



# Statewide Lifespan Respite Programs: A Study of 4 State Programs

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*The mission of the ARCH National Respite Network is to assist and promote the development of quality respite and crisis care programs; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.*

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## Executive Summary

The nation is on the verge of major changes that will affect long-term care and the health of the nation's families. An estimated 25 million family caregivers provide significant care at home to spouses, young and adult children and other relatives and friends. When families caring for children with disabling and chronic conditions are taken into account, the number is significantly higher. While families overwhelmingly choose to provide this loving care at home and enjoy tremendous gratification as a result, there are many family caregivers who do so at enormous cost to their own and their families' health and well-being.

Respite is the family support service most frequently requested by family caregivers to help them continue to provide this care at home. As the ARCH National Resource Center for Respite and Crisis Care (ARCH) has demonstrated through an outcome evaluation study, respite has proven to help reduce or delay more costly out-of-home placements, improve caregiver's health and well-being, prevent abuse or neglect, and help sustain marriages.

State policy makers are often trend setters in identifying and implementing successful strategies to help families. Such is the case with State Lifespan Respite Programs (LRPs), which have paved the way for establishing a national respite policy. Lifespan Respite Programs are coordinated systems of accessible, community-based respite services for family caregivers and individuals regardless of age, race, ethnicity, special need or situation.

When considering federal policy, or when implementing new programs, the availability of best practice information is critical to decision making and program planning. It is with this intention that ARCH endeavored to secure the most current information about the existing State Lifespan Respite Programs by conducting state surveys and follow-up interviews. While only four states have implemented State Lifespan Programs (OR, NE, WI, OK), several salient findings have emerged from early lessons learned.

### **Highlights:**

- A state level program with a focus on respite is welcomed by state and local agencies across disciplines and age groups and is helping to improve access to services for families previously unserved or underserved.
- Lifespan Respite Programs report savings to the state in reduced administrative costs and sharing of resources.
- A high level of collaboration is illustrated by strong working relationships between the Lifespan Respite Program and other federal and state respite funding streams, including Medicaid and/or the National Family Caregiver Support Program.
- Lifespan Respite Programs have as their primary goal to assist families who otherwise would fall through the cracks with finding and using respite services. While there may be income eligibility restrictions for financial assistance, everyone is eligible for information and referral, and most programs tailor assistance in finding and matching families and respite providers. All families and caregivers benefit from the coordinated approach that eases the burden on families to find and use respite services.
- Such collaborative efforts have allowed states to maximize use of existing resources and leverage new dollars from public and private sources.
- All state LRPs report that they maintain a unique ability to respond to specific shortages or gaps in respite services as current resources allow, and most offer recruitment and training opportunities to enhance and improve the supply of available respite services.

- All states report that they were able to initiate and establish state and local infrastructures with minimal cost.
- Critical to the success of the Lifespan Respite Program is the flexibility allowed in designating an administering state agency and how it is run locally. Each program is unique in its design, administration and even in services offered based on state and local community and family needs.
- A willingness to collaborate, share resources and generally buy-in to the Lifespan Respite approach without fear of losing control over limited resources is still high among participating state and local agencies. However, in light of recent state economic hardships, and significant cuts to collaborating programs, such as Medicaid or Developmental Disabilities, many Lifespan Respite Programs report feeling the pinch. States are reporting unserved or underserved populations, including children and adults under 60 with mental health conditions and developmental disabilities, people under the age of 60 with MS, acquired brain injury, chronic and terminal illnesses, and grandparents under the age of 60 raising a child with no disabilities.

## Introduction

Respite has been shown to be a key component – one that families and caregivers most often request – of child care, elder care, comprehensive family support, family caregiver, health and long term care, family violence or child abuse prevention strategies. Yet respite remains in critically short supply for all age groups, for all families in crisis, and for caregivers of the elderly and individuals with disabilities. Without respite and other supports for family caregivers, many older individuals as well as children and adults with disabilities are more likely to receive more costly care services in facility-based or foster care placements.

The need for state and national respite infrastructure is compelling. While there are numerous federal programs which have the potential to fund respite or crisis services for caregivers of individuals with specific disabilities, specific ages, or for one narrow purpose, there is no single, coordinated, family/caregiver-friendly federal program to support the development or implementation of Lifespan Respite Services nationwide.

Lifespan Respite is a coordinated system of accessible, community-based respite care services for caregivers and individuals regardless of age, race, ethnicity, special need or situation. Respite care is planned or emergency short-term relief to caregivers from the demands of ongoing care for an individual with special needs or at risk of abuse or neglect. As defined in existing state Lifespan Respite legislation, special needs may include any disability, any chronic or terminal illness, or a physical, emotional, cognitive or mental health condition requiring ongoing care and supervision, including Alzheimer's disease and related disorders, developmental disabilities, children with special medical needs, and any other condition determined by the state. Crisis respite may also be used to provide a temporary safe haven for the care recipient in the event of an emergency brought on by a situation such as domestic violence, substance abuse, or a housing, health or job crisis.

Oregon, Wisconsin, and Nebraska have enacted and implemented Lifespan Respite legislation establishing state and local infrastructures for developing, providing, coordinating and improving access for lifespan respite to residents of the state who are eligible for such services. Oklahoma implemented a Lifespan Respite Program without legislation, and Michigan's Governor recently signed a Lifespan Respite bill into law. A number of other states are considering similar legislation.

In May 2000, under the leadership of the ARCH National Respite Coalition, a group of individuals from across the country began to meet and discuss strategies for a national approach to lifespan respite. A Lifespan Respite Task Force was formed with representation from a large number of agencies representing individuals with special needs. Task force members "envision an America where respite is readily available and easily accessible to all caregivers."

On March 5, 2003 the Lifespan Respite Care Act of 2003, was introduced in the United States Senate and the United States House of Representatives. The bill passed in the US Senate on April 10, 2003. This proposed bill would authorize grant funds to states and other eligible entities to develop Lifespan Respite Programs to help families access quality, affordable respite care. Specifically, the bill would authorize funds for the development of state and local Lifespan Respite Programs, based on models and best practices; evaluation of such programs; planned or emergency respite care services; training and recruitment of respite care workers and volunteers; and caregiver training.

For more information on the Lifespan Respite Care Act of 2003 visit the National Respite Coalition website at <http://www.archrespite.org/NRC.htm> or the Lifespan Respite Task Force ([www.archrespite.org/tforce.htm](http://www.archrespite.org/tforce.htm)).

### **Purpose of the Study**

The purpose of this study is to increase understanding about the implementation and development of State Lifespan Respite Programs including:

- Differences and similarities between states' lifespan respite legislation;
- Characteristics, nature and availability of their respite care service;
- Demographics of the population being served;
- Provider recruitment and training strategies utilized;
- Program evaluation efforts;
- State infrastructure required to coordinate a system of lifespan respite services; and,
- Relationship between State Respite Coalitions and State Lifespan Respite Programs.

The study articulates critically important information which will provide state and federal policymakers with a comprehensive view of existing State Lifespan Respite Programs. It is the authors' hope that this information will better prepare them to make sound policy and funding decisions related to Statewide Respite Care Programs.

The findings should also be helpful in informing other states about lessons learned during the implementation and development of State Lifespan Respite Programs and the systems of care, and increase understanding of how states are funding Lifespan Respite Programs.

### **Survey Methodology**

ARCH staff contacted the agencies responsible for administering Lifespan Respite Programs (LRPs) in the 4 states operating these programs to explain the study and assess their willingness to participate. All states were eager to assist and agreed to complete a written survey about the administration of their programs at the state level and participate in a telephone interview.

#### ***Written Surveys:***

The written survey included 20 questions, some of which were open-ended and others which required checking a box or filling in a blank. The surveys were mailed, completed and returned to ARCH in March 2004.

#### ***Telephone Interviews:***

ARCH staff subsequently scheduled telephone appointments with those who completed the written surveys in order to interview respondents on 5 additional topics about which they were informed in the written survey. The authors reviewed the completed surveys and identified items that needed clarification. Follow-up interviews with the managers of the LRPs were administered via teleconference between March 22 and April 19, 2004. The teleconference also provided an opportunity to obtain missing information and to clarify information provided in the written survey. The primary intent of the interview allowed for an in-depth discussion on five topics

- How is Lifespan Respite implemented and administered in your state?
- What are the savings to the state by having one agency administer the program, as opposed to multiple agencies?
- How is your state working with Medicaid?
- What are the actual costs for local respite programs? Can you provide us with a “typical” program budget? Is there any leveraging of funds to match the state dollars?
- Anything else about your Lifespan Respite Program you would like to have included in the report?

***Other information collected:***

Available state-specific written materials, such as the legislation, policies and procedures and/or annual reports were collected and reviewed.

Appendix A of this report is a Side-By-Side Comparison of the State Lifespan Legislation. Appendix B are the completed State surveys.

## **Survey Results**

### **A. Overview of State Lifespan Respite Programs**

#### ***Oregon***

In 1997, Oregon was the first state to pass Lifespan Respite legislation and implement a Lifespan Respite Program. The Oregon Lifespan Respite Program, funded through the state general fund, is administered by a State agency, the Oregon Department of Human Services. Funding is distributed through contracts to local sponsoring agencies, or local networks, in order to maintain their infrastructure. Although there are 36 counties, some have consolidated, leaving 28 contractors or local networks. Each local network has an advisory committee made up of community partners and consumers. Local networks have their own registries of providers and often share recruitment and training activities with other programs such as Medicaid.

*Contact Information:* Oregon Department of Human Services  
500 Summer St. NE E25, Salem, OR 97301-1098,  
Phone: (503) 945-5944; Fax: (503) 378-2897  
[www.dhs.state.or.us/seniors/caregiving/respite\\_care.htm](http://www.dhs.state.or.us/seniors/caregiving/respite_care.htm)

#### ***Nebraska***

The Nebraska Lifespan Respite Program, Respite Subsidy Plan Across the Lifespan, was created by legislation in 1999 and is administered by Health and Human Services (HHS), Aging and Disability Services. Funding for the state program and the respite subsidy component comes from tobacco settlement funds. The purpose of the Nebraska program is to establish a statewide system for the coordination of respite resources that serve the lifespan. Contracts are in place between HHS and six local entities (networks), one in each region, which are responsible for Information and Referral for families needing access to respite, recruitment of respite providers, marketing activities to increase the public’s awareness of respite, coordinating training opportunities for providers and consumers, and quality assurance and program evaluation. The subsidy program is administered through the state Health and Human Services Central Office. Applications for financial assistance are available on the HHS website, from Network Coordinators, or HHS local or central offices. Each network receives a small allotment annually, in addition to operating funds, to sponsor specific respite programs for families (e.g., family fun days, modification of day care center in exchange for a respite slot, etc).

*Contact Information:* Health and Human Services System,  
P.O. Box 95044  
Lincoln, NE 68509-5044  
Phone: (402) 471-9282; Fax (402) 471-6352  
[www.hhs.state.ne.us](http://www.hhs.state.ne.us)

### **Wisconsin**

In 1999, Wisconsin became the third state in the nation to adopt Lifespan Respite Care legislation. The legislation authorized the Wisconsin Department of Health and Family Services (DHFS) to contract with the Respite Care Association of Wisconsin (RCAW) to administer the program. Funding to support the program comes from state general funds. A portion of the LRP funds are used by the RCAW to provide I & R services, maintain a website, provide training and technical assistance, conduct outcome based evaluation and manage grants. The remaining funds are distributed to Lifespan Respite Networks in five counties. The “networks” are community based respite programs, typically housed in a larger provider agency. They are required to demonstrate strong collaboration and networking with other agencies in the community. The provider agencies are allowed latitude in the manner in which they operate their program, each having their own policies and procedures, but RCAW does require the program’s eligibility be inclusive of any age or type of disability.

