Lifespan Respite 101: An Historical Look Back
Lifespan Respite “101”: An Introduction to Best Practices Webinar

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Department of Health and Human Services
Lincoln, NE

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Oklahoma Respite Resource Network
Developmental Disabilities Services Division
Oklahoma City, OK
Agenda

- Greg Link, AoA  
  Welcome

- Jill Kagan, ARCH  
  What is Lifespan Respite?

- May Martin, OR  
  Oregon Lifespan Respite Program

- Marcia Alber  
  Nebraska Lifespan Respite Program

- Rose Ann Percival  
  Oklahoma Lifespan Respite Program

- Jill Kagan  
  Legislative Overview and Program Implementation

- Questions

Caregiver Programs & Lifespan Respite: Technical Assistance Centers

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Family Caregiving in the US

- 65.7 million unpaid family caregivers
- Provide 80% of long-term care in the US.
- Valued at over $375 billion a year in uncompensated care, more than what was spent on Medicaid in 2007.
Family Caregiving Across Ages and Conditions

- Majority of family caregivers caring for someone under age 75 (56%).
  - 28% of family caregivers caring for someone between the ages of 50-75.
  - 28% are caring for someone under age 50, including children.

Lifespan Respite

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

- State-funded Statewide Programs up and running in OR, WI, NE, OK.
- Newer programs authorized in AZ & Texas
- Twelve New Federal Grantees
Why Do We Need Lifespan Respite Systems?

- Confusing Eligibility Criteria
- Affordability Issues
- Limited Providers
- Trust
- Bureaucratic Maze of Funding Streams and Services
Building Blocks for Lifespan Respite

- Medicaid Waivers and Medicaid Amendments in Deficit Reduction Act of 05
- National Family Caregiver Support Program
- Block Grants (TANF, Maternal and Child Health, Social Services, Children’s Mental Health)
- Federal Categorical Funding Streams, such as CAPTA, Family Support, Alzheimer’s Demos
- State Respite or Family Caregiver Support Programs
Characteristics of State Lifespan Respite Programs

- Identify and coordinate existing respite resources
- Identify service gaps and create and monitor new respite services
- Recruit, train, and pool paid and volunteer respite providers
Characteristics of State Lifespan Respite Programs (con’t)

- Provide public awareness information
- Connect families with respite payment resources, providers, and training to promote consumer direction.
Examples of State Lifespan Respite Systems

Oregon

Nebraska

Oklahoma

Please type in questions in the question box at any time and they will be answered at the conclusion of the last presentation.
Oregon’s Lifespan Program: Structure

- **State Agency:** In 1997, Oregon Department of Human Services (DHS) charged by state law to develop statewide respite coordination

- **Local Structure:** DHS works directly with 22 local respite networks (LRNs) serving all 36 counties in Oregon

- **State Advisory Council**
Oregon’s Lifespan Program: Client Services

- Connect families to respite services
- Recruit respite providers
- Coordinate access to respite payment resources and respite providers
- Facilitate access to training for families and respite providers
- Promote awareness about respite care
Oregon’s Lifespan Program: Who is Served

Care Recipients Served by Age
FY 2008-09

- Children 0-12: 35%
- Adolescents 13-17: 6%
- Adults 18-59: 12%
- Seniors 60-75: 17%
- Elderly 76+: 30%

March 3, 2010
Please mute your phone by pressing *6
Oregon’s Lifespan Program: Who is Served
Care Recipients Served by Special Needs
FY 2008-09

- Developmental disability: 18%
- Physical disability: 11%
- Mental, Emotional and/or behavioral disorder: 15%
- Alzheimer's disease dementia related disorders: 14%
- At risk of abuse and/or neglect: 8%
- Medically Fragile: 6%
- Elderly Frail: 3%
- Chronic Illness: 5%
- No disability or special need: 3%
- Other/Not Reported: 12%
- No disability or special need: 8%

