Hitting the High Notes with Lifespan Respite: Progress at the Five-Year Point

16th Annual National Lifespan Respite Conference
October 9, 2014
Overview

• The Administration for Community Living (ACL)
• ACL and the Lifespan Respite Program
• Program status – Progress at the Five-Year Point
  – Accomplishments, outcomes & lessons learned
  – Looking ahead
"For too long, too many Americans have faced the impossible choice between moving to an institution or living at home without the long-term services and supports they need. The goal of the new Administration for Community Living will be to help people with disabilities and older Americans live productive, satisfying lives."

_Secretary Kathleen Sebelius_
About ACL

• The Administration for Community Living (ACL) is an operating division within the U.S. Department of Health & Human Services which brought together:
  • the Administration on Aging (AoA)
  • the Office on Disability (OD)
  • the Administration on Developmental Disabilities (ADD)

• ACL is charged with developing policies and improving supports for seniors and persons with disabilities of all ages.
Background

HHS established ACL to achieve several important objectives:

• Reduce the fragmentation that currently exists in federal programs addressing the community living service and support needs of older adults and persons with disabilities
• Enhance access to quality health care and long-term services and supports for all individuals
• Promote consistency in community living policy across other areas of the federal government
• Complement the community infrastructure, as supported by Medicaid and other federal programs, in order to better respond to the full spectrum of needs among these populations
ACL’s Mission & Vision

Mission

• Maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers.

Vision

• All people, regardless of age and disability, live with dignity, make their own choices, and participate fully in society.
ACL Today: Authorizing Statutes & Programs

- **Older Americans Act of 1965** (as amended)
- **Public Health Service Act Programs**
  - Section 398 – Alzheimer’s Disease Supportive Services Program (ADSSP)
  - Title XXIX – Lifespan Respite Care Program
- **Health Insurance Portability and Accountability Act of 1996** (HIPAA) – Health Care Fraud and Abuse Control (HCFAC) funds
  - Senior Medicare Patrol
- **Developmental Disabilities Assistance and Bill of Rights Act of 2000** (DD Act)
- **Help America Vote Act** (HAVA)
ACL & Lifespan Respite – A perfect fit!

- ACL and Lifespan Respite Program Objectives
  - Addresses fragmentation of (respite) programs and services
  - Focus on (respite) quality improvement
  - Cross-(respite)program/policy focus
  - Improve response to the (respite) needs of families

- Works across age and disability populations to maximize independence and well-being

- Family support as a key objective
THE LIFESPAN RESPITE PROGRAM
Federal Lifespan Respite Care Program

ACL/AoA administers competitive state grants for mandatory uses of the funds:

- Development or enhancement of State and local Lifespan Respite systems
- Planned or emergency respite for all ages
- Training and recruitment of providers/volunteers
- Provision of information to caregivers about respite services, and assistance in gaining access
Lifespan Respite Program Status

- 32 states and DC funded since 2009
  - Up to $200,000 for initial three year projects
  - Expansion supplements - 10 states (FYs 11 & 12)
- Technical Assistance Resource Center (FY 09 & 12)
- FY 2012 & 2013 – Integration and Sustainability Grants
  - Up to $250,000 each/18-month projects
  - Builds on the initial three-year grant
  - Focus on integrating respite/caregiver supports and sustainable approaches
- FY 2014 – One New State/16 Building Long-Term Sustainability
## Evolving Focus of Grantee Activities

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<th>Basic Infrastructure</th>
<th>Service Delivery Performance Measurement</th>
<th>Systems Integration &amp; Long-Term Sustainability</th>
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<tr>
<td>Environmental Scans &amp; Needs Assessments</td>
<td>Development of new service delivery models (e.g., vouchers, emergency respite programs)</td>
<td>Public/private partnerships to support community living</td>
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<td>Coalition building</td>
<td>Mini-grants to foster local solutions and innovation</td>
<td>Integration of respite across state LTSS programs</td>
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<td>Partnership development</td>
<td>Initial development and testing of performance and outcome metrics</td>
<td>Outreach to/inclusion of employers</td>
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<td>Statewide strategic planning</td>
<td>Provider recruitment and training</td>
<td>Greater focus on rural, minority, underserved populations</td>
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<td>Marketing, outreach, public awareness campaigns</td>
<td>More than 2000 family caregivers across the age and disability spectrum received respite services</td>
<td>Improved linkages with critical pathways for family caregivers</td>
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<td>ADRC expansion</td>
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<td>Coalition visibility and empowerment for better advocacy</td>
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<td>Respite registry development/expansion</td>
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<td>Measuring systems change</td>
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<td>Volunteer &amp; faith-based efforts</td>
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<td>New partnerships with higher education</td>
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<td>Caregiver education</td>
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What have we learned so far???

• It takes time....
• Partnership, partnership, partnership
• Look to model approaches
• Stay flexible
• Performance measurement from day one
• Sustainability focus from the beginning
LOOKING AHEAD
Program Sustainability

• Engage grassroots/community
• Embed grant activities into ongoing state LTSS reform efforts
• Grow and support State Respite Coalition to focus on sustainability
• Long-term strategic planning
• Supported through current TA efforts
Performance Measurement

• Need to demonstrate program success and progress
• Determine appropriate measures
  – Systems Change
  – Consumer Outcomes
• New reporting framework (eventually)
• Ongoing Technical Assistance
Building an Evidence-Base for Respite

- Expert Panel on Respite Research
- Annotated bibliography
- Recommendations for the future of respite research
- ARCH database of promising practices in respite
Contact Information

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