*Contact information:* RCAW  
6320 Monona Street  
Monona, WI 53716  
Phone (608) 222-2033 or (866) 702-7229; Fax (608) 222-2034  
[www.respitecarewi.org](http://www.respitecarewi.org)

### **Oklahoma**

The Oklahoma Respite Resource Network (ORRN) began offering statewide respite services in 2000. ORRN is a statewide partnership of public and private agencies whose goal is to support families and caregivers by increasing the availability of respite care. State agencies, including developmental disabilities, mental health, aging, maternal and child health and others, have come together voluntarily with private agencies and foundations to pool resources via 3 year contracts for respite. Funds are disbursed to family caregivers through a voucher program managed by OASIS, the statewide I & R agency. Families applying to the state for a respite voucher submit their applications for service to OASIS who forwards them to the appropriate state agency for approval under their respective eligibility criteria. This system allows a blending of funds without agencies fearing loss of control. Family caregivers in turn hire their own providers and negotiate payment.

*Contact Information:* ORRN  
P. O. Box 25352  
Oklahoma City, Ok. 73125  
Phone 405-522-0600; Fax (405)522-0729



## B. Summary of Major Findings

Lifespan Respite programs rely on a wide variety of strategies to inform families about respite options.

<b>Table 1</b>	<b>Oregon</b>	<b>Nebraska</b>	<b>Wisconsin</b>	<b>Oklahoma</b>
Referrals from other social service agencies	X	X	X	X
Word of mouth	X	X	X	X
Referrals from medical professionals		X	X	X
Public Service Announcements	X	X	X	
Newspaper advertisements		X	X	
Other:				
Presentations and exhibits at conferences				X
Church bulletin inserts and flyers		X		
Information disseminated via the statewide infrastructure		X		X
Websites	X	X	X	X

All Lifespan Respite Programs offer families information and referral services and offer some families financial assistance in paying for respite services – most often through vouchers.

- OR, WI, and OK responded that vouchers are given directly to families or caregivers.
- None of the states give vouchers directly to respite care providers or to community-based programs
- The Respite Care Association of Wisconsin gives grants to the provider agency who in turn issues vouchers to the families or caregivers
- In Oregon, some of the local networks voucher payments to families; if providers are paid directly, it's done as a reimbursement for services.
- In Nebraska, families are permitted to bank up to three months of subsidies for a planned special event. One-time benefits are also available for families who do not have ongoing needs.

Most critical to the success of the State's Lifespan Respite Program is its ability to coordinate and share resources with other state, federal, and local programs. To varying degrees, State LRPs are successfully working with numerous federal funders of respite. Two of them, the National Family Caregiver Support Program and/or Medicaid, are highlighted in Table 2.

Table 2	Oregon LRP	Nebraska LRP	Wisconsin LRP	Oklahoma LRP
<b>National Family Caregiver Support Programs (NFCSP)</b>	Administers the NFCSP funds designated for respite	Collaborates on recruitment & training of providers and referrals. Individuals not eligible for NFCSP referred to LRP and vice versa	This is handled by another agency with which RCAW does not have an established relationship	Administers the respite funds in the NFCSP
<b>Medicaid</b>	1) State is recent recipient of CMS grant for respite for children with disabilities; conducting feasibility study to determine if LRP could provide infrastructure for that effort; 2) local community Lifespan respite registries share providers, training resources and criminal background checks with. Medicaid Case Managers from Home and Community Based Waiver programs	Regional Lifespan Respite Network Coordinators recruit providers for Medicaid, as well as for the Lifespan Respite Program. Medicaid matching funds available for Network Coordinators	Medicaid waivers fund respite services on the county level. RCAW's role is to seek interpretations and clarifications of the Medicaid rules and regulations and to advocate for additional funding	Currently, state Medicaid program claims respite does not meet their definition of medical necessity. ORRN is writing a demonstration grant to show value of respite under Medicaid in preventing out-of-home placement, improving caregiver health and reducing hospitalizations
<b>State Respite Coalitions</b>	The Oregon Respite Advisory Council, which serves as the OR Respite Coalition, provides guidance and advocacy for the LRP	Most respite Network Coordinators attend Respite Coalition meetings	The Wisconsin Coalition, RCAW, administers the LRP	The Oklahoma Coalition, ORRN, coordinates the LRP
<b>Area Agencies on Aging (AAAs)</b>	A number of AAAs are sponsoring organizations or administer local networks, and most participate on LRP advisory committees	Established working relationship and communication between AAA's and LRP. Work together to recruit and train providers	RCAW has not worked with the AAAs	AAAs are partners in ORRN and are contracted to provide respite vouchers for ORRN
<b>Faith-Based Organizations</b>	Relies on these as community partners		Faith-Based Organizations are a part of network	Faith-Based Organizations are a part of network

Oregon and Wisconsin report that overall state budget cuts have affected their ability to reach the intended populations.

- Oklahoma and Nebraska reported no effects due to their funding sources, although both reported still unserved or underserved groups.
- Oregon reported there is an increased demand for respite as a result of the cuts to many other social service programs, including the Family Support Program for Developmental Disabilities and the Medicaid Long-term Care Waivers. Community partners have fewer resources to contribute to the local lifespan respite networks and services and sponsoring organizations have fewer resources to provide administrative support of the Lifespan Respite Programs
- Wisconsin's long-range plan had been to expand the program from 5 counties to 72 counties. Due to budget cuts, that expansion has not occurred.

In LRP states, all families are eligible to receive information and referral. States must adhere to eligibility requirements imposed by participating state and federal programs, but strive to serve those who are currently not eligible for any of these participating programs.

- In Oregon, funds for direct services come from a variety of pools. Eligibility criteria are determined by the funding source. Supplemental services such as support groups do not have eligibility requirements.
- In Oklahoma, there are no eligibility requirements for individuals over age 60 and those in the early intervention program; all other applicants are eligible for a respite voucher if they earn less than \$60,000 annually.
- Nebraska requires income levels of the client, or anyone who is legally and financially responsible for them, to be below 312% of the Federal Poverty Level in order to receive a respite subsidy. Clients must require continuous ongoing care and the caregiver and the client must reside together in the same dwelling.
- Wisconsin has no eligibility system in place.

State Lifespan Respite Programs experience little or no fraud or abuse and rely on proven mechanisms to prevent abuse.

- Wisconsin reports that respite programs verify vouchers are actually used to purchase respite.
- Nebraska doesn't require medical documentation of need unless families are requesting services for more than 2 children or other unusual circumstances. The rules and regulations allow Prudent Person Principle (an accepted rule of conduct that one is judicious in practical affairs; economical or thrifty) for verifying any questionable data as well as collection of over payments and prosecution for fraud. All claims are reviewed by 2 persons prior to being processed.
- Oklahoma conducts random audits for all programs. After vouchers are spent, ORRN conducts random phone calls and/or home visits to find out what folks did while receiving respite. Everyone is informed that they might be subject to random audit. At the time of the interview they had only documented one true case of fraud since the program's inception.
- Oregon built fraud/abuse prevention into respite funding source systems, such as Medicaid.

Risk management systems are in place as protection against liability (or are not considered to be needed).

- As grantor, the Respite Care Association of Wisconsin, does not incur any risks. Each community network develops risk management systems.
- Since caregivers hire their own providers in Oklahoma and Nebraska, there is no risk to the State LRP.
- In Oregon caregivers also hire their own providers but the State LRP provides information and training for family caregivers as employers of respite providers.

Three states report serving families at risk of abuse or neglect (OK, WI, OR), however none of the 4 states were sure as to whether crisis respite programs were part of the state LRP. Oregon and Wisconsin reported local programs attempt to meet emergency respite needs of families.

All of the LRPs rely on maximizing use of existing state and federal funds to help families pay for respite for which they are already eligible. Minimal additional funds are provided by the state for state and local infrastructure and administration, and to help pay for respite for families who are not eligible for any existing program.

- 100% of the funding in Oregon comes from the state general funds. A little over \$1 million is distributed in contracts to local sponsoring agencies. Each local network receives \$15,000 to \$25,000 to provide the local infrastructure. Funds for direct services come from a variety of existing state and federal sources for which families are eligible.
- 100% of the funding for the respite subsidy program in Nebraska comes from tobacco settlement funds. Local programs do not administer direct services except for the \$25,000 they receive annually for special projects. Network Coordinators' administrative budgets come from Medicaid, the Tobacco Settlement funds, the Department of Education, and at one time, child care.
- The Respite Care Association of WI (RCAW) receives \$225,000 annually from state general funds to operate the WI Lifespan Respite Program. Of that total, \$105,000 is used by RCAW to provide I&R services, a website, training and technical assistance, outcome based evaluation and grants management. The remaining \$120,000 is given out in \$25,000 grants to fund the Lifespan Respite Networks in 5 counties. Lifespan respite networks estimate their overall income is derived from the following sources: 60% from state general funds; 10% from private contributions; 10% United Way or other local funds; 10% city and county general funds. Source of the remaining 10% is unknown.
- For voucher expenses, Oklahoma estimates that 15% comes from state general funds; 10% Community-Based Child Abuse Prevention; 5% Promoting Safe and Stable Families Act; 2% Adoption Assistance/Opportunities Act; 1% Social Services Block Grant; 1% Maternal & Child Health (Title V); 8% Mental Health; 30% other federal funds; 10% services for the aging; 10% TANF; and 5% private and foundations. By expanding the number of agencies pooling resources, the budget increased from \$65,000 to \$1.8 million over a three year period.

State LRPs assert that a critical component of the program's success is the unique ability to maximize use of existing diverse funding streams and pool resources to successfully leverage other state, federal and private funds.

- Oregon leverages a percentage of Medicaid funds as a match. Local Lifespan Respite Programs leverage a match with National Family Caregiver Support Program. Lifespan funds are also used as a match for private foundation grants.
- Oklahoma's effort has increasingly encouraged additional state agencies to join the effort so that currently, at least 8 federally funded streams for respite are funneled through the state's lifespan program. Up to 5% of funds have been leveraged from private organizations and foundations.
- The Nebraska Network Coordinators are able to leverage Medicaid funds to help recruit providers for the Medicaid waiver programs.

A key to the LRP's success, is the ability to respond to the shortage of services by supporting and offering respite provider training and recruitment to meet identified needs.

- Oregon reports there is no state plan for provider recruitment and training though it has been considered on several occasions. However, local networks recruit and train providers based on local needs and resources.

- Oklahoma reported no plan as families recruit and train their own providers. The state will make any training available free of charge if requested by a family.
- In Nebraska the 6 Network Coordinators are responsible for recruiting respite providers and for the provision of general training. Families are responsible for specific training. Training varies and is not a requirement for providers. As new trainings are developed on various topics, providers are notified of training availability.
- Wisconsin's RCAW developed a provider training manual for respite provider trainees, although neither RCAW or the state have requirements regarding provider training. The RCAW conducts training on provider recruitment and the local programs are responsible for recruiting and training the direct care providers.

States report savings as a direct result of Lifespan Respite Program implementation.

- Nebraska LRP reports that having one agency administer the program saves dollars that otherwise would have been expended on administrative and other staff salaries and training for individual respite initiatives. The state LRP manager can even assume additional duties in addition to those required by the LRP.
- Oklahoma has reduced costs by establishing only one fiscal agent with no administrative costs charged to the program. As in-kind contributions, the various agencies absorb the minimal administrative costs that result from evaluating families' income eligibility for the respite voucher. ORRN estimates that about 25% of the funds that would have been used for administrative purposes can now go directly to families to help them pay for respite.
- Oregon maintains that funding only one position at the state level versus several, reduces administrative overhead. More consistent leadership allows program continuity and focus at the state level and helps reduce program expenditures.
- Wisconsin reports there is a savings to the state through decreased operating and administrative costs. The Wisconsin LRP is very efficient and has become creative in leveraging additional private funds.

