

Building Oregon's Lifespan Respite Care System

Contents

A wellness concept...	<i>page 3</i>
What is respite care?...	<i>page 4</i>
What is Lifespan?...	<i>page 5</i>
Local networks...	<i>page 6</i>
Guiding principles...	<i>page 7</i>
Roles & responsibilities...	<i>page 8</i>
History...	<i>page 10</i>
Lessons learned...	<i>page 13</i>
Appendices...	<i>page 14</i>

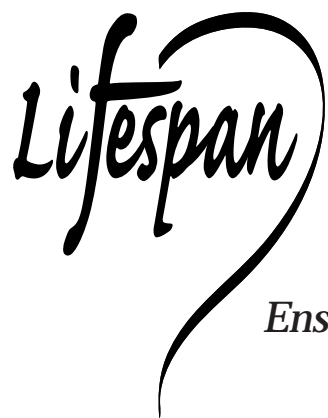
Respite — “a wellness concept”

Families are Oregon’s most important and constant care providers for individuals with special needs — of all ages. Citizens and state policymakers agree that accessible respite care services and related in-home supports are essential to the preservation and well-being of the family.

Oregon is taking steps to ensure that these services are available to all families. In July of 1997, legislators passed the Lifespan Respite Care bill, with no dissenting votes. It established the Oregon Lifespan Respite Care Program to assist local communities in building respite access networks.

This booklet highlights the structure of Oregon’s respite care system, key elements, network components and lessons learned.

The Lifespan Respite Care Program is pleased to share this information with others interested in building lasting supports for families.



Ensuring access to respite care services in Oregon

What is respite care?

Being a caregiver can be a rewarding but difficult job. To provide good care, caregivers need to take care of themselves.

Many caregivers face health and emotional problems. People providing ongoing intensive care sometimes experience feelings of depression, frustration and isolation.

Caregiver stress also affects the individual receiving care. Frail elderly people and children with disabilities experience a higher rate of abuse and neglect. Stressed caregivers are also more likely to seek out-of-home alternatives for the family member.

An occasional break, or respite, from the extraordinary demands of providing ongoing care strengthens the stability of families and caregivers.

A definition

Respite care is temporary, short-term care for an individual with special needs, such as:

- ◆ developmental and physical disabilities
- ◆ mental illnesses
- ◆ emotional and behavioral disorders
- ◆ chronic illness
- ◆ Alzheimer's Disease and related disorders
- ◆ medical fragility
- ◆ those at risk of abuse and neglect

Respite provides families and caregivers the relief they need to stay healthy. It helps families continue to provide at-home care for a loved one and to stay together.

What is Lifespan?

Traditionally, respite services in Oregon have targeted specific populations, each with its own eligibility criteria. The system has been fragmented and difficult for families to navigate.

In response, the Lifespan Respite Care Program was established to assist communities in building access networks to serve all families and individuals regardless of age, income, race, ethnicity, special need or situation.

Community-based Lifespan Networks are designed and driven by diverse local partnerships of family caregivers, providers, state and federal agencies, nonprofit organizations, health services, schools, faith communities and volunteers.

An outcomes-based program

The Lifespan program is driven by the following key outcomes:

- ◆ **Increase access to respite care services** by developing and supporting local Lifespan respite networks, which serve as the central point of contact for families seeking respite and related services.
- ◆ **Increase respite resources** by integrating services, eliminating duplication, pooling existing respite dollars, identifying gaps in services, creating new resources, recruiting and training volunteer and paid respite providers.
- ◆ **Improve the quality of services** by developing minimum requirements for all volunteer and paid respite providers, such as an initial screening, criminal history check, orientation, coordinating additional training opportunities, gathering and compiling data and conducting satisfaction surveys.
- ◆ **Increase public awareness** by educating policymakers, agency staff and community members about the need for accessible and affordable respite care services.
- ◆ **Increase community involvement** by developing diverse partnerships that include family caregivers, providers, faith communities, local, county and state agencies, nonprofit organizations and community volunteers.