March 3, 2010
Oregon’s Lifespan Program: Provider Training and Recruitment

- LRNs maintain own database of recruited paid and volunteer respite providers, or use existing statewide registries: Home Care Commission (HCC), Child Care Resource & Referral (CCR & R)

- Recruitment: various community activities, ESD, higher ed programs

- Training: DHS/CW, HCC, CCR & R, various agencies serving different populations
Oregon’s Lifespan Program: State Funding for Infrastructure

$1,034,000 (2009-11) for 22 local networks

- Start-up funds for a community-based system of local respite services
- Exclusively for program development and staffing
- Local Advisory Councils
Oregon’s Lifespan Program: State Funding for Client Respite

- DD Family Support Services (children 0-17)
- Commission on Children and Families
- Oregon Project Independence (adults 60+ or Alzheimer’s/dementia & other criteria)

** Other non-state funds generated locally: private donations, foundations, cooperative system
Oregon’s Lifespan Program: Federal Funding for Client Respite

- DD In-Home Services (children intensive in-home)
- DD Brokerage Supports Services (adults 18+)
- DD In-Home Services (adults’ comprehensive)
- DD Crisis/Diversion (children & adults)
- MH Services through Oregon Health Plan
- Family Caregiver Support Program (OAA)
- Community Services Block Grant (ARRA)
Nebraska’s Lifespan Program: Structure for Coordination

- *Nebraska* Lifespan Respite Services Program created by legislation in 1999
  - Lifespan Respite Network
  - Lifespan Respite Subsidy (up to 312% of poverty)
- *State Agency*: Implemented by Nebraska Department of Health & Human Services (DHHS)
Respite Network Map

- **Local Structure**: HHSS contracts with six (6) regional entities to form the Lifespan Network.
Nebraska’s Lifespan Program: Services

Each Regional Entity is Responsible for:

- Information and referral – match family to provider
- Provider Recruitment
- Provider and Consumer Training
- Quality assurance and program evaluation
- Public awareness
Nebraska’s Lifespan Program: Provider Training and Recruitment

- Ensure consumer and provider Training by coordinating existing resources and recruiting additional resources
- Local Networks Required to Offer Training
- Training Methods:
  - Video Conferences using TeleHealth Network;
  - Paying for caregivers and or providers to attend diagnosis-specific trainings and/or conferences;
  - Developed training in cooperation with Community College;
  - Paying for Nursing assistance classes for both caregivers and providers; and
  - Partnering with other organizations to sponsor training (e.g. Alzheimer’s, Autism, AAA, and others)
Nebraska’s Lifespan Program: Who is Served

- Eligibility Categories
  - Lifespan
  - Special need
  - Continuous ongoing care

- Disability categories by percentage served

<table>
<thead>
<tr>
<th>Disability Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental Disabilities</td>
<td>20%</td>
</tr>
<tr>
<td>Behavior Disorders</td>
<td>16%</td>
</tr>
<tr>
<td>Alzheimer/Dementia</td>
<td>9%</td>
</tr>
<tr>
<td>Autism</td>
<td>8%</td>
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<tr>
<td>Multiple Impairments</td>
<td>7%</td>
</tr>
<tr>
<td>Brain Injury</td>
<td>6%</td>
</tr>
<tr>
<td>Neurological Disabilities</td>
<td>4%</td>
</tr>
<tr>
<td>Orthopedic Impairments</td>
<td>4%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>4%</td>
</tr>
<tr>
<td>Heart Condition</td>
<td>4%</td>
</tr>
<tr>
<td>Speech-Language Impairments</td>
<td>3%</td>
</tr>
<tr>
<td>Parkinson</td>
<td>2%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2%</td>
</tr>
<tr>
<td>Visual Impairments</td>
<td>2%</td>
</tr>
<tr>
<td>Cancer</td>
<td>2%</td>
</tr>
<tr>
<td>Respiratory System Disorder</td>
<td>1.5%</td>
</tr>
<tr>
<td>Arthritis</td>
<td>1%</td>
</tr>
<tr>
<td>Hearing Impairments</td>
<td>1%</td>
</tr>
<tr>
<td>Spinal Disorder/Injury</td>
<td>0.5%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
</tr>
</tbody>
</table>
Ages Served (%)