Additional resources are needed to ensure that each state Lifespan Respite Program is able to conduct the appropriate and most useful evaluations.

- OR, NE, and OK reported there is no requirement for evaluation, but all states have conducted at least one client satisfaction and/or outcome survey.
- Wisconsin participated in the ARCH Outcome Evaluation Initiative and has collected data on participant outcomes. A peer review process has also been used. The RCAW is considering moving to an Outcomes Management System model in which grantees will project their outcomes for the coming year in addition to measuring those outcomes.

**C. Consumer Information**

Except for Wisconsin which focuses on children and adults with disabilities under age 60, it is evident that to the greatest extent possible, states are serving individuals across the lifespan regardless of disability.

<b>Table 3</b>	<b>Oregon</b>	<b>Nebraska</b>	<b>Oklahoma</b>	<b>Wisconsin</b>
<b>Families currently on wait lists for respite services</b>	do not track	do not track	do not track	Wisconsin reported that at the time of the survey an estimated 1,000+ individuals were on the wait list in counties without a Lifespan Respite Program. In the 5 counties with Lifespan Respite Programs the wait list has been almost entirely eliminated
<b>Families turned away from services in the past year</b>	do not track	333 didn't qualify for services	425	
<b>Number of families who received respite in the past year</b>	do not track	estimated 325 families based on the number of individuals; otherwise they don't track families, only individuals served	estimated serving 2,200 families	estimated 350
<b>Number of children or dependent adults who received respite in the past year</b>	an estimated 2,074 were served; 4675 respite referrals and 9968 information and referral contacts were made	518 (453 were served with LRP funds + an additional 65 through the Disabled Children Program (DCP); the DCP serves siblings while LRP does not)	they estimate serving 3400 last year	reported serving 414
<b>Number of hours of respite provided in the past year</b>	do not track	do not track	estimated 200,000 hours for the year	reported providing 12,463 hours for the year
<b>Number of days of respite provided in the past year</b>	do not track	do not track	do not track	do not track

<b>Table 4: Percentages of special populations served</b>				
<b>Condition</b>	<b>Oregon</b>	<b>Nebraska</b>	<b>Oklahoma</b>	<b>Wisconsin</b>
<b>Risk of abuse/neglect</b>	17%	0	9%	4%
<b>Developmental disabilities</b>	16%	16.8%	23%	38%
<b>Attention deficit disorders</b>	0	0	1%	0
<b>Physical disabilities</b>	14%	0	6%	7%
<b>Autism</b>	0	4.2%	2%	0
<b>Speech and language disabilities</b>	0	3.8%	0	0
<b>Mental illness</b>	9%	1.5%	5%	1%
<b>Visual impairments</b>	0	2.1%	0	0
<b>Hearing impairments</b>	0	.1%	0	0
<b>Chronic or terminal illness</b>	11%	0	4%	0
<b>Medically fragile conditions</b>	4%	0	4%	7%
<b>HIV/AIDS</b>	0	.1%	1%	0
<b>Adults with dementia</b>	8%	8.9%	45%	6%
<b>Other *</b>		62.5%		21%

*\* 21% of WI's population consists of those with emotional/behavioral disorders and those with multiple needs*  
*\*Nebraska has many more discrete categories, which account for the 62.5%.*

#### Numbers served by age

- Although not all of the networks in Oregon track ages, those that do track it served 757 individuals between birth and 12 years; 214 between 13-18 years; 465 between 19-59 years; and 479 over the age of 60
- Nebraska served 66 from birth to 3 years; 43 between 4-6 years; 71 from 7-12; 36 from 13-18; 12 from 19-21; 56 from 22-65; and 169 over the age of 65 with 5 being over 100 years of age
- Oklahoma does not categorize by age, but 2,312 (68%) of the total population served were over the age of 60 an estimated 1,988 were served between birth and 59 years (the 68% includes grandparents raising grandchildren)
- Wisconsin served 38 between birth and 3 years; 66 between 4-6; 87 between 7-12 years; 64 from 13-18; 101 from 19-65; and 58 over the age of 65 years

### Percentage of families served by income levels

- Oregon and Wisconsin do not track family income levels
- Nebraska's intent is to serve families who "fall through the cracks" in qualifying for other respite services such as those provided through foster care, Developmental Disabilities, Medicaid Waiver, Title XX block grant and the Disabilities Children's Program. Nebraska provides respite subsidies to those families not eligible for these programs, but whose incomes fall below 310% of the federal poverty level.
- Oklahoma served 15% below \$9,999; 15% between \$10,000-\$14,999; 15% from \$15,000-\$24,999; 20% from \$25,000-\$34,999; 25% from \$35,000-\$44,999; 10% between \$45,000-\$59,999, and 0 over \$60,000
- Wisconsin does not track income levels of program participants.

### Unserviced or under served populations

- Oregon does not track for these populations although they are hearing that there are many people who aren't being served, which they speculate is due to the increased demand for services because of fewer resources. Those hardest hit were individuals with mental health conditions or with developmental disabilities.
- Nebraska reports all those whose incomes exceed 312% of the federal poverty level are unserved by the LRP. However, the state is having a significant impact on meeting the needs of additional families. Nebraska has data on numbers served pre and post LRP; 130 were served prior to the implementation of LRP compared to 943 after implementation
- Oklahoma reported that among the under served are spouses caring for their loved ones and people under the age of 60 with MS, acquired brain injury, chronic and terminal illnesses, and grandparents under the age of 60 raising a child with no disabilities.
- Wisconsin claims that individuals with Autism, Developmental Disabilities, children with emotional and behavior disturbance, children with special health care needs and those with physical disabilities are among the under served.

## Conclusion and Recommendations

This document contains information collected from the four Statewide Lifespan Respite Programs in operation in the spring 2004. The data can provide other states with important facts as they move forward in creating their own statewide program.

Lifespan respite programming is still in its infancy and there are many lessons yet to be learned in the planning and implementation of this program. In many cases responses to our queries varied tremendously which is an indication that the programs were designed and implemented based on the unique needs and preferences of the consumers and funders of the state. The defining characteristic of each program is a coordinated approach to ensure respite services are available to those in need in the geographic areas served by the Lifespan Respite Program.

Oregon, Nebraska and Wisconsin have established community-based networks that rely on the development of local partnerships to build and ensure respite capacity. These local partnerships strive to be inclusive with representation of family caregivers, providers, state and federally funded programs, Area Agencies on Aging, non-profit organizations, health services, schools, local business, faith communities and volunteers. The networks provide a "one-stop" resource for families and caregivers by serving as the central point of contact for those seeking respite and related support regardless of age, income, race, ethnicity, special need or situation.



Providing a single point of contact for families to access respite information and services is crucial to assisting families in helping themselves.

Some services typically offered by Lifespan Respite Program Networks include

- Providing respite stipends to family caregivers
- Conducting public awareness campaigns and distributing information about respite to the community
- Building diverse respite partnerships
- Recruitment and training of paid and volunteer respite providers, connecting and matching families with respite payment resources and providers, coordinating respite related training for providers and caregivers, identifying gaps in services and creating respite resources by building on existing services.

## Recommendations

The ARCH National Resource Center on Respite and Crisis Care's outcome-based evaluation pilot project demonstrates that families use respite because of a tremendous need for assistance and relief. Respite has been shown to help sustain family stability, avoid out-of-home placements, and reduce the likelihood of abuse and neglect. Data from ARCH's outcome-based evaluation study strongly suggest that respite reduces the likelihood of divorce and helps to sustain marriages.

***It is recommended that federal legislation be passed with an adequate level of funding to ensure that every family caregiver have access to at least minimum levels of respite provided in their own communities regardless of the age, race, ethnicity, special need or situation of the individual requiring care.***

A myriad of federal and state funding streams list respite as an allowable service. However, because of competing demands and limited resources, respite is often overlooked. Respite is often the most frequently requested family support service by family caregivers, but no federal program currently exists that has respite as its sole purpose and would permit states to identify gaps in services, startup new respite services to meet unmet need, recruit or train new providers, or improve respite access for families regardless of age or disability.

***It is recommended that federal legislation have as its primary focus the improvement and expansion of accessible respite services through collaboration, coordination, capacity building, and quality improvement strategies. States should retain flexibility in selecting the state agency and local entities that administer the program in order to best meet state, community and families' needs.***

Statewide entities are in the best position to have knowledge of and access to the myriad number of federal, state and private funding streams that can potentially fund respite and flow directly into a statewide Lifespan Respite Program.

***It is recommended that Lifespan Respite Programs be administered on a statewide level or at a very minimum, at a level that oversees a large population, a large number of services, funding and resources. Lifespan Respite Programs should be required to maximize and leverage already existing funds and channel them for respite in a quality, coordinated, and efficient way.***

"Lifespan respite care" is defined as a coordinated system of accessible, community-based respite care services for family caregivers of individuals regardless of the individual's age, race, ethnicity or special need. The benefits of collaboration and coordination of services are well understood.

***It is recommended when planning a State Lifespan Respite Program the planning body include individuals who represent the various stakeholder groups including the different disability, racial, ethnic, cultural, and age groups, as well as representatives from different geographic areas of the state. Consumers of services should always be an integral part of all stages of the planning process. Program implementation and operation should require ongoing collaboration and networking.***

Respite is an important component of a continuum of comprehensive family support services available to caregivers not only on a planned basis, but also in emergency situations.

***It is recommended that both planned and emergency respite services be available to meet the needs of family caregivers.***

The needs of caregivers for respite services vary widely. While some caregivers need 24 hour care in the home of a provider recruited by the Lifespan Respite Program, other caregivers will only need assistance in the form of a voucher for service.

***It is recommended that family caregivers have an array of options and can choose respite services that meet their unique needs. The array of respite options should be available and include in-home and out-of-home care, hourly and overnight care, a voucher option, and a diverse pool of providers that can meet families' needs. Culturally competent providers should be available to all families and family caregivers should be free to choose their respite providers.***

Family caregivers should be assured that the family member receiving care will be safe from harm, receive developmentally appropriate services, and have their physical, mental and emotional needs met by a competent and culturally sensitive respite provider.

***It is recommended that program standards be developed for State Lifespan Respite Programs which will ensure the well being of our most vulnerable population.***

Funders, policymakers and the community should be assured the goals of the Lifespan Respite Program are being met.

***It is recommended that State Lifespan Respite Programs monitor, evaluate and report their program outcomes, the service outcomes for individuals who receive respite, and the outcomes for their family caregivers including consumer satisfaction.***

A national entity is necessary to ensure that respite is developed and implemented utilizing best practices at the state and local level. ARCH has demonstrated that a national resource center's respite expertise can be directly responsible for the success, growth, and continuation of local and state respite efforts. Other more broad based family caregiver and family support resource centers and organizations often list respite as one area for which they provide training and technical assistance. However, because of competing demands and too few resources, the much needed focus on building and improving respite services is often overlooked.