Local Lifespan Networks

Local Lifespan Networks are a combination of shared respite resources and information. They serve as the central point of contact for families and caregivers seeking respite and related supports. Lifespan Networks are developed and driven by local respite partnerships. Network components include:

Information and referral

- ◆ provide respite and related information to the community
- ◆ match families with trained respite care providers and resources
- ◆ connect families with respite payment options

Recruitment

- ◆ identify and recruit individuals interested in providing respite care services across age and need categories
- ◆ recruit respite mentors and volunteers
- ◆ identify gaps in respite care options and support the development of new resources

Training

- ◆ provide families with tools and materials to help them select caregivers
- ◆ offer Lifespan respite care orientation training
- ◆ coordinate and publicize respite and related community trainings

Evaluation and outcomes

- ◆ develop local strategic plan
- ◆ track and report on state Lifespan Respite Program outcomes
- ◆ submit semiannual progress reports

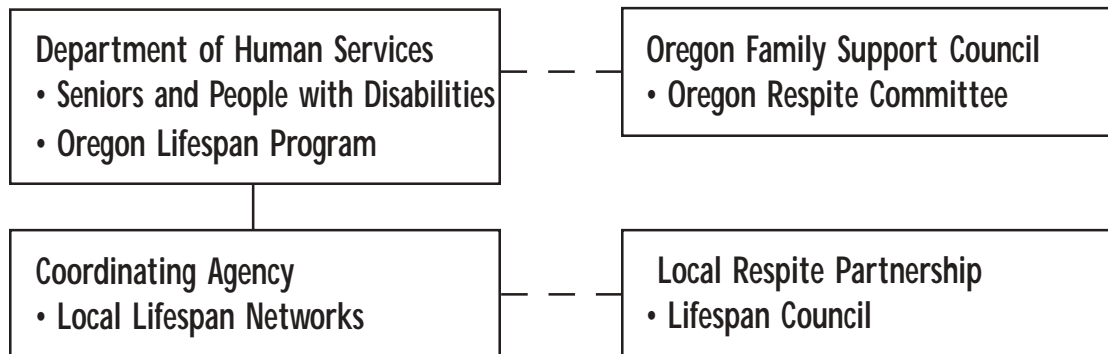
Community involvement

- ◆ build diverse respite care partnerships
- ◆ serve on local advisory council and subcommittees
- ◆ recruit volunteers
- ◆ hold fund raisers
- ◆ engage in awareness and media activities

Guiding principles

- ◆ Designed and driven by a diverse local respite partnership with members representing all ages and special need categories.
- ◆ Supported by governments, faith communities, civic and business groups and other community organizations.
- ◆ Has a diverse respite advisory council or steering committee with at least 51 percent family caregiver membership.
- ◆ Promotes and practices Family Support Principles and Values.
- ◆ Provides respite information and referral services and support to families caring for individuals with special needs.
- ◆ Maintains a list of trained in-home providers, volunteers, advocates and other local respite options.
- ◆ Recruits, screens and trains volunteer and paid in-home respite providers and respite family advocates.
- ◆ Maintains a list of respite payment options for families needing assistance with covering the costs of respite care services.
- ◆ Provides information to the public through media articles and presentations to increase awareness about the need for available respite care and support services.
- ◆ Coordinates community respite and health related trainings available to family caregivers, providers, agency staff and volunteers.
- ◆ Utilizes a customer feedback process to measure the quality of respite care services for both family caregivers and respite providers.

Roles & responsibilities



The Oregon Department of Human Services (DHS) is charged by state law to develop and encourage statewide coordination of respite care services. The Department works with community-based private nonprofit, for-profit, public agencies and citizen groups to identify gaps in services, generate new resources and develop community programs to meet those needs.

Throughout Oregon, DHS joins with local respite partnerships to help plan, develop and implement Lifespan Respite Networks that reflect each community's strengths and needs. They provide technical assistance around partnership development, meeting facilitation, problem solving and strategic planning.

The Oregon Lifespan Respite Care Program is housed in Seniors and People with Disabilities of DHS and is responsible for implementing House Bill 2013, administrative rules, contracts, funding and program evaluation. The program offers technical assistance with program specific issues, works directly with Lifespan Networks and promotes the state respite agenda.

