

Legislative Agenda for Respite Program Capacity Building Initiative



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Objectives



- Identify information to best assist attendees in educating legislators about Family Caregiving and Respite Care
- Describe how to keep momentum going across multiple years of limited results in expansion of service delivery
- Identify ways to work with state legislature as additional strategy strengthening federal Lifespan Respite Care Program

History of Respite Care in Maryland



- State Funded Respite Care – 1984
- Group of interested parties began 1997
 - ✦ *1st Respite Awareness Day in Maryland September 28, 1998*
 - ✦ *“A Need For All Seasons”*
- Established 501c3 in 2000
- Hosted 14 Annual Respite Awareness Day conferences
- Successful grant funding to support Respite activities
- Introduced legislation Maryland Family Caregiver Support Act
 - ✦ *Creates Maryland Family Caregivers Support Coordinating Council in Dept. Human Resources*
 - ✦ ***Now** Maryland Commission on Caregiving and Dept. of Human Services*

Engaging Legislators



- 2013 challenge from Senator Kelley
 - *Scope of issue and experience of Marylanders*
 - *Opportunities to reach other legislators, raise awareness*
- 2016 Task Force Report on Family Caregiving and Long Term Supports

Statewide Caregiver Survey



- **Methods**

- 2014-2015 online and paper-based survey, incl. Spanish
- Lifespan focus
- Leveraged a number of existing caregiver survey questions
- Caregivers were essential in the survey design
- Council members disseminated broadly throughout state

- **Responses**

- Approx. 1700 responses
- Achieved broad-geographic representation
- Reached a narrow demographic sample

Statewide Caregiver Survey (cont'd)



- **Quantitative Results (n ~ 1,700)**
 - Respite #1 need of caregivers
 - Burden is HIGH among those with greater access to resources (e.g. education, SES, employment)
 - ✦ Assume burden is higher among other groups
 - Emotional burden high, awareness of services low
 - More than half we surveyed work full time
 - 5-15% gave up work entirely
- **Qualitative Results (n=508)**
 - Need for more/better
 - ✦ Information and Access to Resources
 - ✦ Financial Assistance
 - ✦ In-Home Care
 - ✦ Self-Care/Opportunities for Social Interaction
 - ✦ Accessible, Affordable and/or Available Transportation
 - ✦ Better Trained and Available Workforce
 - ✦ Respite
 - Frustration with the system and available supports

Legislative Activity



- Painting results for local government:
 - ✦ Raise awareness of available services
 - ✦ Improve contact information on services
 - ✦ Work with gov't, employers, non-profits toward universal caregiver support options
 - ✦ Participation of 30+ community partners
- 2016 Legislative Session
 - ✦ New statute clauses
 - New members
 - Provide ongoing analysis of best practices in family caregiver support programs in this and other states
 - Monitor implementation of the Commission's recommendations
 - ✦ New name!

Commission vs. Coalition



Caregiver Commission/Council

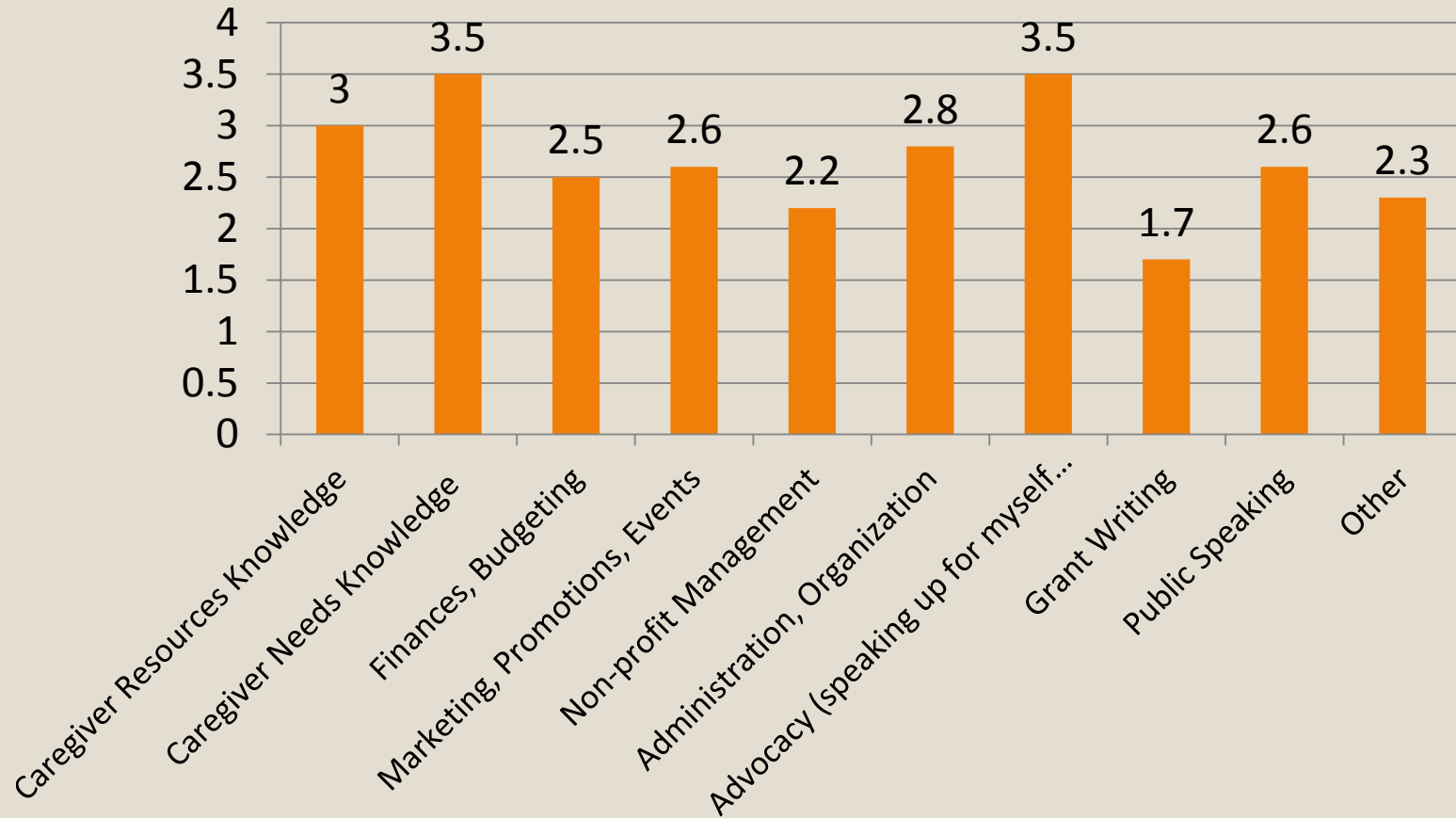
- Formal body requires participation of state government
- Purpose defined in law (mandate)
- Addresses broad caregiver needs