***It is recommended that a National Resource Center on Respite be established and funded to ensure that states and community-based services have access to specific respite expertise in the areas of program and outcome evaluation, program start-up, implementation and development, best practices, sustaining funding sources and meeting the needs of the unserved. The resource center will offer quality training and technical assistance and national networking opportunities.***

# Appendices

**State Lifespan Respite Laws, Bills, and Programs  
Side-By-Side Comparison**

Provision	Oregon	Nebraska	Wisconsin	Oklahoma
<b>Program or Legislation Name</b>	Oregon Lifespan Respite Program	Nebraska Lifespan Respite Services Program	Wisconsin Lifespan Respite Program	Oklahoma Respite Resource Network
<b>Caregiver Definition</b>	An individual providing ongoing care for an individual with special needs.	An individual providing ongoing care for an individual unable to care for himself or herself.	An individual who lives in the home of a person with special needs and provides care or supervision for that person.	An individual providing ongoing care for an individual with special needs.
<b>Noncategorical Care Definition</b>	Care without regard to the status, including but not limited to age and type of special need of the individual receiving care.	Care without regard to the age, type of special needs, or other status of the individual receiving care.		
<b>Respite Definition</b>	The provision of short-term relief to primary caregivers from the demands of ongoing care for an individual with special needs.	The provision of short-term relief to primary caregivers from the demands of ongoing care for an individual with special needs.	Care provided to a person with special needs, or a person at risk of abuse or neglect, in order to provide temporary relief to the caregiver of that person or when the caregiver is unable to provide care.	The provision of short-term relief to primary caregivers from the demands of ongoing care for an individual with special needs.
<b>Special Needs Definition</b>	(a) Alzheimer's disease and related disorders; (b) Developmental Disabilities; (c) physical disabilities; (d) chronic illness; (e) mental and emotional conditions that require supervision; (f) situations in which a high risk of abuse or neglect exists; (g) such other situations or conditions as the Dept. Of Human Resources may establish by rule.	None	A person's need resulting from an emotional, behavioral, cognitive, physical or personal condition that necessitates receipt of care or supervision in order to meet the person's basic needs or to prevent harm from occurring to him or her.	Caregivers caring for: Family member with a developmental disability (no age limit); adopted child with health care needs who was once in the custody of the Department; child receiving SSI-Disabled Children's Program Services; spouse over the age of 60 who has Alzheimer's or other chronic health concerns; grandchildren; children receiving services through mental health centers contracted with Department of Mental Health Substance Abuse Services Program; children who meet Head Start eligibility criteria; child who has been dually diagnosed with MR and MI; family member with HIV/

Provision	Oregon	Nebraska	Wisconsin	Oklahoma
<p><b>Community Lifespan Respite Care Program Definition</b></p>	<p>A noncategorical respite services program that: a) is operated by community-based private, nonprofit, for-profit, or public agencies that provides respite care services; b) receives funding through the Oregon Lifespan Respite Care Program; c) serves an area of one or more counties; d) acts as a single local source of information and referral; and e) facilitates access to local respite care services.</p>	<p>A noncategorical respite services program that: a) is operated by a community-based agency or a public agency that provides respite services; b) receives funding through the State Lifespan Respite Services Program; c) serves an area in one or more of the six regional service areas of the department; d) acts as a single local source for respite services information and referral; and e) facilitates access to local respite services.</p>		<p>AIDS. In addition, families participating in Healthy Families Programs with the Health Department, and two parent families raising a child with a disability. Gap funding is available in northeastern OK through the Zarrow Foundations.</p>
<p><b>Respite Provider Definition</b></p>	<p>An individual or agency selected by a family or caregiver to provide respite care to an individual with special needs.</p>	<p>An individual or agency selected by a family or caregiver to provide respite services to an individual with special needs.</p>	<p>“Provider” means an individual or agency selected by a family or caregiver to provide caregiver support services to an individual with special needs or the individual's family.</p>	<p>An individual or agency selected by a family or caregiver to provide respite care to an individual with special needs.  Respite care may be provided by: a) private nonprofit, for-profit, or public agencies; b) individuals selected by parents/legal guardian; volunteers; or c) independent contractors who have completed the required training curriculum set up by state agencies.</p>

Provision	Oregon	Nebraska	Wisconsin	Oklahoma
<p><b>Lead Agency Requirements</b></p>	<p>Director of Human Resources shall establish the Oregon Lifespan Respite Care Program (OLRCP).</p> <p>(1) Provide policy and program development support, including but not limited to, data collection and outcome measures; (2) Identify and promote resolution of local and state-level policy concerns; (3) Provide technical assistance to community lifespan respite care programs; (4) Develop and distribute respite care information; (5) Promote exchange of information and coordination among state and local government, community lifespan respite care programs, agencies serving individuals with special needs, families, and respite care advocates to encourage efficient provision of respite care and reduce duplication of effort; (6) Ensure statewide access to community lifespan respite care programs; and (7) Monitor and evaluate implementation of community lifespan respite services program.</p>	<p>Director of Health and Human Services shall establish the Nebraska Lifespan Respite Services Program.</p> <p>(1) Provide policy and program development support, including but not limited to, data collection and outcome measures; (2) Identify and promote resolution of local and state-level policy concerns; (3) Provide technical assistance to community lifespan respite services programs; (4) Develop and distribute respite services information; (5) Promote exchange of information and coordination among state and local governments, community lifespan respite services programs, agencies serving individuals unable to care for themselves, families, and respite care advocates to encourage efficient provision of respite services and reduce duplication of effort; (6) Ensure statewide access to community lifespan respite services programs; and (7) Monitor and evaluate implementation of community lifespan respite services program.</p>	<p>Department of Health and Family Services shall contract with an organization for the administration of a lifespan respite care project. Organization must be a private, nonprofit that is capable of operating on a statewide basis and has expertise in respite care issues.</p> <p>(1) Oversee office grants awarded, monitor, provide technical assistance to, and evaluate lifespan respite care projects (See state administration below); (2) Develop best practice guidelines and training curriculum that may be used by lifespan respite care projects and if appropriate by any respite care provided in the state; (3) Promote exchange of information and coordination among state, local government, lifespan respite care projects, entities serving persons with special needs and their families, and advocates for respite care services to enhance the efficient provision of respite care services; (4) Act as statewide clearinghouse of information about respite and existing respite programs and resources; operate a library of materials that may be lent upon request; (5) Conduct analyses of respite care.</p> <p>Policies and proposals: identify and promote respite care policy at legislative state and local levels.</p>	<p>Oklahoma Respite Resource Network (ORRN)</p> <p>ORRN is available to provide the following assistance:                      (1) Promote statewide access to community respite care;                      (2) Promote the exchange of information and coordination among state and local government, community respite care programs, agencies serving individuals with special needs, families and respite care advocates to encourage efficient provision of respite care and reduce duplication of effort; (3) Develop and distribute respite care information; (4) Identify and promote resolution of local and state level policy concerns; (5) Provide technical assistance to community respite care programs; (6) Provide policy and program development support; (7) Data collection and evaluating outcome measures.</p>

Provision	Oregon	Nebraska	Wisconsin	Oklahoma
<p><b>State Program Administration</b></p>	<p>1) The department, through the Oregon Lifespan Respite Care Program shall coordinate establishment of community lifespan respite care programs. The program shall accept proposals to operate community lifespan respite care programs, submitted in the form and manner required by the program, from community-based private nonprofit, for-profit agencies or public agencies that provide respite care services. According to criteria established by the Department, the Oregon Lifespan Respite Care Program shall designate and fund agencies to operate community respite care programs (at least 12 by July 1, 1999), and by July 1, 2003, the Department shall ensure that individuals in all Oregon counties have access to respite care);</p> <p>2) the Director of HR shall create the position of administrator of the Oregon Lifespan Respite Care Program, to carry out the duties of the program.</p>	<p>The Department, through the Nebraska Lifespan Respite Services Program (NLRSP) shall coordinate the establishment of the community lifespan respite services program. The program shall accept proposals submitted in the form and manner required by the program from community-based private nonprofit or for-profit agencies or public agencies that provide respite services to operate community lifespan respite services programs. According to criteria established by the Department, the NLRSP shall designate and fund agencies to operate community lifespan respite programs (at least six by July 1, 2000); (2) The Director of HS shall create the position of program specialist for the NLRSP to administer the program.</p>	<p>(1) Prescribe criteria for the distribution of grants to conduct lifespan respite care projects. The criteria must be developed after consultation with DBFS, county departments, Indian Tribes or boards, providers and caregivers. The criteria must include the requirement that grant funds be equally distributed among five DBFS administrative regions; (2) Solicit applications from an award of up to one grant in each of the five administrative regions to any of the following to conduct a lifespan respite care project: a county department, an Indian Tribe or board, a community-based private, nonprofit entity, a community-based private entity that is operated for profit. The grants must be awarded using the criteria developed by the contracting organization;</p> <p>3) Require that the grantee provide matching funds for the operation of the lifespan respite care project.</p>	
<p><b>State Governing Board or State Level Advisory Committee Make-Up and Responsibilities</b></p>	<p>The Family Support Advisory Council shall appoint a subcommittee of the council to act as an advisory council to the Oregon Lifespan Respite Care Program. The subcommittee shall be composed of Family Support Advisory Council members and nonmembers including respite care providers, respite care program managers, and respite care consumers, family members and other interested individuals.</p>		<p>1) At least 51% of the members of the organization's governing board must be consumers of respite care or caregivers; 2) The membership of the organization's governing board must include providers and elected officials and represent the diverse geographical areas and cultural groups of the state.</p>	

Provision	Oregon	Nebraska	Wisconsin	Oklahoma
Not Supplant Language			Grants may not be used to supplant money otherwise available and prior to receipt of the grant, dedicated by the grantee to respite care.	Oklahoma Area-Wide Services Information System (OASIS).
<b>Contracted Community Agency (community lifespan respite services program) Required Activities:</b>				
<b>1) Planning</b>	Involve key local individuals and agencies in the community lifespan respite services planning process.	Involve key local individuals and agencies in the community lifespan respite services planning process.		
<b>2) Training</b>	Yes, identifying local training resources and organizing training opportunities for respite care providers.	Yes, identifying local training resources and organizing training opportunities for respite care providers.	Yes, same as Oregon.	Yes, "Myths & Realities" Training developed and piloted by Office of Child Care to dispel day care provider fears about caring for children with disabilities; training provided to any respite provider who needs additional training or who opts to become certified.
<b>3) Cultural Competency</b>	Yes (see under respite services below).	Yes (see under respite services below).	Yes, operate in a culturally competent manner and be sensitive to the unique needs and strengths of a person with special needs and his or her family or caregiver.	Yes (see under respite services below).
<b>4) Provider Recruitment</b>	Yes, will also screen providers.	Yes, will also screen providers.	Yes, same as Oregon.	Yes, of paid and unpaid providers.



Provision	Oregon	Nebraska	Wisconsin	Oklahoma
5) Identify, Coordinate and Develop Community Respite Resources	Yes	Yes	Yes	Yes
6) Facilitate Access	Yes, matching of families and caregivers with providers and other types of respite care.	Yes, matching of families and caregivers with providers and other types of respite care.	Yes, facilitate access by caregivers and families of persons with special needs to an array of respite care options for which the person with special needs is eligible, that are responsive to caregiver and family needs, and that are available before families and primary caregivers reach a crisis situation.	Yes, linking families and caregivers with providers and other types of respite care.
7) Assist Caregivers with Funds and Resources	Yes, linking families and caregivers with payment resources, and assist families and caregivers to identify respite care needs and resources.	Yes, linking families and caregivers with payment resources, and assist families and caregivers to identify respite care needs and resources.	Yes, assist caregivers and families of persons with special needs to identify and coordinate funds and resources available for respite care for which the persons with special needs is eligible; authorize and provide a variety of funds and resources for additional respite care services for persons with special needs, under eligibility criteria established by the project.	Yes, link families and caregivers with payment resources, and assist families and caregivers to identify respite care needs and resources.
8) Local Advisory Committee	Yes, to advise community lifespan respite care program on how to best serve needs of families and caregivers of individuals with special needs. Members must include family members and caregivers of individuals with special needs, respite care providers, reps. of local service agencies and other community reps. Membership shall represent senior citizens, individuals with special needs, and families at risk of abuse/neglect.	Yes, to advise the community lifespan respite services program on how the program may best serve the needs of families and caregivers of individuals unable to care for themselves. Members must include respite providers, representatives of local service agencies, consumers, and shall represent senior citizens, individuals with special needs, and families at risk of abuse or neglect.	Yes, each grantee must create an advisory committee to advise the project on how to best serve persons with special needs and their caregivers. Consumers of respite care services and caregivers must comprise at least 51% of the advisory committees and be representative of the diversity of persons who receive service under the project. Other members of the advisory committee must include providers, representatives of local service agencies and members of the community.	