# Respite Cases

- Under 19
- 19 - 59
- 60 or Older

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Nebraska’s Lifespan Program: Funding

• Infrastructure Funding
  - Tobacco Settlement Funds ($255,000)
  - State General Funds ($210,000)
  - Federal Administrative Medicaid Match ($184,000)
  - IDEA Early Intervention ($50,000)

• State Funding Streams for Client Respite
  - Tobacco Settlement Funds ($810,000)
  - Developmental Disabilities State General Funding

• Federal Funding Streams for Client Respite:
  - Medicaid Waivers
  - Social Services Block Grant
  - Title III of Older Americans Act (Family Caregiver Support)
Oklahoma’s Lifespan Program: Structure

- **State Agency**: Oklahoma Respite Resource Network (ORRN) is a statewide partnership of public and private agencies.

- Partnering State Agencies include: developmental disabilities, aging services, mental health, aging, maternal and child health and others.
Oklahoma Structure

- No local/regional structure

- ORRN relies on a statewide resource and referral system (OASIS) through an 800 toll-free number to link families to the program, to respite services and to training opportunities.
Caregivers are eligible for respite vouchers of $200-400 every three months as long as funds are available. By using OASIS, caregivers receive information on other services and supports besides respite. If a caregiver has a problem with the voucher process, OASIS is available to assist, or to refer, the caregiver to the appropriate approver. The number for the OKDHS Finance Division staff person responsible for issuing and paying respite vouchers is on all correspondence sent to caregivers.
Oklahoma’s Lifespan Program: Who is Served

- Disability categories by percentage served

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGING – 55+</td>
<td>62%</td>
</tr>
<tr>
<td>DDSD – All Ages</td>
<td>16%</td>
</tr>
<tr>
<td>MI – Children (all disabilities)</td>
<td>14%</td>
</tr>
<tr>
<td>FSS – Children (deemed to have disability by SSA)</td>
<td>8%</td>
</tr>
</tbody>
</table>

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Ages by percentages served

- Under 18: 37.2%
- 18 - 55: 11.4%
- 55 - 70: 6.8%
- Over 70: 44.6%
Oklahoma’s Lifespan Program: Eligibility
(corresponds to funding stream criteria)

- Grandparents over age 55 raising grandchildren with developmental disability or other relatives as parent.

- Family Caregivers including spouses, adult children or other relative caring for a person age 60 or older who needs assistance with daily living due to chronic health problems including Alzheimer’s, dementia or other condition.

- Families who have adopted a child with special health care needs who was once in the custody of the Dept. of Human Services (DHS).
Eligibility (con’t)

• Families with a member of any age with a developmental disability and NOT receiving either the Home & Community Based Waiver, the In-Home Support Waiver; or the Family Support Subsidy ($250 monthly payment).

• Families who have a child receiving SSI and services through the SSI Disabled Children's Program (DCP) at DHS.

• Two-parent families with a child with emotional, physical or developmental disabilities
Oklahoma’s Lifespan Program: Provider Training and Recruitment

• No Formal Training Packet or Certification Process
• ORRN Recognizes Family Caregiver as Expert Trainer
• ORRN Partners Provide Training to Family Caregivers and Providers at No Cost
  ➢ OK State Department of Human Services
  ➢ OK State Department of Health
  ➢ OK Department of Rehabilitation
  ➢ OK Department of Mental Health
• Caregivers Can Use Voucher Dollars to Pay for Provider’s Time While Receiving Training
Oklahoma’s Lifespan Program: Funding

- OKDHS acts as fiscal intermediary for respite voucher program. All funds received from partners placed in interest bearing accounts until used.

