

RESPIRE FOR THE FAMILY CAREGIVER: WHAT IS IT AND HOW TO FIND IT

First Annual Older Americans Month
Senior Symposium
D.C. Office on Aging
Washington, DC



May 25, 2012

Family Caregiving in the US

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- ❑ **62 million unpaid family caregivers**
- ❑ **Provide 80% of long-term care in the US.**
- ❑ **Valued at over \$450 billion a year in uncompensated care, more than total Medicaid spending in 2009.**



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Family Caregiving in DC

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- ❑ In 2009, almost 100,000 family caregivers in DC provided 65 million hours of care.
- ❑ The value of their caregiving is estimated at \$760 million annually.
- ❑ But they cannot do it alone!

Source: Lynn Feinberg, L., Reinhard, Susan, C, Houser, A. and Choula, R. (2011). *Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving, 2011 Update*, AARP Public Policy Institute Issue Brief Insight on the Issues, Washington, DC: AARP

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Respite is...

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- ▣ ***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

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Benefits of Respite

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

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Respite: Too Little, Too Late

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- **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.**



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Barriers to Respite

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For All Family Caregivers

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- **Bureaucratic Maze of Funding Streams and Services**
- **Confusing and Restrictive Eligibility Criteria**
- **Affordability Issues**
- **Limited Providers**
- **Reluctance to identify as caregiver or ask for help**

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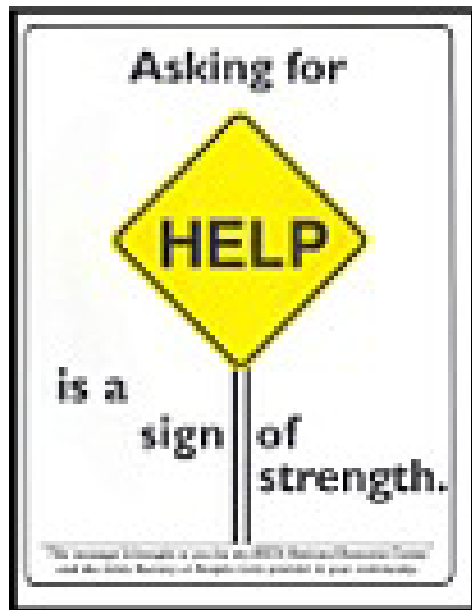
Do I Need Respite?



Everyone Needs Respite!

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- There may be signs that you are long overdue!



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Making Respite Work for You

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- Use early in your caregiving experience**
- Plan ahead if possible**
- Use as regularly and as frequently as possible**
- Make the best use of your respite time**

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What Types of Respite are There?

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- In-Home**
- Out-of Home**
- Volunteer**
- Community or Faith-Based**
- Consumer Directed**
- Facility Based**
- Emergency Respite**

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How do I pay for respite?

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- Medicaid Waiver: DC's waiver applied to adults with intellectual or developmental disabilities
- Family Caregiver Support Program
- Veterans Programs

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Assurances for Safe and Meaningful Respite

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- Telephone Screening
- Personal Interview
- Ask for and check references
- Evaluate costs and financing
- Write a contract that provides specific details

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Resources

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- **National Respite Guidelines**

<http://archrespite.org/productspublications/products-and-publications#Guidelines2011>

- **The ABCs of Respite: A Consumer Guide for Family Caregivers**

<http://archrespite.org/consumer-information>

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Where do I find respite?

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- National Respite Locator Service

www.respitelocator.org

- Veteran's Caregiver Support Program

1-855-260-3274 or www.caregiver.va.gov

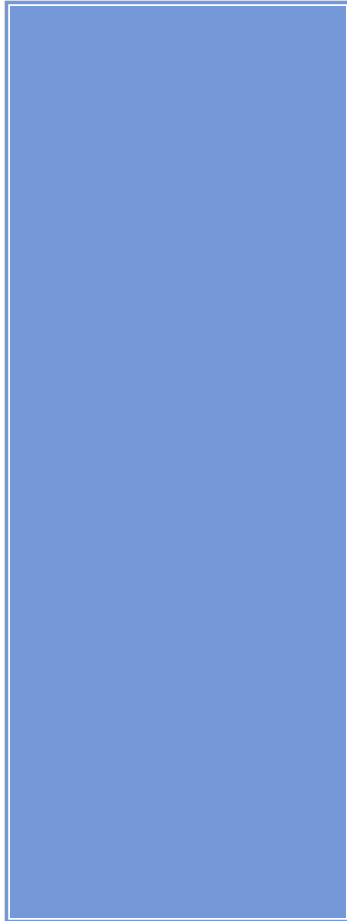
- DC Lifespan Respite/DC Respite Coalition

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What is Lifespan Respite?