- Opportunities for collaboration
- Can be a member of both

Respite Coalition

- Community-based group determines its own structure
- Members determine mission, goals, activities, etc.
- Exclusive focus on Respite
- Only Organization named in Statute

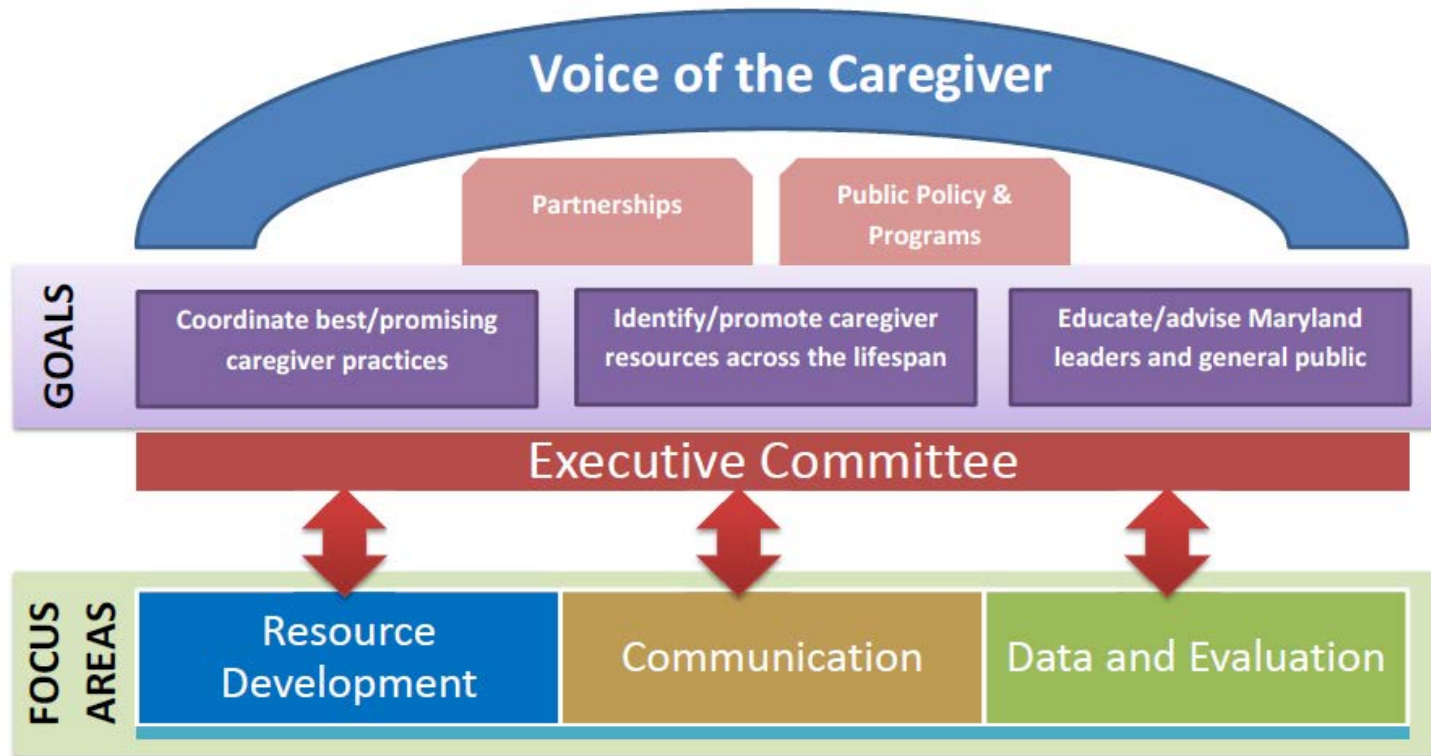
Individual Strengths



Strategic Plan 2018



Maryland Commission on Caregiving Strategic Plan FY18



Vision for Future



- Ongoing collaboration requires strategic planning and willingness to stay focused but open to new opportunities
- Succession Planning
- Open Discussion and Questions and Answers