ENGAGING THE CHILD ABUSE PREVENTION COMMUNITY IN STATE LIFESPAN RESPITE SYSTEMS

Preventing Child Maltreatment and
Promoting Well-Being
Network for Action
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Presenters

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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.***

In CBCAP, Respite is…..

Defined as short term care services provided in the temporary absence of the regular caregiver (parent, other relative, foster parent, adoptive parent, or guardian) to children who—

- (A) are in danger of abuse or neglect;
- (B) have experienced abuse or neglect; or
- (C) have disabilities, chronic, or terminal illnesses.

In CBCAP Respite is…..

Defined as short term care services, including crisis nurseries, provided in the temporary absence of the regular caregiver (parent, other relative, foster parent, adoptive parent, or guardian) to children who—

- (A) are in danger of abuse or neglect;
- (B) have experienced abuse or neglect; or
- (C) have disabilities, chronic, or terminal illnesses.

Children with Disabilities

- An estimated 9-15% of all children have some type of disability. Most recent survey found 13.9 percent of US children (approximately 10 million) had special health care needs (National Survey of CSHCN, U.S. HRSA, 2008).

- An estimated 4.5 to 6.3 million children and youth in the US suffer from a serious mental health condition (about 10%); about 65% to 80% of these children and youth do not receive the specialty mental health services and supports they need (SAMHSA, 2011).

Importance of Abuse and Neglect Prevention for this Population

- In 2009, children with disabilities accounted for11% of child victims of abuse and neglect. However, this is an undercount, as not every child receives a clinical diagnostic assessment from CPS (National Child Abuse and Neglect Data Systems, 2010).
- Children with disabilities almost 4 times more likely to be victims of neglect, physical or emotional abuse, and 3 times more likely to be sexually assaulted than children without disabilities.
- About 30% of children in foster care have severe emotional, behavioral, or developmental problems.
- Approximately 25% of children with disabilities acquired disability as a result of abuse; 52% of neglected children acquire a permanent disability.

Other Children at-risk

- More than six and a half million children living in households maintained by grandparents or other relatives.

- Estimates as high as 3.3 million children are witnesses to domestic violence each year. Child abuse occurs in 30 to 60 percent of family violence cases that involve families with children.

Previous CBCAP Law

SEC. *205 LOCAL PROGRAM REQUIREMENTS.*

(3) provide—

(A) **core** family resource and support services such as—

(i) parent education, mutual support and self help, and leadership services;

(ii) outreach services;

(iii) community and social service referrals; and

(iv) follow-up services;

(B) **other core services,** which must be provided or arranged for through contracts or agreements with other local agencies, including voluntary home visiting and **all forms of respite care services to the extent practicable**;

CBCAP Reauthorization

- **SEC. *205 LOCAL PROGRAM REQUIREMENTS.***

  *Provide for **core** child abuse and neglect prevention services, such as—*

  (i) parent education, mutual support and self help, and parent leadership services;

  (ii) respite care services;

  (iii) outreach and follow-up services, which may include Voluntary home visiting services; and

  (iv) community and social service referrals; and

Benefits of Respite

- **Improves family caregiver physical and emotional health and reduces stress levels;**
- **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.**

Evidence for Respite as Abuse Prevention Tool

- In a study of mostly grandparent caregivers of special needs adopted children in southern California, it was found that:
  - respite was associated with substantially reduced stress levels among caregivers;
  - improved family relationships;
  - increased ability of adoptive parents to participate in social and recreational activities; and
  - reduction of risk factors that increase likelihood of abuse and neglect, specifically, parental stress and strain on family relationships (ARCH, 2005).

Evidence

- An evaluation of five crisis nurseries in Illinois from 2000 to 2003 found that caregivers reported that perceptions of risk of maltreatment improved during each of the 3 years studied.
  - In 2003, 98% of the 745 caregivers completing evaluations reported a reduced risk of maltreatment, up from 73% of 248 caregivers who completed evaluations in 2001.
  - In FY 2003, 90% also reported a decrease in stress (Cole, S., Wehrmann, K., Dewar, G., Swinford, L., 2005).

