Promising Practices in Long Term Care Systems Reform: Oregon's Home and Community Based Services System

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Oregon's Home and Community Based Services System

As home and community-based support systems continue to grow and evolve, states are examining whether their current systems reflect fundamental participant and community values. A number of states are concluding that they need to put in place systemic reforms to ensure that their home and community-based support systems promote dignity, independence, individual responsibility, choice, and self-direction.

Systemic reforms are simultaneously addressing multiple aspects of community long term support systems in order to improve responsiveness to participants' needs and preferences. These initiatives are developing entirely new ways of designing, organizing, and managing community-based supports as a system rather than as a random collection of uncoordinated individual services. In some cases, this has required states to make fundamental changes to the administrative infrastructure of their home and community- based support programs.

Two design features in particular have repeatedly emerged as essential components of systemic reform initiatives:

- *Single Entry Points*, which provide persons with a clearly identifiable place to get information, advice and access to a wide variety of community supports; and
- *Person-Centered Services*, which place participants, not services or providers, as the central focus of funding and service planning.

The Centers for Medicare and Medicaid Services contracted with Medstat to examine approaches nine states took to developing Single Entry Points and Person-Centered Services to assist persons with disabilities to live productive and full lives in integrated community settings. We conducted on-site interviews with state officials, advocacy organizations and local program administrators and extensively reviewed written documents on policy proposals, administrative rules, and program evaluations. The emphasis of the resulting nine case study reports is on identifying transferable models that can be adapted for replication in other states and communities across the country, while acknowledging that some aspects of state systems may be unique to each state's culture, history and traditions.

Since most states have separate service systems for different populations, each case study will focus on a particular population. In Oregon, our focus is on long term supports for older persons and adults with physical disabilities.

Overview of Oregon's Home and Community Based Services System

Oregon's system of home and community based services for older persons and adults with physical disabilities has long been considered a national model that many states and communities across the country have sought to emulate. The state has been relentless in its efforts to shift the balance of its public funding for long term care from a primary reliance on nursing home care to an expansive array of community based supports.

It has succeeded. Despite a 30 percent population growth in Oregon since 1981, the number of people receiving Medicaid financed nursing home services has declined by 33 percent. Meanwhile, the percentage of persons receiving publicly financed long term supports in the community rather than in institutions reached 83 percent in 2002.

The majority of Oregon's community based supports are provided through two programs—the Medicaid Home and Community Based Services Waiver Program and Oregon Project Independence. Two additional programs, Oregon Spousal Pay Program and Independent Choices, fill a more specialized role. Key features of each are highlighted below.

The Medicaid Home and Community Based Services (HCBS) Waiver Program serves older people and adults with physical disabilities who meet the state's financial and functional criteria for Medicaid financed nursing home care. Supports provided to people living in their own homes include in-home services, home delivered meals, minor home adaptations, adult day care and transportation. Supports are also provided to persons living in adult foster care, relative foster care, assisted living, residential care facilities and specialized living.

Oregon Project Independence is funded with state general revenues and serves persons who have needs similar to those receiving waiver services but are not financially eligible for Medicaid. Participants are either age 60 and over or under age 60 with a diagnosis of Alzheimer's disease. Covered services are similar to those provided in participants' homes through the HCBS waiver program, but do not include supports provided in residential facilities. Participants pay a portion of their service costs based upon their incomes.

The Oregon Spousal Pay Program, also funded with state general revenues, serves people who are financially eligible for Medicaid and have exceptionally high levels of need that far exceed the state's criteria for nursing facility placement. Participants receive supports through this program rather than through the HCBS waiver because their spouses are their primary caregivers and therefore cannot be paid with Medicaid funds. Often participants' complex care needs make it difficult to recruit a non-relative provider.

Independent Choices provides persons who meet the state's financial and functional Medicaid criteria for nursing home placement with a monthly cash payment equivalent to the cost of services they would have received if they were enrolled in Oregon's HCBS waiver program. Authorized by an 1115 Medicaid waiver, this demonstration is operating in five counties with an enrollment ceiling of 300 participants. A grant from the Robert Wood Johnson Foundation supports training, technical assistance, and evaluation costs.

Although this case study focuses on Oregon's long term care system for older persons and adults with physical disabilities, it has also created service systems for persons with developmental disabilities. Growing out of a recent court settlement requiring the state to eliminate service wait lists for people with developmental disabilities, Oregon has been implementing a new HCBS waiver that provides in-home and family services through support service brokerages. This program complements its long standing waiver program that offers more comprehensive services to people living in group and foster homes. The Medicaid state plan also covers personal care

services, which state staff note are provided primarily to persons with developmental disabilities and are therefore not addressed in this report except in the section on Future Directions.

Oregon's long term care data tells the story of a system that has leveled the playing field between institutional and home and community based services spending. Only 43 percent of the state's Medicaid long term care spending for older people and adults with physical disabilities is devoted to nursing home care. Nationally, institutional spending accounted for 70 percent of long term care expenditures for all populations, a proportion that would be even higher if it were adjusted to isolate spending on behalf of older persons and adults with physical disabilities.