Provision	Oregon	Nebraska	Wisconsin	Oklahoma
9)Quality Assurance and Evaluation	Yes	Yes		
10) Publicize the telephone number and address where families and caregivers may contact the program	Yes	Yes		
Voucher System				<p>(1) Purchase of respite services by relatives or caregivers exempt from the competitive bidding process and contracting requirements;</p> <p>(2) In addition to any other forms of assistance provided under Title V funds or family preservation funding, state agencies are authorized to pay a voucher for the sole purpose of acquiring respite care services;</p> <p>(3) Administration of the respite voucher program, including but not limited to, establishing financial eligibility criteria and limits of vouchers, established by rules promulgated by state agencies providing funding;</p> <p>(4) The Department of Human Services will act as fiscal intermediary for any or all funds made available for respite services through a voucher program.</p>
Voucher Eligibility Requirements				<p>1) Family cannot be receiving DDSD Family Subsidy Assistance Payments, or residential or waiver services from DDSD or Aging; 2) Annual household income under \$45,000 will receive \$400 voucher every three months. Annual household income over \$45,000 but less than \$60,000 will receive a \$300 voucher</p>

Provision	Oregon	Nebraska	Wisconsin	Oklahoma
<p><b>Voucher Eligibility Requirements (cont.)</b></p>				<p>every three months;3) Any public or private agency that contracts with DHS can set specific eligibility and geographical criteria.</p>
<p><b>Requirements of Respite Care Made Available Through the State Program</b></p>				
<p><b>1) Include a flexible array of respite care options</b></p>	<p>Options must be responsive to family and caregiver needs and available before families and caregivers are in crisis.</p>	<p>Options must be responsive to family and caregiver needs and available before families and caregivers are in crisis.</p>	<p>(See contracted community agency lifespan respite services required activities above.)</p>	
<p><b>2) Be Culturally competent and sensitive</b></p>	<p>Be sensitive to the unique needs, strengths, and multicultural values of an individual, family or caregiver.</p>	<p>Be sensitive to the unique needs, strengths, and cultural values of an individual, family or caregiver.</p>		
<p><b>3) Offer most efficient access</b></p>	<p>Access should be to an array of coordinated respite care services built on existing community support and services.</p>	<p>Access should be to an array of coordinated respite care services built on existing community support and services.</p>		
<p><b>4) Be Community-Driven</b></p>	<p>Be driven by community strengths, needs and resources.</p>	<p>Be driven by community strengths, needs and resources.</p>		
<p><b>5) Use a variety of funds and resources</b></p>	<p>Such funds and resources can include, but not be limited to: family or caregiver funds; private and volunteer resources; public funds; and exchange of care among families or caregivers.</p>	<p>Such funds and resources can include, but not be limited to: family or caregiver funds; private and volunteer resources; public funds; and exchange of care among families or caregivers.</p>		

Provision	Oregon	Nebraska	Wisconsin	Oklahoma
<b>Use of Funds</b>	To carry out the purposes described; for costs related to developing provider recruitment and training, information and referral, outreach, and other components of local respite care; one time only start-up costs related to establishment of the community lifespan respite care program; and minimum administrative costs for maintaining ongoing program operation.	To establish and carry out activities of NLRSP; costs related to developing provider recruitment and training, information and referral, outreach, and other components of the provision of respite services; one-time only startup costs related to the establishment of the community lifespan respite services program; minimum administrative costs for operating the NLRSP.		
<b>Funds Appropriated</b>	FY 1997-1999: \$250,000 FY 1999-2001: \$765,000 FY 2001-2003: \$1.2 million	FY 1999-2000: \$513,700 FY 2000-2001: \$511,500	FY 1999-2000: \$50,000 FY 2000-2001: \$225,000	Funds voluntarily pooled from Dept of Human Services: Developmental Disabilities Services Division, Division of Children & Family Services, Division of Aging, and Family Support Division, Field Operations, and Marriage Initiative/TANF; Department of Health: Department of Mental Health; Maxine and Jack Zarrow Foundation, Anne and Henry Zarrow Foundation, Oklahoma Association of Community Action Agencies, Oklahoma Commission on Children & Youth. TOTAL: \$851,820 (3/01)
<b>Evaluation Required</b>	Yes, by OLRCP, and under respite services, quality assurance and evaluation.	Yes, by NLRSP and under respite services, quality assurance and evaluation.	Yes, by June 1, 2004, the statewide organization must evaluate the lifespan respite care projects. If following the evaluation, the DHF and the statewide organization together determine that it is feasible to integrate the lifespan respite care project with the Family Care Program, the DBFS shall provide statutory language to affect this integration.	

Provision	Oregon	Nebraska	Wisconsin	Oklahoma
<b>Contact</b>	Oregon Lifespan Respite Program Lee Girard 500 Summer Street NE, E-10 Salem, OR 97310-1076 503-947-1199 <a href="mailto:Lee.A.Girard@state.or.us">Lee.A.Girard@state.or.us</a>	Linda Sand/Marcia Alber Respite Subsidy Plan Across the Lifespan Health and Human Services, Aging & Disability Services P.O. Box 95044 Lincoln, NE 68509 402-471-1689 <a href="mailto:linda.sand@hhss.state.ne.us">linda.sand@hhss.state.ne.us</a>	Jim Schroeder Respite Care Association of Wisconsin 6320 Monona Drive Suite 314 Madison, WI 53716 608-222-2033 <a href="mailto:jschroeder@respitecare.wi.org">jschroeder@respitecare.wi.org</a>	Rose Ann Percival OK Dept. of Human Services/ Oklahoma Respite Resource Network (ORRN) P.O. Box 25352 Oklahoma City, OK 73125 405-522-0600 <a href="mailto:Roseann.percival@okdhs.org">Roseann.percival@okdhs.org</a>
<b>Effective Date</b>	July 1, 1997	August 28, 1999	Fall, 1999	Program implemented without legislation March 2000.

Prepared by National Respite Coalition. Updated September 2004.  
For more information, contact Jill Kagan, 4016 Oxford Street, Annandale, VA, 22003, 703-256-9578, or [jbkagan@aol.com](mailto:jbkagan@aol.com)



# Lifespan Respite Survey

## A. Agency Information

Program Name Respite Subsidy Plan Across the Lifespan

Contact Person Linda Sand/Marcia Alber

Address Health & Human Services, Aging & Disability Services, P.O. Box 95044

City Lincoln State Nebraska Zip 68509

Web URL www.hhs.state.ne.us/chd/rspindex.htm Email linda.sand@hhs.state.ne.us

Phone (402) 471-1689 Fax (402) 471-6352

We began offering Statewide Respite Services in (year) 2002

What kind of organization administers the Lifespan Respite Program?

- Child/Family/Adult Public Welfare Agency
- Child/Family /Adult Private Welfare Agency
- Statewide Respite Coalition
- Long Term Care Agency
- Mental Health Agency
- Other (please specify below)

## B. State Lifespan Respite Program Description

1. How do families find out about the respite options in your state? (Check all that apply)

- Referrals from medical professionals
- Referrals from social service agencies
- Newspaper advertisements
- Word of mouth (friends)
- Public Service Announcements (radio, TV, newspaper)
- Posters
- Other (Please specify): Statewide infrastructure, 6 Respite Network Coordinators do marketing

2. Does your state use a voucher system of payment?  Yes  No  
If yes, are vouchers given

- Directly to families or caregivers?  Yes  No
- To direct care providers?  Yes  No
- To the community based respite programs?  Yes  No

3. Has your State Lifespan Program worked with the agency that administers the National Family Caregiver Support Program (NFCSP)?  Yes  No

If so, have you been able to administer the funding designated for respite?  Yes  No

Nebraska

4. Has your State Lifespan Program worked with the Area Agencies on Aging?  Yes  No  
If so, how have you worked together or if not, why not?

**We made the AAAs aware of program, provided applications. Have an established working relationship/communication. Our agency contracts with AAAs for Medicaid Waiver Service Coordination and Respite Network Coordinators also recruit waiver providers.**

5. In what ways does your State Lifespan Program work with the State Respite Coalition?

**Most of the Respite Network Coordinators attend Respite Coalition meetings as do Program Administrators although we are not official members. Some effort is being made to establish another respite coalition in the western part of the state. The two Coalitions would work together and it would enable more attendance, awareness, and participation statewide.**

6. In general, what have been the effects of the recent state budget cuts on Lifespan Respite services?

**Because our funding comes from Tobacco Settlement Funds, we have had no cuts.**

7. Is there an income eligibility system in place or can anyone of any financial situation receive respite funds or services? If there is an income eligibility system in place, please describe.

**Income must be below 312% of the Federal Poverty Levels. Limits are adjusted annually when we get the FPLs. We also have resource limits. We count only liquid resources. Resources with significant penalties for early withdrawal may be disregarded. What is significant is determined case by case.**

8. Please describe what mechanisms, if any, are in place to prevent fraud and abuse of the system?

**Rules and Regs allow Prudent Person Principle for verifying any questionable data. Network Coordinators will make contact with clients, if needed. We have the option to require medical documentation. All claims are reviewed by 2 persons before they are processed. Rules and Regs allow for collection of over payments and prosecution for fraud.**

9. What risk management systems are in place to protect against liability?

**Our program is totally client-directed. Clients/caregivers hire, train, schedule and negotiate pay rates for themselves. Network Coordinators will provide clients with a list of providers but clients do all the contacting of the providers.**

10. Are there faith-based programs in the Statewide Lifespan Respite Network?  Yes  No

11. Are crisis nurseries or crisis respite programs part of the Lifespan Respite in your state?  Yes  No

12. What percentage of funding comes from the following sources? *(Percentages should add up to 100%)*

- |  |   |
|--|---|
| _____ % User fees  | _____ % Adoption Assistance/Opportunities Acts                  |
| _____ % Private contributions, fund raisers & planned giving                               | _____ % Social Services Block Grant/Federal Child Welfare Funds |
| _____ % United Way or other local private funding  | _____ % Maternal & Child Health Act (Title V)                   |
| _____ % City/County general funds  | _____ % Mental Health Funds                                     |
| _____ % State general funds  | _____ % Child Care Development Block Grant                      |
| _____ % Medicaid Waivers<br>(Home & Community Based Services)                              | <b>100*</b> % Other Federal Funds                               |
| _____ % Community Based Family Resource & Support  | _____ % Services for the Aging                                  |
| _____ % Profit-making business   | _____ % TANF (Temporary Aid for Needy Families)                 |
| _____ % Foundations  | _____ % Other sources of funding (please describe)              |
| _____ % Promoting Safe and Stable Families Act<br>(formerly Family Preservation & Support) | _____ % Don't know  |

**\*Tobacco Settlement Funds**

Are the percentages an accurate count?  or an estimate?