Evidence

- In a study utilizing comparison groups of similar children at high risk for maltreatment in northern California, the study found that:
  - Parents who received crisis respite services had an increased number of CPS referrals because of a higher level of scrutiny by mandated reporters, but a statistically significant lower level of substantiated reports than children who did not receive crisis respite.
  - Over a quarter of the families using crisis respite thought it was likely that their children might have been placed in foster care had the nurseries not been available (ARCH National Respite Network, July 2007).

Access to Respite

- More than 80% of families caring for a child under 18 with a disability or chronic condition do not use respite.

- In a study of a nationally representative profile of children ages 0-17 Supplemental Security Income (SSI) because of a disability, only 8% reported using respite, but three quarters of families had unmet respite needs.

Examining Barriers to Respite

- Small Groups
- Read Scenarios
- Respond to Questions
- Report Back

What is Lifespan Respite?

Lifespan Respite

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

- **Original Lifespan Respite Programs for Best Practice: OR, OK, WI, and NE**

- **Twenty-four (24) New Federal Grantees**

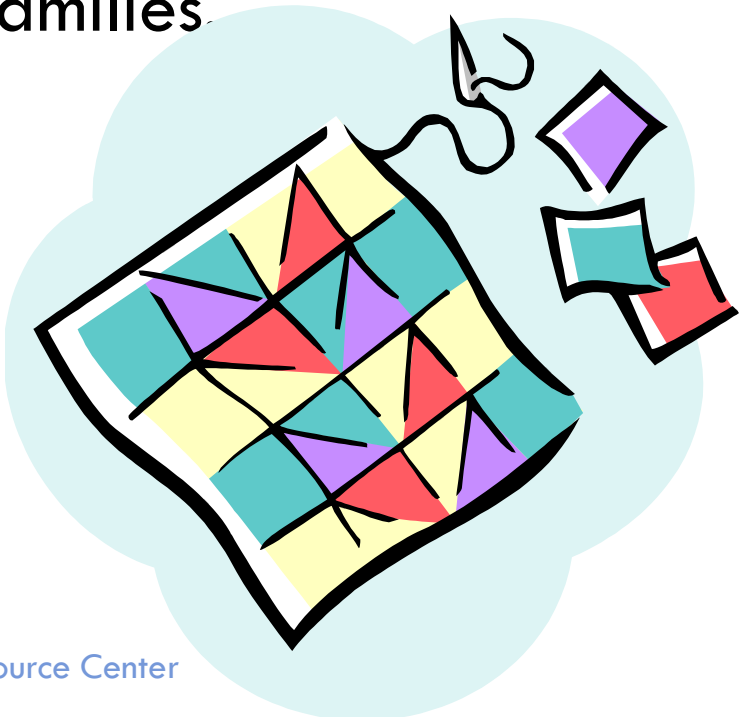
Why Do We Need Lifespan Respite Systems?

Barriers to Respite

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

Lifespan Respite is like a Quilt

- It weaves together important, but fragmented funding streams, disparate and duplicative programs, and silos to form a seamless system that makes barriers invisible to families.