Oregon Long Term Care Expenditures and Recipients
Seniors and Persons with Physical Disabilities

	2002 Expenditures	2002 Program Participants	2002 Average Monthly Census
HCBS Medicaid Waiver	$255,501,972	33,852	27,247
Oregon Project Independence	$5,579,872	4,318	2,196
Oregon Spousal Pay Program	$3,066,954	236	190
Independent Choices Waiver*	$346,370	150	70
Medicaid Nursing Home Services	$197,960,047	10,577	5,978
Total:	$462,455,215		

* Increasing numbers served each month - partial year start-up

Source: Seniors and People with Disabilities

Although the data reported above separately presents expenditures for home and community based services and nursing homes, Medicaid long term care funding for seniors and persons with physical disabilities is consolidated into a single budgetary line item—an administrative approach unique to Oregon and Washington state. In other words, the legislature makes one appropriation covering all Medicaid long term care services. In establishing the total size of the long term care budget, the legislature adopts certain assumptions about the proportion of persons who will receive supports in various settings and enacts provider rates for all types of publicly funded supports, ranging from in-home services, residential supports and nursing home care.

Once the long term care budget is appropriated, the executive branch manages it as one allocation that can be spent at the individual level for either community based supports or for nursing home care. Thus in Oregon, program funding can truly follow the individual from one setting to another. To mesh this flexible allocation of funds with the reality of a fixed budget, state and local administrators closely monitor monthly program census data to track the number of participants receiving supports in each setting and the total cost of services authorized to date.

While Oregon's approach to budgeting and managing long term care resources is key to its success in achieving a more equitable balance between community based and institutional supports, other factors have been equally important. Oregon has been able to expand its

investment in home and community based services, maximize participant choice, and control total costs by combining a broad array of policy strategies. It is unlikely that one or two approaches alone would have achieved such successful results. Strategies adopted include:

- Consolidating administration and regulation of all state programs and policies for institutional, residential, and in-home services into a single state agency whose primary mission is long term care
- Providing participants with equal access to services delivered in both community and institutional settings
- Establishing a single entry point at the local level for streamlining participant access to all long term care services
- Funding a wide array of community supports
- Maximizing the ability of people to direct their own supports
- Reforming the Nurse Practice Act
- Controlling the supply of nursing home beds

All of these approaches were implemented within the context of a well articulated set of goals and values that served as a guidepost for state policy development. Over the past two decades, the synergy among these strategies has created a long term care delivery system that enables public financing to support individuals in the service settings they prefer, consistent with their changing needs.

Like many other states across the country, Oregon is currently facing a serious budget crisis. As a result, funding for the state's long term care programs is being reduced and about 15 percent of current program participants have lost eligibility for services. However, because of the way in which these reductions are being made, the basic structure and policy framework for long term care services in Oregon remains intact. The state's approach to implementing these program reductions is discussed in greater detail in the "Future Directions" section of this report.

To provide a complete picture of the strategies employed in Oregon over the past two decades to achieve a more equitable balance in spending between community and institutional options, this report highlights the historical evolution of its community services system and the critical roles stakeholders played in defining the system's guiding principles, shaping its initial design and guiding on going policy development. In addition, an in depth description is presented of the essential components of Oregon's service delivery system along with lessons other states can gain from its experiences.

Evolution of Oregon's Home and Community Services System

Oregon has long been recognized as a national leader that broke new ground in dramatically changing the way people with long term care needs receive supports. The program policies and structures it rapidly and comprehensively established in the early 1980s form the basis for its national reputation; however, the incremental changes it has adopted over the past two decades illustrate that long term care systems reform is a continuing process.

Impetus for Systems Reform

When Oregon's long term care system was established in 1981, the state's economic situation was remarkably similar to today's conditions, with funding reductions equal to 15 percent of total state spending required to achieve a balanced budget. Unlike current times, however, dramatically rising Medicaid nursing home expenditures were seen as spiraling out of control. Thus, the state legislature concluded that curbing the growth of long term care spending would be a major step towards solving the state's fiscal crisis.

Previously, in 1975 the state established Oregon Project Independence, a state general revenue funded program providing community based services. Then in 1979 it received approval from the U.S. Administration on Aging and the Health Care Financing Administration to conduct a demonstration in several geographic areas using Medicaid funds for community based services and setting up a formal process to improve service coordination. At approximately the same time, the legislature enacted a law requiring pre-admission screening for people seeking Medicaid funded nursing home services. These efforts laid the groundwork for a more comprehensive long term care initiative.