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Lifespan Respite

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■ **Definition:**

Coordinated systems of accessible, community-based respite services for all family caregivers regardless of age or special need.

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Characteristics of Lifespan Respite Programs

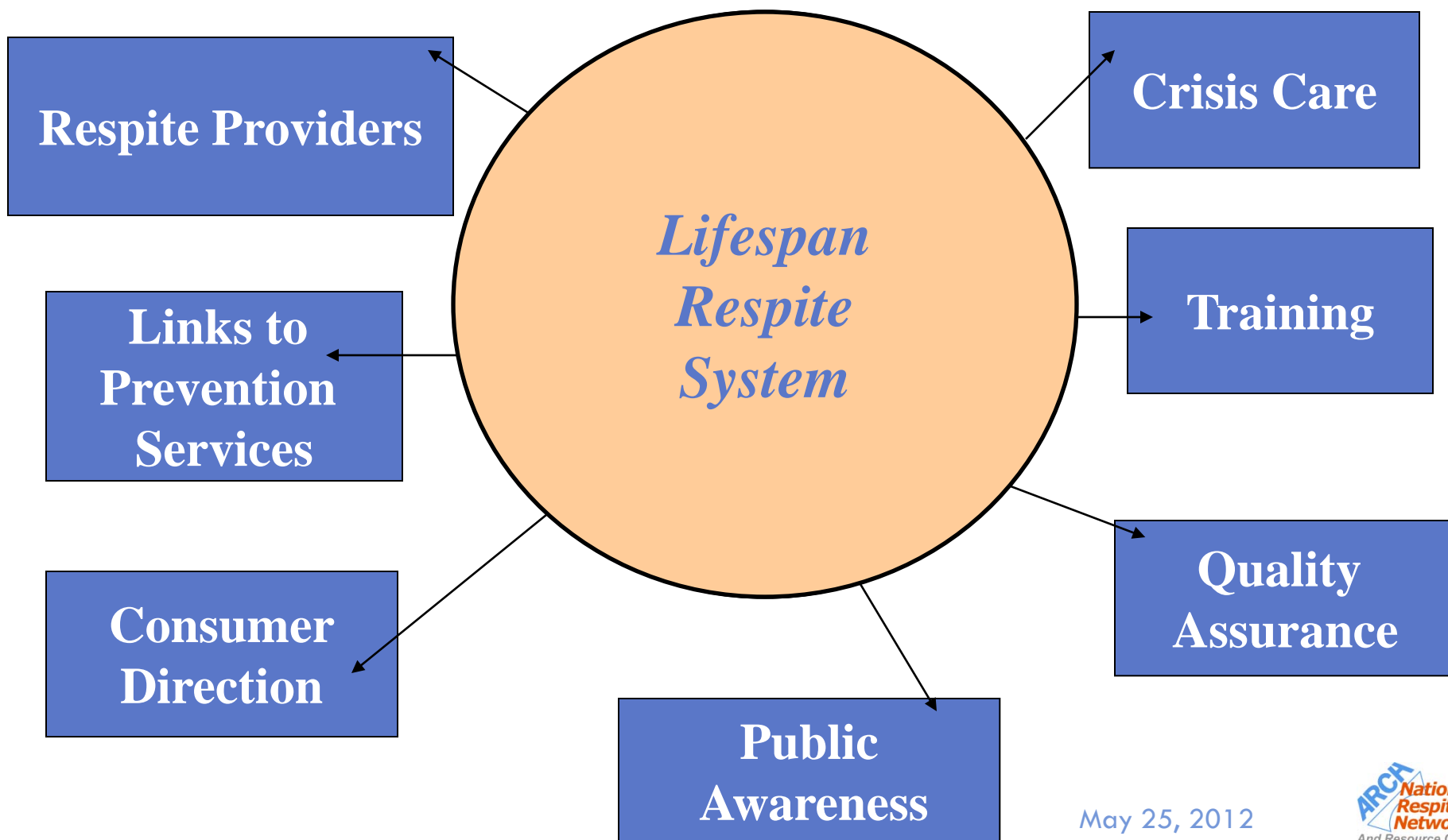
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- ❑ **Identify and coordinate existing respite resources at the state level**
- ❑ **Identify service gaps and create and monitor new respite services**
- ❑ **Recruit and train respite providers**
- ❑ **Connect families to respite services, providers, and payment resources**
- ❑ **Promote public awareness about respite**

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Perspective from the ~~Outside~~ *Inside*

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For More Information

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



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