The Family Support Council advises the DHS Cabinet to ensure that all DHS programs focus on families and their strengths, respect the culture and values of each family, and involve the family in planning, implementation and evaluation of services. Family support is a philosophy of partnership between families, service providers and communities.

Roles & responsibilities

The Oregon Respite Committee is a subcommittee of the Family Support Council by statute. It was established to advise and support the Oregon Lifespan Program and to promote increased access to respite care services for Oregon caregivers. Members include family caregivers and representatives from state agencies, advocacy groups and nonprofit organizations.

The Local Respite Partnerships address the respite care needs of their community, advocate for services, and design and develop the local access system. Membership includes families, respite providers, county and state agencies, faith communities, civic and social clubs, nonprofit organizations and community volunteers.

The Local Lifespan Council serves as the steering committee for the Respite Partnership. Members represent various need categories and age groups. Family caregivers make up 51 percent of the membership. The council advises and supports the Lifespan Network and coordinating agency to ensure that services are delivered in a manner consistent with the local strategic plan.

The Lifespan Coordinating Agency hosts the local Lifespan Network and has contract, fiscal and personnel responsibilities. Coordinating agencies are selected by the local respite partnerships and vary statewide.

*Experience, knowledge and commitment
of state and local partners are key to
building a strong, diverse respite system
that meets the needs of all families.*

History of Lifespan

The birth of the concept

Prior to 1992 a limited number of Oregon communities had available respite care services. The services were offered to specific populations with special needs. There has been considerable effort across Oregon to improve access to respite care services. The following events shaped the development of Oregon's Lifespan Respite Care Program.

Nov 1992 Statewide Respite Conference was held and sponsored by the Oregon Developmental Disabilities Council. Conference outcomes included assessing respite care capacity by regions across the state and an identified need for a coordinated respite initiative.

Feb 1994 Oregon Mental Health and Developmental Disability Services Division provides one-time-only funds to 14 counties to begin to develop local respite capacity for families and individuals with developmental disabilities.

June 1994 Oregon Developmental Disabilities Council establishes the Respite Care Initiative to begin statewide respite coordination and technical assistance.

Sept 1994 Through a coordinated effort among Service to Children and Families, Mental Health and Developmental Disability Services Division, and Oregon Developmental Disabilities Council, the Family Access to Respite (FAR) project is established. Funded by a 3-year grant, the FAR project helped build a statewide network for respite care.

Oct 1994 Klamath County chosen as one of 17 counties to receive Family Access to Respite (FAR) funds to recruit and train providers to care for children with emotional, behavioral and developmental disabilities.

History of Lifespan

- June 1995** Lifespan Respite community meeting is held in Klamath County to address respite care issues for families regardless of the age or special needs of the individual in care. A partnership of families, local agencies, organizations and faith communities is formed. A respite task force begins to design a respite care services delivery system to serve all Klamath County families.
- Jan 1996** The Klamath County Lifespan Respite Care Program is one of six service integration projects selected by the Oregon Department of Human Services' Community Partnership Team. Funding and technical assistance allow Klamath County to develop a model respite access system.
- Sept 1996** First respite summit held in Klamath Falls with local community partners, families, respite advocates and DHS Administrators. They discuss the future of respite care and related support services for families in Oregon. Summit outcome: a plan to write legislation.
- Oct 1996** Advocates draft a bill to establish a statewide Lifespan respite care program.
- Apr 1997** Governor Kitzhaber proclaims April 24, 1997, to be the first Respite Care Awareness Day in Oregon.
- June 1997** Advocates visit the state capitol to urge passage of the Lifespan legislation. Families and caregivers testify about their experiences and frustrations finding and paying for quality help.

With support from legislators and the leadership of the Department of Human Services, the bill moves quickly through both chambers of the state legislature.

