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
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

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<thead>
<tr>
<th>Caregiver Commission/Council</th>
<th>Respite Coalition</th>
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<tbody>
<tr>
<td>• Formal body requires participation of state government</td>
<td>• Community-based group determines its own structure</td>
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<td>• Purpose defined in law (mandate)</td>
<td>• Members determine mission, goals, activities, etc.</td>
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<td>• Addresses broad caregiver needs</td>
<td>• Exclusive focus on Respite</td>
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<td>• Only Organization named in Statute</td>
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• Opportunities for collaboration
• Can be a member of both
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