The Lifespan Respite Program

Brookdale Foundation Group
October 2014  Denver, CO
Presentation Overview

- Background on Family Caregiving
- What is respite and why is it important?
- Barriers to respite
- Lifespan Respite helps overcome barriers
- The federal Lifespan Respite program
- ARCH Resources for Relative Caregivers
Four in ten adults in the U.S. are caring for an adult or child with significant health issues, up from 30% in 2010.

Source: PEW Research Center, June 20, 2013
Family Caregiving is Lifespan!

Majority of family caregivers caring for someone under age 75 (56%).

- 28% of family caregivers care for someone age 50-75.
- 28% care for someone under age 50, including children.

Relatives as Caregivers

- 7.8 million children live in grandparents’ or other relatives’ homes.
- More than 2.5 million grandparents have primary responsibility for these children
- One child in 10 in the US lives with a grandparent, a share that increased slowly and steadily over a decade before rising sharply from 2007 to 2008.
Respite is...

 Planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

Lifespan Respite Care Act definition
PL 109-442
Benefits of Respite

- Improves family caregiver stress levels, which can affect physical and emotional health;
- Improves overall family well-being, family relationships and stability;
- Reduces hospital costs and helps avoid or delay more costly foster care, nursing home or other out-of-home placements.
Respite Benefits for Relative Caregivers

- Study shows respite can have benefits for relative caregivers who adopt, including:
  - substantially reduced stress levels
  - increased ability of caregivers to participate in social and recreational activities
  - reduction of risk factors that increase likelihood of abuse and neglect
Respite: Too Little, Too Late

- 89% of family caregivers do not receive respite.
- Of those who do, they receive too little, often too late.
- Respite needs to be meaningful for caregivers, as well as care receiver.
Respite Barriers

- Affordability
- Too few trained providers or respite options
- Reluctance to identify as caregiver or ask for help
- Multiple Funding Streams
- Confusing and Restrictive Eligibility Criteria
Challenges for Relative Caregivers

- Often more isolated than other family caregivers
- Face unique legal and financial challenges
- Children more likely to have disabilities
- Grandparent caregivers often face their own range of physical and mental health concerns
- Reluctance to use respite
Lifespan Respite ...not just care or a service, but.....

*Lifespan Respite Definition:*

- Coordinated **SYSTEMS** of accessible, community-based respite services for all family caregivers regardless of age or special need.
Characteristics of Lifespan Respite Programs

- Identify and coordinate existing respite resources/funding at state level
- Maximize use of existing resources/leverage new ones
- Identify service gaps to help create and monitor new respite services
- Connect families to respite services, providers, and payment resources
- Recruit and train respite providers
- Promote public awareness about respite
Federal Lifespan Respite Program
US Administration for Community Living, Administration on Aging administers competitive state grants for mandatory uses of 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 States (as of 2014)

2009 Lifespan Respite States
2010 Lifespan Respite States
2011 Lifespan Respite States
2012 Lifespan Respite States

2013 Lifespan Respite State
2014 Lifespan Respite State
2012 & 2013 Integration & Sustainability Grantees
2014 Long-Term Sustainability

Courtesy of Greg Link, ACL/AoA
Lifespan Respite Built on Collaboration

ADRC

State Respite Coalition

State Lead Agency

[Image: Diagram showing a circular flow between ADRC, State Respite Coalition, and State Lead Agency, indicating collaboration.]

[Image: ARCA National Respite Network logo]
State Respite Coalition Significance to Lifespan Respite Program

- Brings Age and Disability Diversity
- Brings Respite Expertise and Skills
- Ensures ongoing support for the program through advocacy
- State Respite Coalition provides best opportunity to get involved with improving respite in your state.
- Contacts at http://archrespite.org/state-respite-coalitions
## Evolving Focus of Grantee Activities

<table>
<thead>
<tr>
<th>Basic Infrastructure</th>
<th>Service Delivery</th>
<th>Systems Integration &amp; Long-Term Sustainability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Environmental Scans &amp; Needs Assessments</td>
<td>Development of new service delivery models (e.g., vouchers, emergency respite programs)</td>
<td>Integration of respite across state LTSS programs</td>
</tr>
<tr>
<td>Coalition building</td>
<td>Mini-grants to foster local solutions and innovation</td>
<td>Outreach to/inclusion of employers</td>
</tr>
<tr>
<td>Partnership development</td>
<td>Provider recruitment and training</td>
<td>Greater focus on rural, minority, underserved populations</td>
</tr>
<tr>
<td>Statewide strategic planning</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>
</tr>
<tr>
<td>Marketing, outreach, public awareness campaigns</td>
<td></td>
<td>Coalition visibility and empowerment for better advocacy</td>
</tr>
<tr>
<td>Respite registry development/expansion</td>
<td></td>
<td>Measuring systems change</td>
</tr>
<tr>
<td>Volunteer &amp; faith-based efforts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver education</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
ARCH Resources to Help Relative Caregivers

- Fact Sheet: Respite Services to Support Grandfamilies

- National Respite Locator Service
  - http://archrespite.org/respitelocator

- US Map of Respite Funding and Caregiver Supports
  - http://archrespite.org/respitelocator/respite-locator-service-state-information-map

- State Respite Coalitions
  - http://archrespite.org/state-respite-coalitions

- State Lifespan Respite grantee contacts
  - http://archrespite.org/lifespan-programs
For More Information

Maggie Edgar, MSW
Senior ARCH Consultant
206-632-5208
edgar@zipcon.net

ARCH National Respite Network and Resource Center
http://www.archrespite.org/

Lifespan Respite
Technical Assistance Center

This project is supported, in part, under a grant from the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. These contents, however, do not necessarily represent the policy of the U.S. Department of Health and Human Services and endorsement by the Federal government should not be assumed.