History of Lifespan

- July 1997** House Bill 2013 passes with no dissenting votes. The bill directs DHS to establish the Oregon Lifespan Respite Care Program to assist counties in the development of community-based Lifespan respite care networks to serve all families regardless of age, income, race, special need or situation.
- Aug 1997** The Respite Care Initiative holds the first statewide respite care conference. Its focus: respite care and related services for all families regardless of age or special need.
- Jan 1998** The Oregon Lifespan Respite Care Program begins Phase I and selects the first 16 counties to receive assistance in establishing community-based Lifespan respite care networks.
- July 1999** The Oregon Lifespan Respite Care Program initiates Phase II expanding access to 8 more Oregon counties.
- July 2000** Local Lifespan Networks serve 24 of Oregon's 36 counties. The remaining 12 counties establish Lifespan partnerships and begin designing their access systems.
- July 2001** Phase III of implementation begins with remaining Oregon counties establishing Lifespan Respite Networks.

Access to respite care services allows families to help themselves, thereby reducing stress, preventing abuse and neglect and decreasing the risk of out-of-home placement.

Lessons learned

- ◆ Respite care is one of the most requested services among families caring for individuals with special needs
- ◆ Providing access to respite care services strengthens families and allows them to help themselves
- ◆ Respite services need to be individualized and sensitive to the unique needs of the family
- ◆ Families have limited payment options
- ◆ Effective networks are built on existing community resources and partnerships
- ◆ Local networks benefit from coordinated opportunities to come together and share experiences
- ◆ Lasting respite partnerships require an ongoing investment of significant effort and time
- ◆ Diverse partnerships at all levels lead to better identification and coordination of existing respite services
- ◆ Ongoing recruitment and training activities are essential in building and maintaining a strong provider pool
- ◆ Shared recruitment and training activities across age and special need categories increase the number and skills of providers and help stabilize the workforce
- ◆ Community awareness and education activities build support for the program among policymakers, state and local administrators and community members
- ◆ Statewide coordination, technical assistance and base funding is critical to the success of local Lifespan Networks

Appendices

A — Legislation: House Bill 2013

B — Administrative Rules

Appendix A — Legislation

69th OREGON LEGISLATIVE ASSEMBLY—1997 Regular Session

Enrolled

House Bill 2013

Sponsored by Representative REPINE; Representatives L. BEYER, DEVLIN, JENSON, JOHNSTON, LOKAN, MONTGOMERY, OAKLEY, PIERCY, ROSS, SHIELDS, WHELAN, Senators BROWN, CASTILLO, FISHER, HAMBY, QUTUB, TROW (at the request of Families As Leaders, the Oregon Developmental Disabilities Council, The ARC of Oregon, Oregon Respite Care Association, Oregon Family Support Network, United Cerebral Palsy of Oregon and SW Washington, Alzheimer's Association Columbia-Willamette Chapter).

AN ACT

Relating to respite care; and declaring an emergency.

Be It Enacted by the People of the State of Oregon:

SECTION 1. As used in sections 1 to 9 of this Act:

(1) 'Caregiver' means an individual providing ongoing care for an individual with special needs.

(2) 'Community lifespan respite care program' means a noncategorical respite care program that:

(a) Is operated by community-based private nonprofit, for-profit or public agencies that provide respite care services;

(b) Receives funding through the Oregon Lifespan Respite Care Program established under section 3 of this Act;

(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.

(3) 'Noncategorical care' means care without regard to the status, including but not limited to age and type of special need of the individual receiving care.

(4) 'Provider' means an individual or agency selected by a family or caregiver to provide respite care to an individual with special needs.

(5) 'Respite care' means the provision of short-term relief to primary caregivers from the demands of ongoing care for an individual with special needs.

(6) 'Respite care services' includes:

(a) Recruiting and screening of paid and unpaid respite care providers;

(b) Identifying local training resources and organizing training opportunities for respite care providers;

- (c) Matching of families and caregivers with providers and other types of respite care;
 - (d) Linking families and caregivers with payment resources;
 - (e) Identifying, coordinating and developing community resources for respite care;
 - (f) Quality assurance and evaluation; and
 - (g) Assisting families and caregivers to identify respite care needs and resources.
- (7) 'Special needs' includes:
- (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; and
 - (g) Such other situations or conditions as the Department of Human Resources may establish by rule.