- Federal Funding Streams for Client Respite
  - Older Americans Act
  - Maternal Child Health Funds
  - TANF Maintenance of Effort Funds
  - Title 4E/Adoptions & Foster Parents
  - Mental Health Systems of Care Funds

- State Funding Streams for Client Respite
  - Aging Services Division
  - Developmental Disabilities Services Division
  - Family Support
The Road to Federal Legislation
Lifespan Respite Care Act of 2006

- Advocacy
- Signed on December 21, 2006
- Based on Model State Programs
- Establishes Respite as a National Priority
Lifespan Respite Care Act

Provides 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 Act (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
Who is Eligible for Lifespan Respite?

Family members of any age, foster parents or other adults (18+) providing **unpaid** care to:

- Adults and children of all ages with all disabling and chronic conditions
State Lead Agency

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

In concert with...

- Aging and Disability Resource Centers
- State Lifespan Respite Coalition
Current Status

Congress appropriated $2.5 million for FY 2009

Twelve New State grantees announced

September 24, 2009
Program Implementation
FY 2009 Lifespan Respite Care Program State Grantees

- Alabama
- Arizona
- Connecticut
- District of Columbia
- Illinois
- Nevada
- New Hampshire
- North Carolina
- Rhode Island
- South Carolina
- Tennessee
- Texas

For more information about the Lifespan Respite Care Program and the FY 2009 Grantees, see http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/LRCP/index.aspx
FY 2009 Grantee Activities: Examples

- Identification & centralization of all respite and caregiver training resources in the state
- Coordination of emergency respite with APS
- Connect the Coalition to the work of ADRCs and AAAs
- Creation of a statewide 800-respite number
- Create a “Respite Care Network” as an information portal
- Modify existing direct support training models for use with respite providers
- Creation of a statewide “Respite Coordination Center”
FY 2010

Congress appropriates $2.5 million for FY 2010

AoA Program Announcement
Expected April 2010
State Role: Getting Ready to Implement Lifespan Respite
Questions to Consider

1. What should our state Lifespan Respite System look like and what should it provide?

2. How do we build or strengthen our state respite coalition? What role will it play?
3. What will be the role of the ADRC?

4. What are the short and long term goals we need to reach to become a Lifespan Respite state?
Mandated Collaboration: What does it Mean for Your State?

- The State’s Application must include:
  - Memorandum of agreement regarding the Joint responsibility for the eligible State agency's Lifespan Respite program between the eligible State agency and a public or private nonprofit statewide respite coalition or organization.
Role of State Respite Coalitions

- **Current State Respite Coalition Activities:** Advocacy, Networking, Provider Recruitment and Training, I&R, Fundraising, Voucher Programs

- **Role in New Programs:** Main portal for respite referrals; building respite data bases; helping establish State Task Forces or Advisory Groups

March 3, 2010
Role of ADRCs

- Outreach
- Respite information clearinghouse and dissemination
- Caregiver training
- Respite hotline
- Advisory role
- Program Administration
Getting Started

- Prepare for Funding and Application Writing
  - Develop relationships, enhance collaborations with Coalitions, Governor’s office, State Agencies
  - Research and Identify Current State Respite Needs/Barriers/Funding Sources
  - Collaborate to Design Your State’s Program – What should it look like??
Supporting Documents & TA

- For a copy of the Lifespan Respite Care Act Public Law 109-442, see http://www.archrespite.org/PublicLaw.pdf
- Last year’s AoA Program Announcement and ARCH Lifespan Respite Training and TA, see http://chtop.org/ARCH/Lifespan-T/TA.html
Live Questions
(read by Emily Turner, Organizer)
or
Email Questions to be answered later to Jill Kagan at ARCH
jbkagan@verizon.net
703-256-2084

Thank you for joining us today