13. Is there a statewide respite provider recruitment and training plan?  Yes  No

Please describe how respite provider recruitment and training occurs in your state.

**Six Respite Network Coordinators have contracts with HHSS. They are responsible for recruiting providers. They provide some general training for providers and caregivers. However, families/clients/caregivers are responsible for training specific to caring for the client.**

14. Are community based respite programs required to conduct program and/or consumer outcome evaluation?  Yes  No



**C . Consumer Description**

**Nebraska**

Do you collect demographic information on individuals served by the community based respite programs in your network? If so, please either complete the following or provide us with other written material that describes the populations served and the unmet need in your state.

1. Please provide the following data (estimate if necessary)

- a. How many families are currently on program waiting lists for respite services? 0  
Is this an accurate count?  or an estimate?
- b. How many families have been turned away from respite care services in the last year? 333  
Is this an accurate count?  or an estimate?
- c. How many families received respite care services in the last year? don't track families--325  
Is this an accurate count?  or an estimate?
- d. How many children and/or dependant adults received respite care services in the last year? 454 (+ 65 funded for DCP program)  
Is this an accurate count?  or an estimate?
- e. How many hours of respite service did the program provide in the last year? do not track } we pay \$125/mo. families negotiate rates, schedule hours, select providers  
Is this an accurate count?  or an estimate?
- f. How many days of respite service did the program provide in the last year? do not track  
Is this an accurate count?  or an estimate?

2. Please check all that apply and indicate the percentage that this population makes up of the total population of individuals receiving respite services.

Condition	Served	% of Total Population	Condition	Served	% of Total Population
Risk of Abuse/Neglect	<input type="checkbox"/>	_____	Mental Illness	<input checked="" type="checkbox"/>	<u>1.5%</u>
A History of Abuse/Neglect	<input type="checkbox"/>	_____	Visual Impairments	<input checked="" type="checkbox"/>	<u>2.1%</u>
Developmental Disabilities	<input checked="" type="checkbox"/>	<u>8.6%</u>	Hearing Impairments	<input checked="" type="checkbox"/>	<u>.1%</u>
Attention Deficit Disorders	<input type="checkbox"/>	_____	Chronic or terminal Illness	<input type="checkbox"/>	_____
Physical Disabilities	<input type="checkbox"/>	_____	Medically Fragile Conditions	<input type="checkbox"/>	_____
Mental Retardation	<input checked="" type="checkbox"/>	<u>8.2%</u>	HIV/AIDS	<input checked="" type="checkbox"/>	<u>.1%</u>
Autism	<input checked="" type="checkbox"/>	<u>4.2%</u>	Adults with Dementia	<input checked="" type="checkbox"/>	<u>8.9%</u>
Speech/Language Disabilities	<input checked="" type="checkbox"/>	<u>3.8%</u>	Other (please specify):	<input checked="" type="checkbox"/>	<u>62.5%</u>

3. How many individuals in each age group received respite services within the last 12 months?

Age Ranges	Numbers Served
0-3 years	<u>66</u>
4-6 years	<u>43</u>
7-12 years	<u>71</u>
13-18 years	<u>36</u>
19-21 years	<u>12</u>
22-65 years	<u>56</u>
over 65 years	<u>169 (Just a note of interest: 5 are age 101!!)</u>

*If the age grouping that you use is different than these, please feel free to use your own age grouping categories.*

Statewide Lifespan Respite Programs

Nebraska

4. Estimate the percentage of families served with respite/crisis care last year in the following income categories: (Numbers should add up to 100%)

\_\_\_\_\_ % \$0-\$9,999                      \_\_\_\_\_ % \$10,000-\$14,999                      \_\_\_\_\_ % \$15,000-\$24,999
\_\_\_\_\_ % \$25,000-\$34,999                      \_\_\_\_\_ % \$35,000-\$44,999                      \_\_\_\_\_ % \$45,000-\$59,999
\_\_\_\_\_ % \$60,000 and up                      **100% below \$31,000. We do not track incomes.**

(If the income categories that you use are different than the above, please feel free to use your own categories.)

5. Do you have data to compare number of families served prior to the implementation of Lifespan Respite with numbers of families now being served?  Yes                       No

If yes, please report the number of families served prior to the implementation of Lifespan Respite 130
The number of families served since Lifespan Respite implementation 943

6. Are there still un-served or under served populations in your state? If so, please describe.

**Families whose income exceeds 312% FPL or whose resources are over \$38,000-\$50,000.**

Please feel free to contact us if you need clarification regarding any of the above questions.

Either Maggie Edgar or I will be contacting you during the week of March 15<sup>th</sup> to schedule a telephone interview. During the interview we will follow up on some of the above questions and facilitate a discussion on other topics related to Lifespan Respite. Five of the questions that we will be interested in discussing are listed below.

- 1. How is Lifespan Respite implemented and administered in your state?
2. What are the savings to the state by having one agency administer the program, as opposed to multiple agencies?
3. How is your state working with Medicaid?
4. What are the actual costs for local respite programs? Can you provide us with a "typical" program budget? Is there any leveraging of funds to match the state dollars?
5. Anything else about your Lifespan Respite Program you would like to have included in the report.

Please include a copy of the following documents with your returned survey.

- State's Lifespan Respite Legislation
• Lifespan Respite Policies and Procedures if available
• Annual Report

Please return your survey and written documents to ARCH National Resource Center for Respite and Crisis Care Services, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514 by March 19, 2004.

Thank you for contributing your state's information to this important report which will be shared with other respite programs, state respite coalitions and state and federal policy makers.

Sincerely,

Linda Baker

Linda Baker, MSW



# Lifespan Respite Survey

## A. Agency Information

Program Name Department of Human Services & Oklahoma Respite Resource Network

Contact Person Rose Ann Percival

Address P.O. Box 25352

City Oklahoma City State Oklahoma Zip 73125

Web URL www.oasis.ouhsc.edu/index.htm Email RoseAnn.Percival@okdhs.org

Phone (405) 522-0600 Fax (405) 522-0729

We began offering Statewide Respite Services in (year) 2000

What kind of organization administers the Lifespan Respite Program?

- |  |   |
|--|---|
| <input checked="" type="checkbox"/> Child/Family/Adult Public Welfare Agency | <input type="checkbox"/> Child/Family /Adult Private Welfare Agency |
| <input type="checkbox"/> Statewide Respite Coalition                         | <input type="checkbox"/> Long Term Care Agency                      |
| <input type="checkbox"/> Mental Health Agency                                | <input type="checkbox"/> Other (please specify below)               |

## B. State Lifespan Respite Program Description

1. How do families find out about the respite options in your state? (Check all that apply)

- |  |  |
|--|--|
| <input checked="" type="checkbox"/> Referrals from medical professionals                                   | <input checked="" type="checkbox"/> Referrals from social service agencies |
| <input type="checkbox"/> Newspaper advertisements  | <input checked="" type="checkbox"/> Word of mouth (friends)                |
| <input type="checkbox"/> Public Service Announcements (radio, TV, newspaper)                               | <input type="checkbox"/> Posters   |
| <input checked="" type="checkbox"/> Other (Please specify): <u>Statewide I&amp;R, Conferences, Website</u> |  |

2. Does your state use a voucher system of payment?  Yes  No

If yes, are vouchers given

- |  |   |  |
|--|---|--|
| Directly to families or caregivers?      | <input checked="" type="checkbox"/> Yes | <input type="checkbox"/> No            |
| To direct care providers?                | <input type="checkbox"/> Yes            | <input checked="" type="checkbox"/> No |
| To the community based respite programs? | <input type="checkbox"/> Yes            | <input checked="" type="checkbox"/> No |

3. Has your State Lifespan Program worked with the agency that administers the National Family Caregiver Support Program (NFCSP)?  Yes  No

If so, have you been able to administer the funding designated for respite?  Yes  No

Oklahoma

4. Has your State Lifespan Program worked with the Area Agencies on Aging?  Yes  No  
If so, how have you worked together or if not, why not?

**Area Agencies on Aging are a partner with ORRN. All eleven AAAs have signed contracts with DHS to provide respite care vouchers. The AAAs have used Older American’s Act money and other discretionary funds totaling \$1.1 million. The AAAs provide information to their clients about the respite voucher program and refer them to OASIS for an application. The AAAs approve the applications and the vouchers are issued by the respite coordinator in Aging Services Division.**

5. In what ways does your State Lifespan Program work with the State Respite Coalition?

**The Oklahoma Respite Resource Network is the State Lifespan Program and coordinates all contracts and funding sources through DHS.**

6. In general, what have been the effects of the recent state budget cuts on Lifespan Respite services?

**None**

7. Is there an income eligibility system in place or can anyone of any financial situation receive respite funds or services? If there is an income eligibility system in place, please describe.

**All applicants over age 60 and “Sooner Start”--no eligibility requirements. For all other applicants--eligible if they make under sixty thousand a year.**

8. Please describe what mechanisms, if any, are in place to prevent fraud and abuse of the system?

**DHS conducts random audits, phone calls, and home visits.**

Oklahoma

9. What risk management systems are in place to protect against liability?

**Since caregivers hire their own providers there is no liability to DHS or any ORRN program.**

10. Are there faith-based programs in the Statewide Lifespan Respite Network?  Yes  No

11. Are crisis nurseries or crisis respite programs part of the Lifespan Respite in your state?  Yes  No

12. What percentage of funding comes from the following sources? (Percentages should add up to 100%)

<u>  0  </u> % User fees	<u>  2  </u> % Adoption Assistance/Opportunities Acts
<u>  0  </u> % Private contributions, fund raisers & planned giving	<u>  1  </u> % Social Services Block Grant/Federal Child Welfare Funds
<u>  0  </u> % United Way or other local private funding	<u>  1  </u> % Maternal & Child Health Act (Title V)
<u>  0  </u> % City/County general funds	<u>  8  </u> % Mental Health Funds
<u> 11  </u> % State general funds	<u>  0  </u> % Child Care Development Block Grant
<u>  0  </u> % Medicaid Waivers (Home & Community Based Services)	<u> 30  </u> % Other Federal Funds
<u> 10  </u> % Community Based Family Resource & Support	<u> 10  </u> % Services for the Aging
<u>  0  </u> % Profit-making business	<u> 10  </u> % TANF (Temporary Aid for Needy Families)
<u>  2  </u> % Foundations	<u>  5*  </u> % Other sources of funding (please describe)
<u>  5  </u> % Promoting Safe and Stable Families Act (formerly Family Preservation & Support)	<u>      </u> % Don't know            * <b>private foundations</b>

Are the percentages an accurate count?  or an estimate?

13. Is there a statewide respite provider recruitment and training plan?  Yes  No

Please describe how respite provider recruitment and training occurs in your state.

14. Are community based respite programs required to conduct program and/or consumer outcome evaluation?  Yes  No

**C . Consumer Description**

Do you collect demographic information on individuals served by the community based respite programs in your network? If so, please either complete the following or provide us with other written material that describes the populations served and the unmet need in your state.

1. Please provide the following data (estimate if necessary)
  - a. How many families are currently on program waiting lists for respite services? Don't have formal waiting list  
Is this an accurate count?  or an estimate?
  - b. How many families have been turned away from respite care services in the last year? 425  
Is this an accurate count?  or an estimate?
  - c. How many families received respite care services in the last year? 2200  
Is this an accurate count?  or an estimate?
  - d. How many children and/or dependant adults received respite care services in the last year? 1800 (includes aging)  
Is this an accurate count?  or an estimate?
  - e. How many hours of respite service did the program provide in the last year? 200,000 hours  
Is this an accurate count?  or an estimate?
  - f. How many days of respite service did the program provide in the last year? unknown, figures by hour  
Is this an accurate count?  or an estimate?
2. Please check all that apply and indicate the percentage that this population makes up of the total population of individuals receiving respite services.

