeting where family caregivers were each given a bell to ring when they heard jargon used. This was done in a light hearted way for the purpose of encouraging clear, non-intimidating conversation among caregivers and bureaucrats.
- Re-engage committee members through expanded roles and meaningful work on committees.