



From Caring to Carer Advocate: How to Start and Sustain a Carer Organization

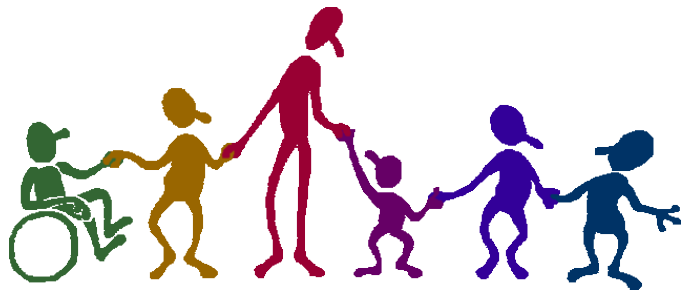
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Caregiving Coalitions

- 80+ grassroots coalitions in the U.S.
- The “typical” coalition
 - Focused on education and support, followed by advocacy
 - Sometimes affiliated with respite care coalitions or home care coalitions
 - Usually includes the local governments, healthcare providers, or social service providers
 - Disparate groups (e.g., rare disease, spousal caregivers) often rely primarily on online meeting spaces, like Facebook



Step 1: Understand How Carers Become Advocates



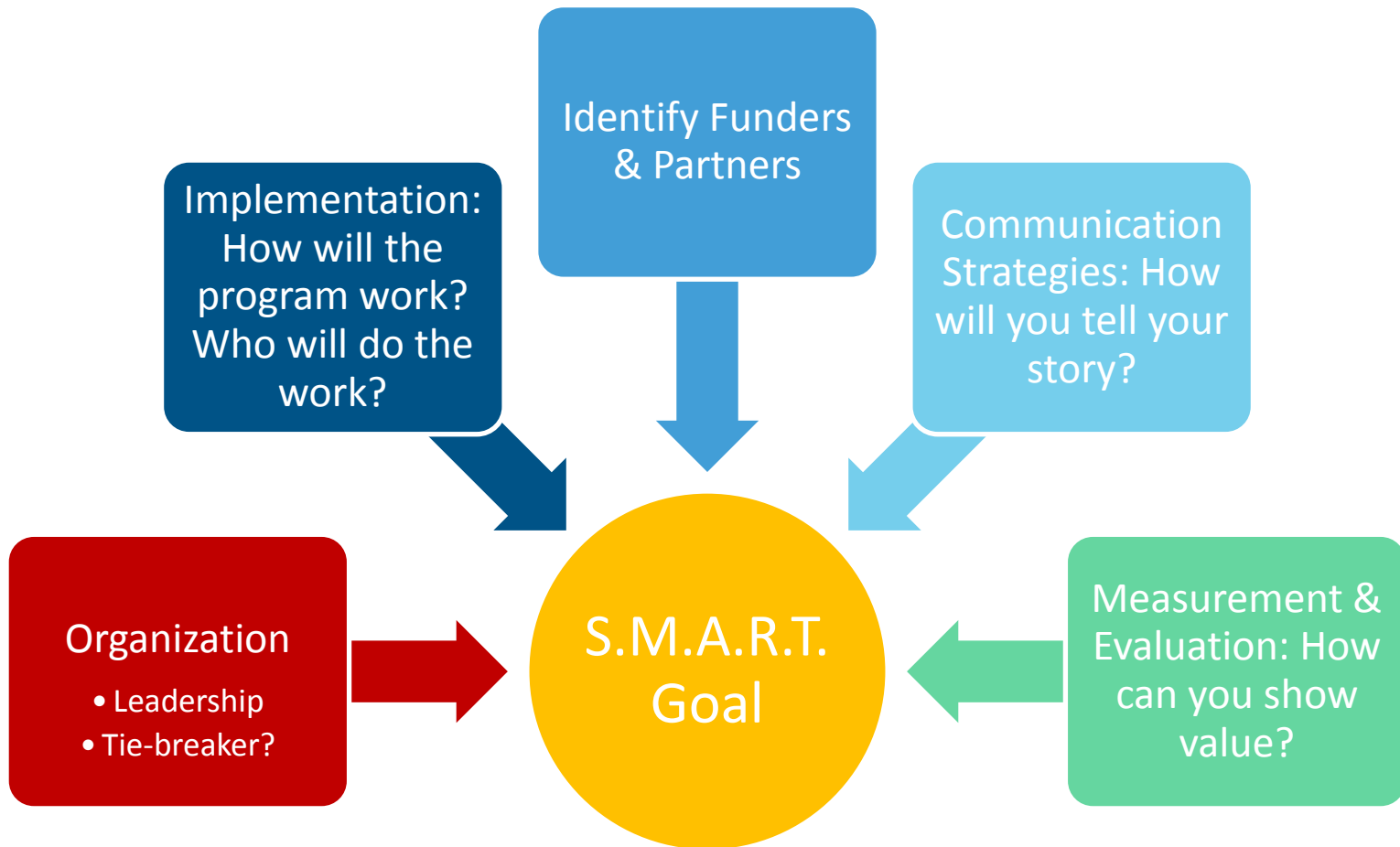
Caregiving begins, often overwhelming the caregiver and creating great stress