Characteristics of Lifespan Respite Programs

- Identify and coordinate existing respite resources
- Identify service gaps and 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 Care Program

US Administration on Aging administers competitive state grants for these mandatory uses of the funds:

- **Development or enhancement of State and local Lifespan Respite systems**
- **Provision of planned or emergency respite for all ages**

Lifespan Respite Care Program (con't)

- Training and recruitment of providers/volunteers
- Provision of information to caregivers about available respite and support services, and assistance in gaining access to such services

Lifespan Respite Programs Must…

- Advance State's Ability to Meet Respite Needs
- Serve all Population/Disability Groups
- Coordinate With, and on Behalf of, Existing Respite Programs and Infrastructures
- Have a Consumer Focus
- Demonstrate Stakeholder Collaboration

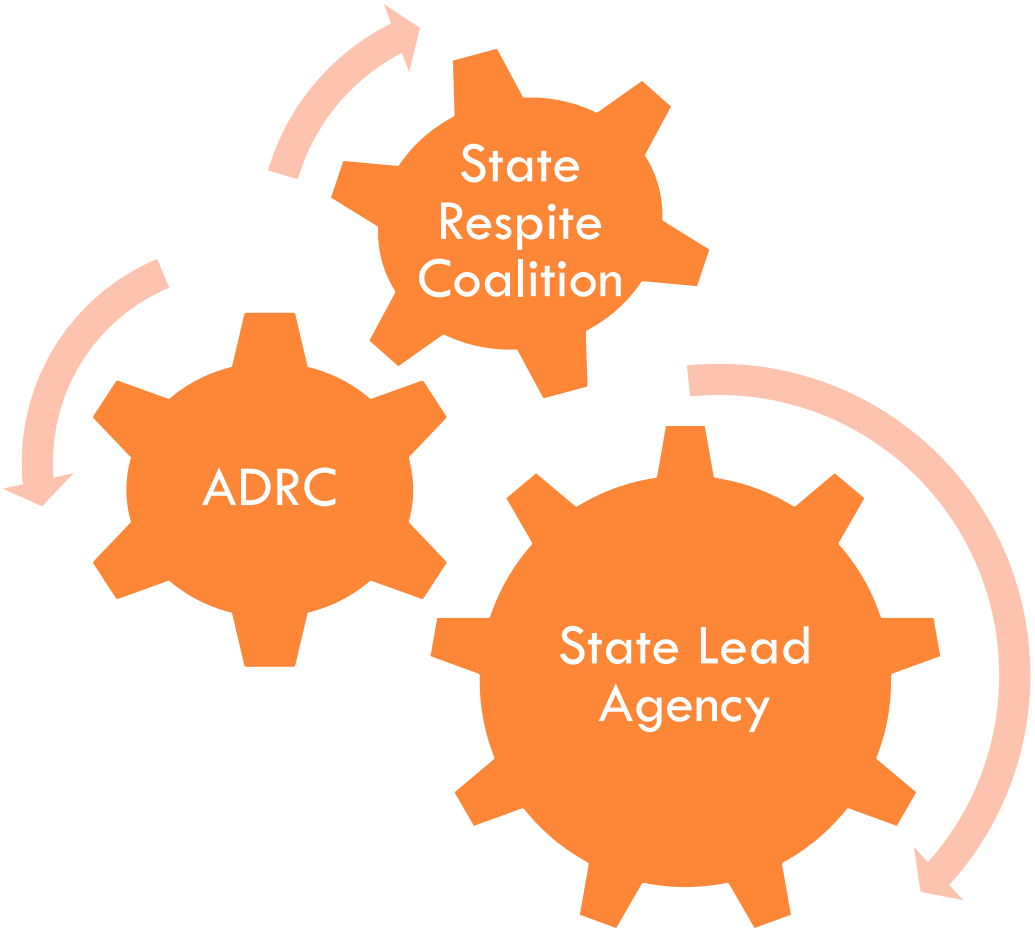
State Lead Agency

- **Eligible State Lead Entities**
  - State Units on Aging
  - State Medicaid Agencies
  - Other State Agencies