SECTION 2. The Legislative Assembly finds that:

- (1) Supporting the efforts of families and caregivers to care for individuals with special needs at home is efficient, cost effective and humane. Families receiving occasional respite care relief are less likely to request admission of an individual with special needs to nursing homes, foster care or other out-of-home care at public expense.
- (2) Respite care reduces family and caregiver stress, enhances family and caregiver coping ability and strengthens family ability to meet the challenging demands of caring for individuals with special needs.
- (3) Respite care reduces the risk of abuse and neglect of children, senior citizens and other vulnerable groups.
- (4) Coordinated, noncategorical respite care services must be available locally to provide reliable short-term relief when it is needed by families and caregivers regardless of where they live in Oregon.

SECTION 3. The Director of Human Resources shall establish the Oregon Lifespan Respite Care Program to develop and encourage statewide coordination of respite care and to work with community-based private nonprofit, for-profit or public agencies and interested citizen groups in the establishment of community lifespan respite care programs. The Oregon Lifespan Respite Care Program shall:

- (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 the 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 care programs.

SECTION 4. (1) The Department of Human Resources through the Oregon Lifespan Respite Care Program shall coordinate the 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 or public agencies that provide respite care services. According to criteria established by the Department of Human Resources, the Oregon Lifespan Respite Care Program shall designate and fund agencies described in this section to operate the community respite care programs.

(2) The Director of Human Resources shall create the position of administrator of the Oregon Lifespan Respite Care Program to carry out the duties of the program.

(3) The Family Support Advisory Council established in ORS 417.346 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, respite care consumers, family members and other interested individuals.

SECTION 5. Each community lifespan respite care program established pursuant to section 3 of this Act shall:

(1) Involve key local individuals and agencies in the community lifespan respite care program planning process.

(2) Create an advisory committee composed of 15 members to advise the community lifespan respite care program on how the program may best serve the needs of families and caregivers of individuals with special needs. At least eight members of the advisory committee shall be family members and caregivers of individuals with special needs. Other members shall include respite care providers, representatives of local service agencies and other community representatives. Committee membership shall represent senior citizens, individuals with special needs, and families at risk of abuse or neglect.

SECTION 6. Respite care services made available through the Oregon Lifespan Respite Care Program shall:

(1) Include a flexible array of respite care options responsive to family and caregiver needs and available before families and caregivers are in a crisis situation;

(2) Be sensitive to the unique needs, strengths and multicultural values of an individual, family or caregiver;

(3) Offer the most efficient access to an array of coordinated respite care services that are built on existing community supports and services;

(4) Be driven by community strengths, needs and resources; and

(5) Use a variety of funds and resources, including but not limited to:

(a) Family or caregiver funds;

(b) Private and volunteer resources;

(c) Public funds; and

(d) Exchange of care among families or caregivers.

SECTION 7. The Department of Human Resources shall adopt all rules necessary for the operation and administration of the Oregon Lifespan Respite Care Program, including but not limited to:

(1) Establishing criteria, procedures and time lines for designation of the community-based private nonprofit, for-profit or public agencies that will receive funding to provide respite services under community lifespan respite care programs; and

(2) Requiring that community lifespan respite care programs publicize the telephone number and address where families and caregivers may contact the program.

SECTION 8. By no later than July 1, 1999, the Department of Human Resources shall establish at least 12 community respite care programs in Oregon. By no later than July 1, 2003, the department shall ensure that individuals in all Oregon counties have access to respite care through community respite care programs.

SECTION 9. The Oregon Lifespan Respite Care Program may use the funds appropriated to the program for the following purposes:

(1) The purposes established in sections 3 and 4 of this Act;

(2) Costs related to developing provider recruitment and training, information and referral, outreach and other components of the provision of local respite care;

(3) One time only start-up costs related to the establishment of the community lifespan respite care program; and

(4) Minimum administrative costs for maintaining ongoing program operation.

SECTION 10. This Act being necessary for the immediate preservation of the public peace, health and safety, an emergency is declared to exist, and this Act takes effect July 1, 1997.

Appendix B—Administrative rules

Oregon Lifespan Respite Care Program Division 015

Purpose and Scope 410-015-0000

Lifespan respite care is a community-based system of accessible respite care services for any individual and/or family regardless of age, income, ethnicity, race, special need or situation. Lifespan respite care services can include providing respite related information to the community, recruitment and training of paid and volunteer respite providers, connecting individuals and/or families with respite care providers and linking individuals and/or families with respite care payment resources.