Patient-advocacy or self-advocacy occurs due to necessity, such as a parent trying to secure a particular treatment for their child, or a caregiver at work needing flex time

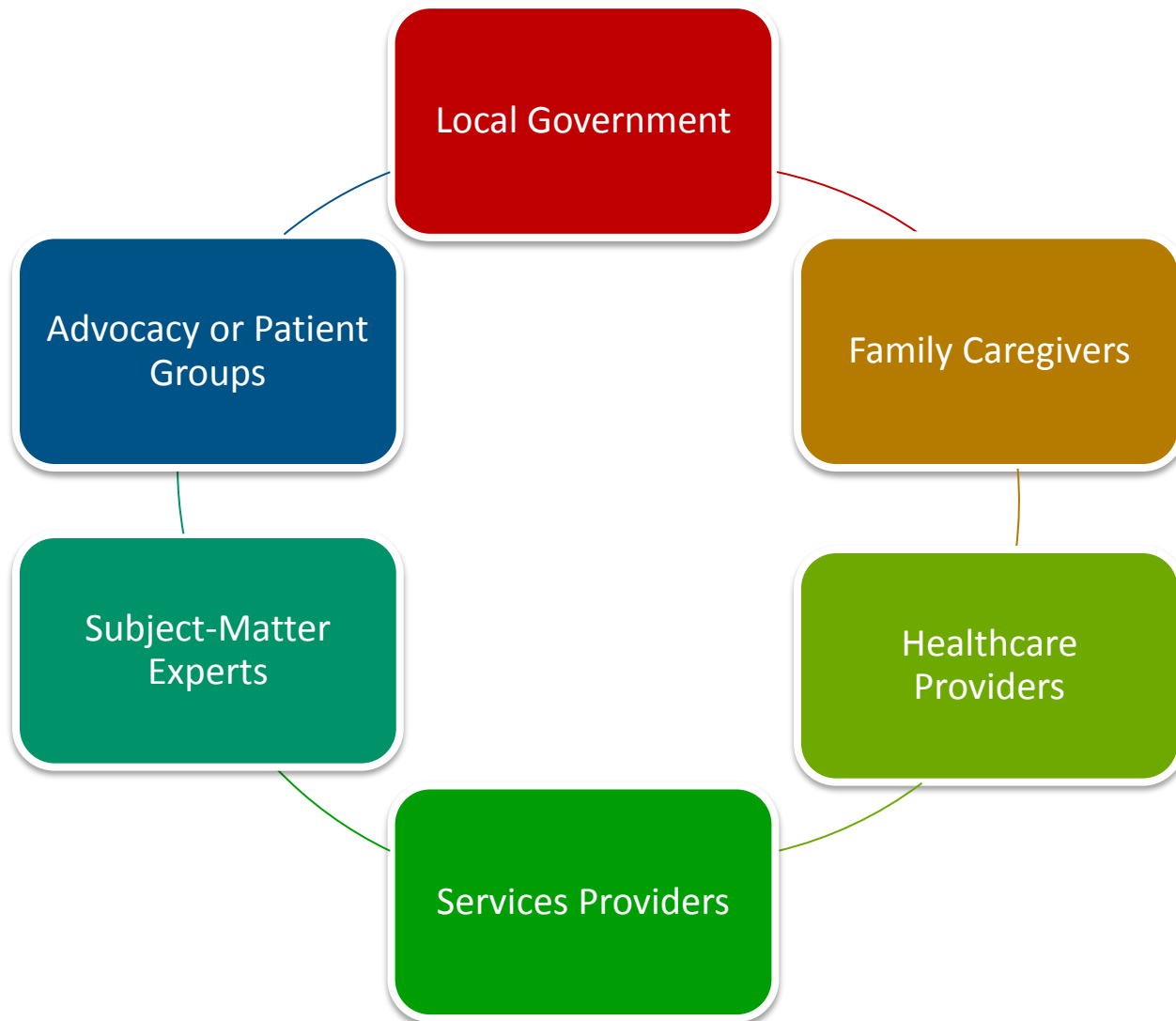
Self-Identification & Seeking Support The caregiver realizes they are going “above and beyond” normal care for a loved one and reaches out for support to caregiving coalitions, employers, medical provider, or community services

Advocacy As the caregiver burden lightens (due to connecting with services or the end of the caregiving role), there is a desire to speak publicly about the experience and improve the situation of other caregivers in similar situations