Condition	Served	% of Total Population
Risk of Abuse/Neglect	<input checked="" type="checkbox"/>	<u>9%</u>
A History of Abuse/Neglect	<input checked="" type="checkbox"/>	<u>?</u>
Developmental Disabilities	<input checked="" type="checkbox"/>	<u>23%</u>
Attention Deficit Disorders	<input checked="" type="checkbox"/>	<u>1%</u>
Physical Disabilities	<input checked="" type="checkbox"/>	<u>6%</u>
Mental Retardation	<input checked="" type="checkbox"/>	<u>included in DD</u>
Autism	<input checked="" type="checkbox"/>	<u>2%</u>
Speech/Language Disabilities	<input type="checkbox"/>	<u>          </u>

Condition	Served	% of Total Population
Mental Illness	<input checked="" type="checkbox"/>	<u>5%</u>
Visual Impairments	<input type="checkbox"/>	<u>          </u>
Hearing Impairments	<input type="checkbox"/>	<u>          </u>
Chronic or terminal Illness	<input checked="" type="checkbox"/>	<u>4%</u>
Medically Fragile Conditions	<input checked="" type="checkbox"/>	<u>4%</u>
HIV/AIDS	<input checked="" type="checkbox"/>	<u>1%</u>
Adults with Dementia	<input checked="" type="checkbox"/>	<u>45%</u>
Other (please specify):	<input type="checkbox"/>	<u>          </u>

3. How many individuals in each age group received respite services within the last 12 months?

Age Ranges	Numbers Served
0-3 years	<u>          </u>
4-6 years	<u>Data</u>
7-12 years	<u>not</u>
13-18 years	<u>Available</u>
19-21 years	<u>          </u>
22-65 years	<u>          </u>
over 65 years	<u>          </u>

*If the age grouping that you use is different than these, please feel free to use your own age grouping categories.*

Oklahoma

4. Estimate the percentage of families served with respite/crisis care last year in the following income categories:  
(Numbers should add up to 100%)

<u>15</u> % \$0-\$9,999	<u>15</u> % \$10,000-\$14,999	<u>15</u> % \$15,000-\$24,999
<u>20</u> % \$25,000-\$34,999	<u>25</u> % \$35,000-\$44,999	<u>10</u> % \$45,000-\$59,999
<u>0</u> % \$60,000 and up		

(If the income categories that you use are different than the above, please feel free to use your own categories.)

5. Do you have data to compare number of families served prior to the implementation of Lifespan Respite with numbers of families now being served?  Yes  No

If yes, please report the number of families served prior to the implementation of Lifespan Respite \_\_\_\_\_

The number of families served since Lifespan Respite implementation \_\_\_\_\_

6. Are there still un-served or under served populations in your state? If so, please describe.

**Yes, spouses caring for spouses under the age of sixty, people under age of sixty with MS, aquired brain injury, chronic and terminal illnesses, grandparents under age 60 raising child with no disabilities.**

*Please feel free to contact us if you need clarification regarding any of the above questions.*

Either Maggie Edgar or I will be contacting you during the week of March 15<sup>th</sup> to schedule a telephone interview. During the interview we will follow up on some of the above questions and facilitate a discussion on other topics related to Lifespan Respite. Five of the questions that we will be interested in discussing are listed below.

1. How is Lifespan Respite implemented and administered in your state?
2. What are the savings to the state by having one agency administer the program, as opposed to multiple agencies?
3. How is your state working with Medicaid?
4. What are the actual costs for local respite programs? Can you provide us with a "typical" program budget? Is there any leveraging of funds to match the state dollars?
5. Anything else about your Lifespan Respite Program you would like to have included in the report.

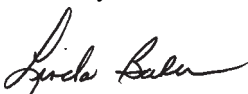
Please include a copy of the following documents with your returned survey.

- State's Lifespan Respite Legislation
- Lifespan Respite Policies and Procedures if available
- Annual Report

Please return your survey and written documents to ARCH National Resource Center for Respite and Crisis Care Services, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514 by March 19, 2004.

Thank you for contributing your state's information to this important report which will be shared with other respite programs, state respite coalitions and state and federal policy makers.

Sincerely,



Linda Baker, MSW



# Lifespan Respite Survey

## A. Agency Information

Program Name **Oregon Lifespan Respite Program**

Contact Person **Lee Girard**

Address **500 Summer St., NE, E-10**

City **Salem** State **Oregon** Zip **97301-1076**

Web URL **www.dhs.state.or.us/seniors/caregiving/respite\_care.htm** Email **Lee.A.Girard@state.or.us**

Phone **(503) 947-1199** Fax **(503) 373-7902**

We began offering Statewide Respite Services in (year) **1998**

What kind of organization administers the Lifespan Respite Program?

- |   |  |
|---|--|
| <input type="checkbox"/> Child/Family/Adult Public Welfare Agency | <input type="checkbox"/> Child/Family /Adult Private Welfare Agency                                    |
| <input type="checkbox"/> Statewide Respite Coalition              | <input type="checkbox"/> Long Term Care Agency   |
| <input type="checkbox"/> Mental Health Agency                     | <input checked="" type="checkbox"/> Other (please specify below)<br><b>State Human Services Agency</b> |

## B. State Lifespan Respite Program Description

1. How do families find out about the respite options in your state? (Check all that apply)

- |   |  |
|---|--|
| <input type="checkbox"/> Referrals from medical professionals                             | <input checked="" type="checkbox"/> Referrals from social service agencies |
| <input type="checkbox"/> Newspaper advertisements   | <input checked="" type="checkbox"/> Word of mouth (friends)                |
| <input checked="" type="checkbox"/> Public Service Announcements (radio, TV, newspaper)   | <input type="checkbox"/> Posters   |
| <input checked="" type="checkbox"/> Other (Please specify): <u><b>OregonCares.org</b></u> |  |

2. Does your state use a voucher system of payment?  Yes  No **in some local programs**  
If yes, are vouchers given

- |  |   |  |
|--|---|--|
| Directly to families or caregivers?      | <input checked="" type="checkbox"/> Yes | <input type="checkbox"/> No            |
| To direct care providers?                | <input type="checkbox"/> Yes            | <input checked="" type="checkbox"/> No |
| To the community based respite programs? | <input type="checkbox"/> Yes            | <input checked="" type="checkbox"/> No |

3. Has your State Lifespan Program worked with the agency that administers the National Family Caregiver Support Program (NFCSP)?  Yes  No

If so, have you been able to administer the funding designated for respite?  Yes  No



Oregon

4. Has your State Lifespan Program worked with the Area Agencies on Aging?  Yes  No  
If so, how have you worked together or if not, why not?

**-A number of AAAs are sponsoring organizations for Lifespan Respite programs (LSR)  
-Some AAAs contract with LSR programs for Family Caregiver Support Program provision  
-Most AAAs participate on local LSR advisory councils**

5. In what ways does your State Lifespan Program work with the State Respite Coalition?

**-The Oregon Respite Advisory Council provides guidance and advocacy regarding the statewide respite system.**

6. In general, what have been the effects of the recent state budget cuts on Lifespan Respite services?

**-Community partners have fewer resources to contribute local LSR networks and services  
-Sponsoring organizations have fewer resources to provide administrative support of LSR programs  
-Increased demand for respite**

7. Is there an income eligibility system in place or can anyone of any financial situation receive respite funds or services? If there is an income eligibility system in place, please describe.

**There are financial eligibility criteria to receive LSR program information, assistance, referral, support groups, etc. Some of the respite funding resources do have income eligibility criteria, that varies by source.**

8. Please describe what mechanisms, if any, are in place to prevent fraud and abuse of the system?

**Fraud/abuse prevention are built into respite funding source systems (e.g., Medicaid). All LSR programs have policies regarding criminal background checks for paid providers.**

9. What risk management systems are in place to protect against liability?

- releases
- criminal history background checks
- information and training for family caregiving on being employers of respite workers

10. Are there faith-based programs in the Statewide Lifespan Respite Network?  Yes  No

**As community partners**

11. Are crisis nurseries or crisis respite programs part of the Lifespan Respite in your state?  Yes  No

**Some of the programs**

12. What percentage of funding comes from the following sources? (Percentages should add up to 100%)

- \_\_\_\_\_ % User fees
- \_\_\_\_\_ % Private contributions, fund raisers & planned giving
- \_\_\_\_\_ % United Way or other local private funding
- \_\_\_\_\_ % City/County general funds
- 100** % State general funds
- \_\_\_\_\_ % Medicaid Waivers  
(Home & Community Based Services)
- \_\_\_\_\_ % Community Based Family Resource & Support
- \_\_\_\_\_ % Profit-making business
- \_\_\_\_\_ % Foundations
- \_\_\_\_\_ % Promoting Safe and Stable Families Act  
(formerly Family Preservation & Support)

Are the percentages an accurate count?  or an estimate?

13. Is there a statewide respite provider recruitment and training plan?  Yes  No

Please describe how respite provider recruitment and training occurs in your state.

14. Are community based respite programs required to conduct program and/or consumer outcome evaluation?  Yes  No

**C . Consumer Description**

**Oregon**

Do you collect demographic information on individuals served by the community based respite programs in your network? If so, please either complete the following or provide us with other written material that describes the populations served and the unmet need in your state.

1. Please provide the following data (estimate if necessary)
  - a. How many families are currently on program waiting lists for respite services? Don't track at state level  
Is this an accurate count?  or an estimate?
  - b. How many families have been turned away from respite care services in the last year? 2074  
Is this an accurate count?  or an estimate?
  - c. How many families received respite care services in the last year? Don't track by family  
Is this an accurate count?  or an estimate?
  - d. How many children and/or dependant adults received respite care services in the last year? 4675 respite ref. 9968 I&R contacts  
Is this an accurate count?  or an estimate?
  - e. How many hours of respite service did the program provide in the last year? N/A  
Is this an accurate count?  or an estimate?
  - f. How many days of respite service did the program provide in the last year? N/A  
Is this an accurate count?  or an estimate?

2. Please check all that apply and indicate the percentage that this population makes up of the total population of individuals receiving respite services.

Condition	Served	% of Total Population	Condition	Served	% of Total Population
Risk of Abuse/Neglect	<input checked="" type="checkbox"/>	<u>17%</u>	Mental Illness	<input checked="" type="checkbox"/>	<u>9%</u>
A History of Abuse/Neglect	<input type="checkbox"/>	_____	Visual Impairments	<input type="checkbox"/>	_____
Developmental Disabilities	<input checked="" type="checkbox"/>	<u>16%</u>	Hearing Impairments	<input type="checkbox"/>	_____
Attention Deficit Disorders	<input type="checkbox"/>	_____	Chronic or terminal Illness	<input checked="" type="checkbox"/>	<u>11%</u>
Physical Disabilities	<input checked="" type="checkbox"/>	<u>14%</u>	Medically Fragile Conditions	<input checked="" type="checkbox"/>	<u>4%</u>
Mental Retardation	<input type="checkbox"/>	_____	HIV/AIDS	<input type="checkbox"/>	_____
Autism	<input type="checkbox"/>	_____	Adults with Dementia	<input checked="" type="checkbox"/>	<u>8%</u>
Speech/Language Disabilities	<input type="checkbox"/>	_____	Other (please specify):	<input checked="" type="checkbox"/>	<u>21%</u>
			<b>no disability/special need or unspecified</b>		

3. How many individuals in each age group received respite services within the last 12 months?

Age Ranges	Numbers Served
0-3 years	_____
4-6 years	_____
7-12 years	<u>757</u>
13-18 years	<u>214</u>
19-21 years	<u>465</u>
22-65 years	
over 65 years	<u>479</u>

*If the age grouping that you use is different than these, please feel free to use your own age grouping categories.*

4. Estimate the percentage of families served with respite/crisis care last year in the following income categories: (Numbers should add up to 100%)

_____ % \$0-\$9,999	_____ % \$10,000-\$14,999	_____ % \$15,000-\$24,999
_____ % \$25,000-\$34,999	_____ % \$35,000-\$44,999	_____ % \$45,000-\$59,999
_____ % \$60,000 and up	<b>Not currently tracking at state level</b>	

(If the income categories that you use are different than the above, please feel free to use your own categories.)

