

Lifespan Respite Grantee and Partner Learning Symposium

Denver, CO

September 23, 2016

Roundtable Discussion: Increasing Stakeholder Diversity in Lifespan Respite

Summary of Groups 1-3



Facilitator: Casandra Firman

Refer to ARCH [*Infographic: What's the Key Ingredient for a Successful, Sustainable Coalition?*](#)

What's Needed:

- People who can and people who are connected to people who can make decisions.
 - A core team of people who are can attend and actively participate
 - People who play well with others
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- “we lack structure because we are a bunch of volunteers”
 - Getting in written into statute may give it clout and funding
 - Statute can be a catch 22 because you lose the grass roots sense but gain clout on the legislative grounds
 - Volunteers can have nebulous roles and responsibilities: If you can clarify roles and a connection to an executive office, it may help
 - Having a statute and rules and roles can also be off putting to different cultures who may have a mistrust of government or are not sure on what the relationship is between the coalition and the government structures.



Are formal meetings related to effective outcomes?



- Not necessarily, in fact relationships between committee members and outside of the committee as well as what action steps happen between meetings are even more important than the meetings themselves
- How many people / organizations are too many to be involved to the point where we actually lose effectiveness?
- Sometimes big meetings with lots of people get less done.
- Sometimes even calling it a coalition implies “nothing is going to get done”
- Sometimes with the funding and the connection to big grants and large groups you can actually lose your voice

Unintended consequences of the legislation / Federal lifespan grant on coalitions:

*it would be helpful to talk about what is like when the coalition has to give things over to the bigger picture (so when the coalition began to be owned by the grant, we lost our mission and vision) and you know what to expect and how to support regional efforts, etc. to still own their piece although the original coalition is no longer “owning or milking the cow”

What is the Coalition / Being part of the Coalition mean?

Gather the voice of your constituents that is not dependent on meetings. Use other methods of input, including Survey Monkey, send draft documents and solicit feedback in a formal / informal way to get their opinions, language suggestions, clarification, etc. These strategies can keep this engaged and informed.



Accountability of funding is important, but we don't want to lose the voice of the grassroots movement in the process.

Sometimes the coalition of volunteers are put off by the receipt of grant funds “you don't need our volunteer efforts anymore because now you have funding”

It's almost like you have to have two parallel tracks: one to insure the presence of the voice of the community and the other to insure effective grant implementation and management.

Goal Setting:



Low hanging fruit: Pick goals that have immediate or quick results to keep members engaged

Positive and possible: measure your goals with what is positive AND possible. Many of the activities are positive and well-meaning but may not be possible (at this time or ever)

Managing the growth without hurting yourself (too many people going to the legislators and talking to them and asking for too many or disjointed things)

Bring everyone to the table and identify roles and responsibilities

Who will do what with whom and sharing what information or data?

Serving as the connector:

- Treasure hunt: reaching the smaller grass roots organizations often yield people who can get things done but lack the bandwidth to know what others are doing or who can help you get things done
- Less meetings can mean more success if you are focusing on building relationships and having real action taking place.
- Sometimes our coalition “membership” actually looks more like building partnerships. *It does involve someone running around and building these relationships.
- Working with AARP to look at who is missing at the table and pulling people together in an opportunity to formalize our strategies and activities as a coalition.



Partnering



- Partnering with agencies and businesses to support your efforts with information, donations (grants and goods) and coalition members
 - Examples: AARP, Banks, Employee Assistance Programs (EAPs)
- *Developing reciprocity* ~ letting companies know what the benefit of your respite information, coalition etc. is so that you can work together to fill each other's needs and gives everyone a role.
- *Learning from other successful movements:*
 - Example: Dementia Friendly America (<http://www.dfamerica.org/>)

Aha moment:

- We have member agencies etc. but we have come to the point where we don't even know who the true members of our coalition even are.
- And do they (the members) know they are a part of the coalition and what the coalition really stands for
- Moving beyond the spreadsheet of members: how do you identify, enroll/accept, manage?
- There can be three levels: families (caregivers / care recipients) free, providers (of respite or persons needing respite) small fee, corporate level (not providing services) larger fee or financial support or donation of goods / services.
- Membership should be mutually beneficial ~ people should have a clear understanding of what they are a member of, what they can bring to the table and what benefit it is to them.
- If the meetings are connected to "training", participants can often come and get something to take back.
- Sometimes there can be incentives to participate, like a voucher for respite care that can be taken back to the agency
- Partner survey (flifespan.com) to gather participants, what their interest area is, etc.



Keys to success



- Moving beyond grassroots and becoming a non profit helped with:
 - Grant writing
 - Helping to access funding
- Some coalitions are 501c3 others have a fiscal agent with a federal ID number to assist in applying for funds.
- Affiliates: can share information, offer services etc.
- Giving the gift of Respite: Providing respite vouchers as gifts to increase visibility to both the cause and the coalition
- It's not what you know, it's who you know: Networking! Everyone knows someone who knows someone
- Community champions: people who can share information, etc. to populations who may not be tech savvy or have the awareness of or trust of your efforts

- It can be difficult to have a coalition serving a large state or a state that is very diverse geographically or otherwise.
 - Regional coalitions who can lead the charge in their communities
 - Provided information/training including on caregiver challenges
 - Offered a meal (without using State or Federal funds)