Step 2: Create Infrastructure



Typical Coalition Members



Example – Caregiving Coalition

- Started as an informal partnership of six organizations working together to offer free caregiver conferences
- Dedicated staff (in-kind donation from convening hospice organization)
- Reaches 1,500+ caregivers each year in northeast Florida
- Resources include an annual conference, workshops for caregivers and recipients, radio show and newsletter

<http://www.mycaregiverconnection.org/>



Step 3: Find Champions



Pilot Program: Champions Events



- 8 states across the U.S., with events reaching over 750 stakeholders
- 14+ state and national policymakers indentified Spurred conversations on caregiving, for example:
 - Georgia: Local human resource society made working caregivers a priority for 2015
 - New York, Minnesota: Used events as advocacy training for the state legislative session
 - Wisconsin: Major employers made aware of the issues facing caregivers in the workforce in their state

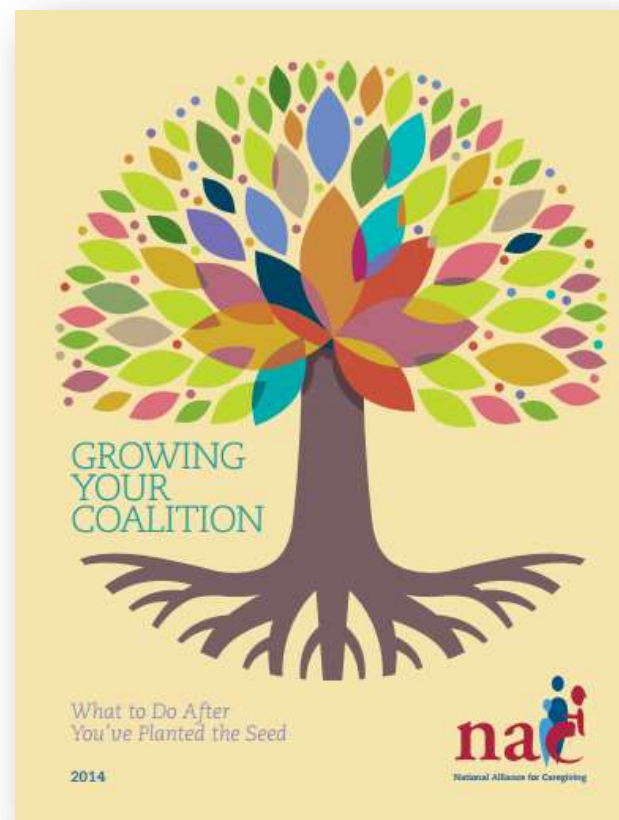
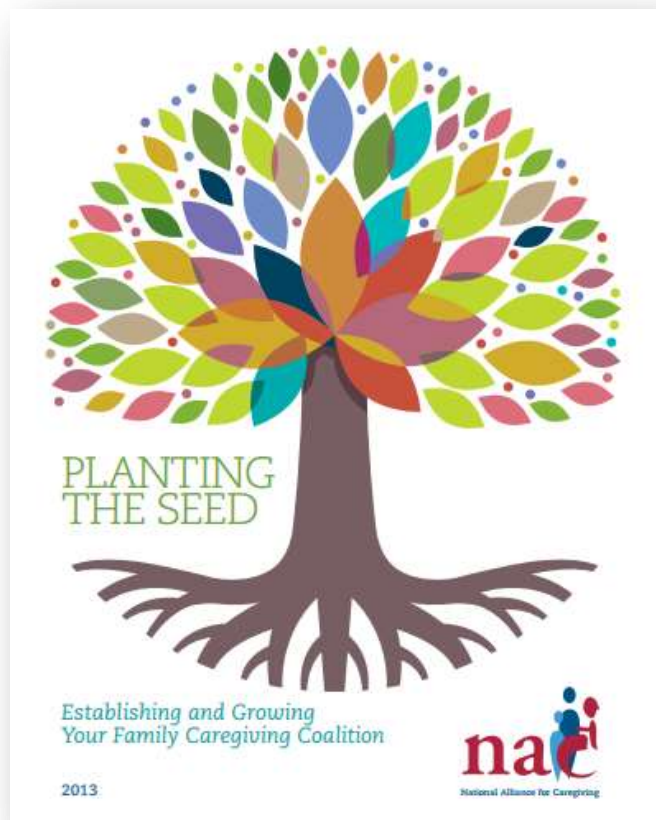


Case Study: Caregivers Respite Coalition

- Mentored by other coalition leaders and advocates
- Hosted a listening session with U.S. Congressional Representative Steve Cohen on caregivers in the workplace
- Event sparked additional events in July 2015
- Developed relationship with congressional staff and comfort with advocating on caregiving issues



Coalition Guidebooks



<http://www.caregiving.org/coalitions/coalition-resources/>

Thank You!

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