Care Out Loud: How to Start and Sustain Your Caregiving Coalition

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Today’s Agenda

• Understanding Caregiver Coalitions

• Best Practices & Coalition Examples

• Identifying Leadership, Goals, and Funding

• Example Policy Goals for State & Local Leaders
About the Alliance

• Nonprofit coalition of over 50 national organizations focused on family caregiving issues
• Established in 1996 to support family caregivers and the professionals who work with them
• NAC Activities:
  • Conduct research and policy analysis;
  • Develop national programs;
  • Strengthen state and local coalitions;
  • Increase public awareness;
  • International work and awareness.
What is a Caregiving Coalition?

• Community that addresses needs of family caregivers across the lifespan
• Includes families of origin and families of choice
• Typically offers information and referral services, educational outreach, and advocacy
• United community voice to meet social, medical, physical, financial, spiritual, and emotional needs of family caregivers
The Evolution of a Coalition

- Loosely organized support group for caregivers
- Formal 501(c)(3) that supports 100+ local caregivers, funded by community partners
- Identification of state laws or municipal regulations that can support family caregivers (such as flexible work policies)
- Advocacy – working with lawmakers and policy makers to recognize caregiver rights and provide formal support
Example – Long-Established

- State Legislature Visits
- Annual Caregiver Day at the State Capitol
- Annual Aging & Disabilities Issues guidebook
- Worked to establish the Kapuna Caucus to focus on caregiving issues

https://www.facebook.com/pages/Hawaii-Family-Caregiver-Coalition/308761075897425
Example – New Coalition

• Established by a former family caregiver
• Hosts annual Caregivers Respite Conference
• Recently began hosting “Listening Sessions” with policymakers and community leaders

http://caregiversrespite.org/
Step 1: Assessing the Need

• Gather information
  • Survey caregivers
  • Survey service providers
  • Survey of other community groups (stakeholders) who already provide a voice in caregiving
  • Formal feedback - Focus Groups, Town Halls
  • Informal feedback - Social Media polls
Step 2: Create Infrastructure

• Leadership
• Managers/Program Directors
• Volunteers
• Partners
• Funders
Example Coalition Structure: Collaborative

- Government or AAA
- Advocacy Groups
- Family Caregivers
- Consultants
- Healthcare Providers
- Services Providers
Example Coalition Structure: Traditional

- **Convener, CEO, or President**
  - **Fundraising**
    - Committee Chair or Director
    - Staff & Volunteers
  - **Program**
    - Committee Chair or Director
    - Staff & Volunteers
  - **Communication**
    - Committee Chair or Director
    - Staff & Volunteers
Step 3: Identify Goals

S.M.A.R.T. Goal

Program Leaders and Managers

Implementation

Funders & Partners

Communication Strategies

Measurement & Evaluation
Goal: Create a Caregiver Support Group

Implementation: How will the program work? Who will do the work?

Identify Funders & Partners

Communication Strategies: How will you tell your story?

Organization
- Tie-breaker?

Measurement & Evaluation: How can you show value?
Step 4: Identify Needed Resources

• Identify Funding Structure & Responsible Parties
  • Budgets, Audits, Records & Filings

• Estimate Program Expenses
  • Count Staff Time/Project Management as well as Direct and Indirect Expenses
  • Research costs to avoid overestimating or underestimating

• Identify In-Kind Support
Example Funding Structure—Outagamie Caregiver Coalition

- **Federal**
  - Older Americans Act National Family Caregiver Support

- **State**
  - Greater Wisconsin Agency on Aging Resources

- **County**
  - Outagamie County Aging and Disability Resource Center

http://www.youradrcresource.org/outagamiecounty.html
Example Funding Structure–Caregiver Coalition of NE Florida

• Started as an informal partnership of six organizations working together to offer free caregiver conferences
• Dedicated staff (in-kind donation from convening hospice organization)
• Corporate grants and sponsorships for events and programs

http://www.mycaregiverconnection.org/
Example Funding Structure – CaregiverU (AGE of Central Texas)

• 100% Foundation Funding
• Subsidiary of AGE of Central Texas, which is funded by grants and donations
• Dedicated staff person and in-kind donations, volunteers support
• Led by a Board of Directors

http://www.caregiverucentx.org/
Potential Funding Sources

- National Family Caregiver Support Program & Lifespan Respite Grants
  - Other Government Grants (USDA, CMMI, NIA)
- Foundation Grants
- Corporate Grants & Corporate Funding
- Individual Donors
- Membership Revenue
State Policy Goal Examples

• Rhode Island Temporary Caregiver Insurance Act

• The Caregiver Advise, Record, Enable (CARE) Act – Model State Legislation currently passed and in effect in 14 states: OK, CO, NJ, WV, NM, MS, VA, AK, CT, NV, IN, NH, OR, and RI

• Mississippi Caregiving Task Force

• Minnesota “Family Caregiver” category under the MN Human Rights Act*
Federal Policy Goal Examples

• Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiver Act

• National Care Corps Act – H.R. 2668

• Older Americans Act Reauthorization - S.192

• Social Security Caregiver Credit Act of 2014*

• Assisting Caregivers Today (ACT) Caucus
From the Data – Policy Goals

Figure 78: Helpfulness of Caregiving Support Policies

N20. Various organizations are thinking about ways to help caregivers like you. Which of the following do you think would be/have been helpful to you?

<table>
<thead>
<tr>
<th>Base: Caregivers of Recipient Age 18+ (n=1,248)</th>
<th>Hours Caregiving per Week</th>
</tr>
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<tbody>
<tr>
<td>Include caregiver name on recipient medical chart</td>
<td>0-20 (n=826) 21+ (n=416)</td>
</tr>
<tr>
<td>Require facilities to instruct medical/nursing tasks</td>
<td>49% 48% 52%</td>
</tr>
<tr>
<td>Require hospitals to inform you of major decisions</td>
<td>43% 42% 46%</td>
</tr>
<tr>
<td>Have respite services available</td>
<td>41% 41% 42%</td>
</tr>
<tr>
<td></td>
<td>33% 30% 41%*</td>
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</tbody>
</table>

From the Data – Financial Policies

Discussion Activity

• Have you approached a lawmaker about the issues facing caregivers in your state or city?

• What public policy solutions would benefit people in your community?

• How would you build a campaign to get people in your community involved with lawmakers?
Alliance Coalition Support

- Coalition Guidebooks
- Annual Conference
- Quarterly Webinar with National Experts
- One-on-One Coaching
- Caregiving Exchange Newsletter, Listserve, Facebook, Twitter & LinkedIn
- Seed Grants

Visit our website at [http://www.caregiving.org/coalitions](http://www.caregiving.org/coalitions) to learn more
Coalition Guidebooks

http://www.caregiving.org/coalitions/coalition-resources/
Thank You!

Interested in starting a Caregiving Coalition in your community? We want to hear from you!

Email Charlotte Dodge at charlotte@caregiving.org

or

Grace Whiting at gracewhiting@caregiving.org