5. Do you have data to compare number of families served prior to the implementation of Lifespan Respite with numbers of families now being served?  Yes  No

If yes, please report the number of families served prior to the implementation of Lifespan Respite \_\_\_\_\_

The number of families served since Lifespan Respite implementation \_\_\_\_\_

6. Are there still un-served or under served populations in your state? If so, please describe.

Please feel free to contact us if you need clarification regarding any of the above questions.

Either Maggie Edgar or I will be contacting you during the week of March 15<sup>th</sup> to schedule a telephone interview. During the interview we will follow up on some of the above questions and facilitate a discussion on other topics related to Lifespan Respite. Five of the questions that we will be interested in discussing are listed below.

1. How is Lifespan Respite implemented and administered in your state?
2. What are the savings to the state by having one agency administer the program, as opposed to multiple agencies?
3. How is your state working with Medicaid?
4. What are the actual costs for local respite programs? Can you provide us with a "typical" program budget? Is there any leveraging of funds to match the state dollars?
5. Anything else about your Lifespan Respite Program you would like to have included in the report.

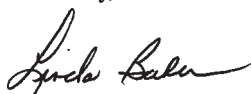
Please include a copy of the following documents with your returned survey.

- State's Lifespan Respite Legislation
- Lifespan Respite Policies and Procedures if available
- Annual Report

Please return your survey and written documents to ARCH National Resource Center for Respite and Crisis Care Services, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514 by March 19, 2004.

Thank you for contributing your state's information to this important report which will be shared with other respite programs, state respite coalitions and state and federal policy makers.

Sincerely,



Linda Baker, MSW



# Lifespan Respite Survey

## A. Agency Information

Program Name Respite Care Association of Wisconsin

Contact Person Jim Schroeder

Address 6320 Monona Drive, Suite 314

City Madison State Wisconsin Zip 53716

Web URL www.respitecarewi.org Email jschroeder@respitecarewi.org

Phone (608) 222-2033 Fax (608) 222-2034

We began offering Statewide Respite Services in (year) 2000

What kind of organization administers the Lifespan Respite Program?

- |   |   |
|---|---|
| <input type="checkbox"/> Child/Family/Adult Public Welfare Agency | <input type="checkbox"/> Child/Family /Adult Private Welfare Agency |
| <input checked="" type="checkbox"/> Statewide Respite Coalition   | <input type="checkbox"/> Long Term Care Agency                      |
| <input type="checkbox"/> Mental Health Agency                     | <input type="checkbox"/> Other (please specify below)               |

## B. State Lifespan Respite Program Description

1. How do families find out about the respite options in your state? (Check all that apply)

- |   |  |
|---|--|
| <input checked="" type="checkbox"/> Referrals from medical professionals                | <input checked="" type="checkbox"/> Referrals from social service agencies |
| <input checked="" type="checkbox"/> Newspaper advertisements                            | <input checked="" type="checkbox"/> Word of mouth (friends)                |
| <input checked="" type="checkbox"/> Public Service Announcements (radio, TV, newspaper) | <input type="checkbox"/> Posters   |
| <input type="checkbox"/> Other (Please specify): _____                                  |  |

2. Does your state use a voucher system of payment?  Yes  No
- If yes, are vouchers given
- |  |   |                             |
|--|---|-----------------------------|
| Directly to families or caregivers?      | <input checked="" type="checkbox"/> Yes | <input type="checkbox"/> No |
| To direct care providers?                | <input type="checkbox"/> Yes            | <input type="checkbox"/> No |
| To the community based respite programs? | <input type="checkbox"/> Yes            | <input type="checkbox"/> No |

3. Has your State Lifespan Program worked with the agency that administers the National Family Caregiver Support Program (NFCSP)?  Yes  No
- If so, have you been able to administer the funding designated for respite?  Yes  No

4. Has your State Lifespan Program worked with the Area Agencies on Aging?  
If so, how have you worked together or if not, why not?  Yes  No

5. In what ways does your State Lifespan Program work with the State Respite Coalition?

**We are the one and the same.**

6. In general, what have been the effects of the recent state budget cuts on Lifespan Respite services?

**Planned expansion from pilot projects in 5 of 72 counties has not occurred.**

7. Is there an income eligibility system in place or can anyone of any financial situation receive respite funds or services? If there is an income eligibility system in place, please describe.

**No income eligibility system in place.**

8. Please describe what mechanisms, if any, are in place to prevent fraud and abuse of the system?

**Programs verify that vouchers were actually used to purchase respite.**

9. What risk management systems are in place to protect against liability?

**Each network develops risk management systems with technical assistance from us.**

10. Are there faith-based programs in the Statewide Lifespan Respite Network?  Yes  No

11. Are crisis nurseries or crisis respite programs part of the Lifespan Respite in your state?  Yes  No

12. What percentage of funding comes from the following sources? *(Percentages should add up to 100%)*

- |  |   |
|--|---|
| _____ % User fees  | _____ % Adoption Assistance/Opportunities Acts                  |
| <u>10</u> % Private contributions, fund raisers & planned giving                           | _____ % Social Services Block Grant/Federal Child Welfare Funds |
| <u>10</u> % United Way or other local private funding                                      | _____ % Maternal & Child Health Act (Title V)                   |
| <u>10</u> % City/County general funds  | _____ % Mental Health Funds                                     |
| <u>60</u> % State general funds  | _____ % Child Care Development Block Grant                      |
| _____ % Medicaid Waivers<br>(Home & Community Based Services)                              | _____ % Other Federal Funds                                     |
| _____ % Community Based Family Resource & Support  | _____ % Services for the Aging                                  |
| _____ % Profit-making business   | _____ % TANF (Temporary Aid for Needy Families)                 |
| _____ % Foundations  | _____ % Other sources of funding (please describe)              |
| _____ % Promoting Safe and Stable Families Act<br>(formerly Family Preservation & Support) | <u>10</u> % Don't know  |

Are the percentages an accurate count?  or an estimate?

13. Is there a statewide respite provider recruitment and training plan?  Yes  No

Please describe how respite provider recruitment and training occurs in your state.

**RCAW developed Provider Training Manual. Programs conduct. RCAW conducts training on provider recruitment. Programs conduct provider recruitment.**

14. Are community based respite programs required to conduct program and/or consumer outcome evaluation?  Yes  No

**C. Consumer Description**

Do you collect demographic information on individuals served by the community based respite programs in your network? If so, please either complete the following or provide us with other written material that describes the populations served and the unmet need in your state.

1. Please provide the following data (estimate if necessary)
  - a. How many families are currently on program waiting lists for respite services? 1000+  
Is this an accurate count?  or an estimate?
  - b. How many families have been turned away from respite care services in the last year? \_\_\_\_\_  
Is this an accurate count?  or an estimate?
  - c. How many families received respite care services in the last year? 350  
Is this an accurate count?  or an estimate?
  - d. How many children and/or dependant adults received respite care services in the last year? 414  
Is this an accurate count?  or an estimate?
  - e. How many hours of respite service did the program provide in the last year? 12,463  
Is this an accurate count?  or an estimate?
  - f. How many days of respite service did the program provide in the last year? Unknown  
Is this an accurate count?  or an estimate?

2. Please check all that apply and indicate the percentage that this population makes up of the total population of individuals receiving respite services.

Condition	Served	% of Total Population	Condition	Served	% of Total Population
Risk of Abuse/Neglect	<input checked="" type="checkbox"/>	<u>4%</u>	Mental Illness	<input checked="" type="checkbox"/>	<u>1%</u>
A History of Abuse/Neglect	<input type="checkbox"/>	_____	Visual Impairments	<input type="checkbox"/>	_____
Developmental Disabilities	<input checked="" type="checkbox"/>	<u>38%</u>	Hearing Impairments	<input type="checkbox"/>	_____
Attention Deficit Disorders	<input type="checkbox"/>	_____	Chronic or terminal Illness	<input type="checkbox"/>	_____
Physical Disabilities	<input checked="" type="checkbox"/>	<u>7%</u>	Medically Fragile Conditions	<input checked="" type="checkbox"/>	<u>7%</u>
Mental Retardation	<input type="checkbox"/>	_____	HIV/AIDS	<input type="checkbox"/>	_____
Autism	<input type="checkbox"/>	_____	Adults with Dementia	<input checked="" type="checkbox"/>	<u>6%</u>
Speech/Language Disabilities	<input type="checkbox"/>	_____	Other (please specify):	<input checked="" type="checkbox"/>	<u>21%</u>
			<b>Multiple Needs</b>		
			<b>Emotional/Behavioral Disorders</b>		

3. How many individuals in each age group received respite services within the last 12 months?

Age Ranges	Numbers Served
0-3 years	<u>38</u>
4-6 years	<u>66</u>
7-12 years	<u>87</u>
13-18 years	<u>64</u>
<del>19-21 years</del>	_____
<del>22-65 years</del> 19-65 years	<u>101</u>
over 65 years	<u>58</u>

*If the age grouping that you use is different than these, please feel free to use your own age grouping categories.*



Wisconsin

4. Estimate the percentage of families served with respite/crisis care last year in the following income categories: (Numbers should add up to 100%)

\_\_\_\_\_ % \$0-\$9,999      \_\_\_\_\_ % \$10,000-\$14,999      \_\_\_\_\_ % \$15,000-\$24,999  
\_\_\_\_\_ % \$25,000-\$34,999      \_\_\_\_\_ % \$35,000-\$44,999      \_\_\_\_\_ % \$45,000-\$59,999  
\_\_\_\_\_ % \$60,000 and up      **Not Tracked**

(If the income categories that you use are different than the above, please feel free to use your own categories.)

5. Do you have data to compare number of families served prior to the implementation of Lifespan Respite with numbers of families now being served?  Yes  No

If yes, please report the number of families served prior to the implementation of Lifespan Respite \_\_\_\_\_

The number of families served since Lifespan Respite implementation \_\_\_\_\_

6. Are there still un-served or under served populations in your state? If so, please describe.

**Yes, particularly autism, DD, children with emotional/behavioral disturbance, children with special health care needs, and physically disabled.**

*Please feel free to contact us if you need clarification regarding any of the above questions.*

Either Maggie Edgar or I will be contacting you during the week of March 15<sup>th</sup> to schedule a telephone interview. During the interview we will follow up on some of the above questions and facilitate a discussion on other topics related to Lifespan Respite. Five of the questions that we will be interested in discussing are listed below.

- 1. How is Lifespan Respite implemented and administered in your state?
- 2. What are the savings to the state by having one agency administer the program, as opposed to multiple agencies?
- 3. How is your state working with Medicaid?
- 4. What are the actual costs for local respite programs? Can you provide us with a "typical" program budget? Is there any leveraging of funds to match the state dollars?
- 5. Anything else about your Lifespan Respite Program you would like to have included in the report.

Please include a copy of the following documents with your returned survey.

- State's Lifespan Respite Legislation
- Lifespan Respite Policies and Procedures if available
- Annual Report

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