Definitions 410-015-0010

(1) “Department” means the Department of Human Resources of the State of Oregon.

(2) “Special Needs” may encompass physical, emotional, and/or mental illnesses and/or conditions an individual may experience which result in the need for ongoing care and supervision, such as:

- (a) Developmental disabilities;
- (b) Physical disabilities;
- (c) Mental illnesses;
- (d) Emotional and behavioral disorders;
- (e) Alzheimer’s disease and related disorders;
- (f) Chronic illness; and
- (g) Medical fragility.

(3) “Special Situations” may include:

- (a) A time in which a high risk of abuse and/or neglect may exist; and/or
- (b) Other circumstances as defined by the governing body of the community-based lifespan program.

Application Procedures 410-015-0020

(1) The Department may solicit applications for the development and implementation of community-based lifespan respite care services systems.

(2) Applicants shall be:

- (a) Private nonprofit;
- (b) For profit;
- (c) Public agency; or
- (d) A coalition that has a designated fiscal agent.

(3) Applicants shall submit the application before the closing date and time specified in the application procedure.

(4) Applications shall contain at a minimum the following information:

(a) The name, address and telephone number of the applicant organization;

(b) The name, address and telephone number of the contact person;

(c) The names, addresses and telephone numbers of community partners participating in the development and implementation of the lifespan respite care program representing children, adults, seniors, and individuals with special needs;

(d) A projected budget detailing the project's financial needs, expenses, and other sources of support; and

e) Any other information requested by the Department in the application packet.

Application Review 410-015-0030

(1) The Department shall review all applications and may request any additional information needed to assure applications are complete.

(2) After an application is determined to be complete and concordant with the intended goals and outcomes of the program, it shall be forwarded to the Lifespan Advisory Review Committee, a subcommittee of the Oregon Family Support Council, for review and possible recommendation for selection approval.

(3) In reviewing applications, the Committee shall consider the following elements:

(a) The amount of available funds for the Oregon Lifespan Respite Care Program;

(b) The existence of a strong community coalition representing children, adults and seniors with special needs and situations. The coalition should include, but not be limited to, members from the following areas:

A) Families and/or consumers;

(B) Respite providers;

(C) Medical and/or health related fields;

(D) State, federal and/or county agencies;

(E) Private businesses;

(F) Civic, social and community organizations;

(G) Faith communities; and

(H) Community volunteers;

(c) The willingness and ability to contract with the Department and participate in all required Oregon Lifespan Respite Care Program activities;

- (d) The ability to articulate program outcomes and strategies, which include Family Support principles, as described in ORS 417.342;
- (e) The amount of in-kind services;
- (f) The stability of other funding sources; and
- (g) Additional departmental administrative costs or responsibilities associated with the individual application.

Selection 410-015-0040

(1) The Director of the Department of Human Resources or his/her designee shall make the final decision regarding selection of community-based lifespan respite programs.

(2) The Department shall notify applicants in writing of the approval or rejection of the applications.

(3) Selected applicants shall:

(a) Develop and maintain a point of contact for access to lifespan respite care services within a designated geographical area;

(b) Develop and maintain a mechanism to recruit and screen potential respite providers and volunteers;

(c) Identify local training resources and coordinate respite training opportunities for caregivers, respite providers, and families;

(d) Publicize the lifespan respite care program phone number and address; and

(e) Comply with all program policies and guidelines established by the Oregon Lifespan Respite Care Program.

(4) Selected applicants shall make available to the Department records and materials necessary to provide funding and to monitor the program, including projected and actual budgets, performance criteria and reports.

(5) If the term and conditions are not met, the Department may, upon written notice, take one or more of the following actions:

(a) Immediately revoke approval of funding;

(b) Require repayment of all or a portion of any funds advanced; or

(c) Take any other appropriate legal action necessary.

If you have a disability and need this booklet in another format, please contact Debbie Bowers, (503) 945-6815 (voice), (503) 945-6214 (voice/TTY) or debbie.bowers@state.or.us (e-mail).

Oregon Department of Human Services

Lifespan Respite Care Program

500 Summer Street NE

Salem OR 97301