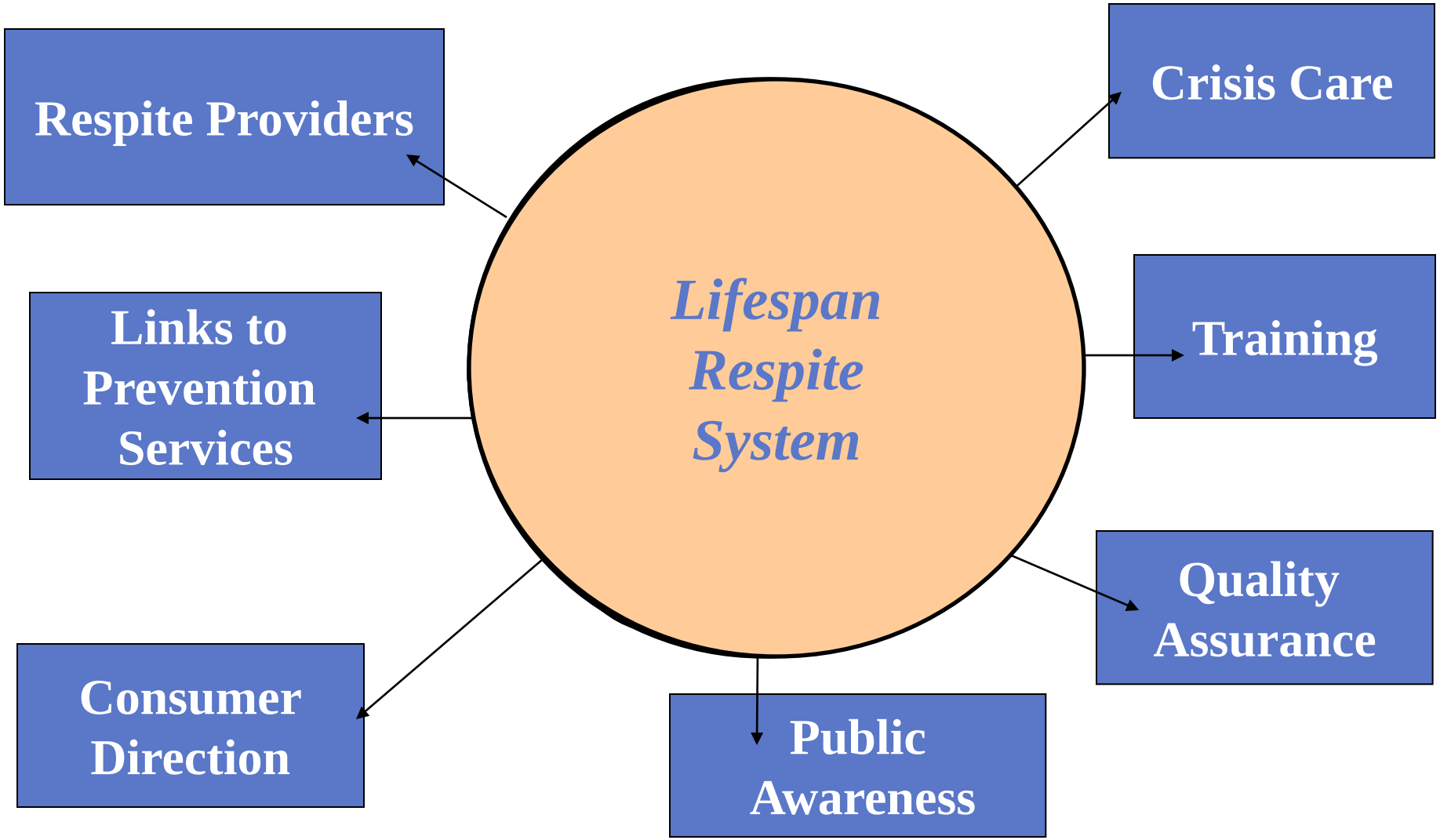
In concert with…

- Aging and Disability Resource Centers
- State Lifespan Respite Coalition

Roles of State Respite Coalitions and ADRCs



Perspective from the ~~Outside~~ *Inside*



For More Information

- ARCH National Respite Network and Resource Center

  http://www.archrespite.org/

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