In 1980, the Governor charged the Commission on Aging (a state appointed body of senior advocates) with the task of formulating a proposal to reorganize the way services for older people are delivered. The Commission created a planning committee whose membership was expanded to include a wide range of stakeholders, including advocacy organizations, service providers and state and local officials and older people themselves. As a first step, it worked to achieve consensus on a set of principles and goals that would serve as a benchmark against which detailed plans could be measured. After a year long effort, the Commission developed a blueprint for a new service system, including a proposed reorganization of state and local administrative structures. The release of the Commission's plan coincided with the legislature's quest for a solution to skyrocketing nursing home expenditures, and in 1981, the plan was enacted into state law along with the values and principles upon which it was based.

At the state level, the Senior Services Division (SSD) was created by merging the functions of the state agency on aging that managed the Older Americans Act and Project Oregon Independence with the long term care unit of the state Medicaid agency that was responsible for nursing home policy and payment. At the local level, there were changes as well. In those parts of the state where area agencies on aging are part of local government, they could choose to assume the responsibilities of the state's district offices and thus become a single entry point for services funded by Medicaid, the Older Americans Act, and Oregon Project Independence. Most area agencies chose this expanded role, which included determining both functional and financial eligibility for Medicaid as well as providing case management and pre-admission screening.

Several months after the new long term care plan was adopted, Oregon applied for and received the country's first Medicaid home and community based services waiver in 1981. Now it would have the funding it needed to begin providing services through its new delivery system.

Stakeholder Roles in Program Design and Implementation

Oregon has a long tradition of citizen involvement in policy development. As previously noted, the Governor's Commission on Senior Services was given the assignment of putting together the plan for reorganizing the state's long term care delivery system. With at least half of its membership composed of persons age 60 and over, the Commission has functioned as an independent body that helps coordinate the efforts of the other aging advocacy organizations in the state. It has been instrumental in promoting the expansion of community based services.

In the 1980's the State Disability Commission was created with roles similar to those of the Commission on Senior Services such as studying issues of concern to people with disabilities, making policy recommendations to the Department of Human Services and the Governor, and serving as a statewide advocate on behalf of persons with disabilities. Members of both Commissions offered concrete examples of their ongoing roles as partners with Seniors and People with Disabilities in developing new or revised program policies.

There was a time, however, during the early start-up years when serious tensions erupted among the stakeholders whose previous collaboration was so instrumental to the creation of Oregon's programs. With such rapid and far reaching changes in the delivery of long term care services, the stakeholders were all engaged in major battles with each other. The Division of Senior Services took a drastic step; a consultant was hired in 1984 to mediate a Negotiated Investment Strategy--a process for identifying major disagreements and attempting to resolve them. Four five-member teams representing the state agency, the area agencies, program participants and providers, met for a full day twice a month for six months. Major state policies covering topics such as oversight, reimbursement systems, provider contracting, financial audits, etc. were developed through negotiations among the teams. In the end, a report titled "Shared Roles and Responsibilities for Delivery of Services through the Oregon Senior Services System" documented the agreements and has served as a benchmark for subsequent policy development.

Although this undertaking was risky for the state agency since in effect it was relinquishing significant policymaking authority to a mediation process, state officials have noted that the process achieved long lasting beneficial results. It gave all participants a better understanding of the areas where federal policy provides either flexibility or constraints. And perhaps more importantly, the goals and values established as part of the initial systems plan were translated into real operating procedures rather than simply being lofty words in state legislation.

Two Decades of Incremental Systems Change

While Oregon's long term care reform plan immediately put in place a set of fairly dramatic changes, over the next two decades, incremental changes continued to build upon its initial features. Two areas in particular have continued to evolve: long term care systems integration and self-directed supports. This section briefly traces changes Oregon has made to its system in each of these areas. Subsequent sections describe their operational aspects in greater detail.

Evolution of long term care systems integration—Consolidating responsibility for community and institutional services into a single agency whose sole purpose is to manage long term care programs gave Oregon the ability to develop coordinated state policies that promote common goals across all service settings. By also consolidating funding for all Medicaid long term care services into a single line item budget, resource allocations between community services and institutional care become a direct and visible trade-off.

Simply consolidating budgets and administrative responsibilities, however, does not automatically yield increased funding for community based supports. Strong state leadership is required to turn the potential incentives inherent in this structure into desired results for program participants. As anyone familiar with Oregon's early history can attest, the first administrator of the Senior Services Division, Richard Ladd, was single minded in his determination to reduce the number of people receiving nursing home care while increasing the availability of community based supports.

Integration of long term care program management at the local level meant that older people gained access to both institutional and community based services through a single agency, making it easier for them to obtain information about the full range of available options. By consolidating responsibilities for assessment, eligibility determination and case management, program participants can make just one contact to receive supports from any of Oregon's long term programs.

In Oregon, unlike most other states, the local single entry point (usually area agencies on aging) also determines an individual's financial eligibility for Medicaid. Some have commented that the Health Care Financing Agency erroneously approved this arrangement since Medicaid rules require that a uniform statewide administrative system determine eligibility for all populations. It has allowed Oregon to continue this practice, but has not approved a similar arrangement in any other state.

At the outset, Oregon's state and local long term care management structures integrated an extremely broad set of functions and programs. Over the next two decades, their scope was incrementally expanded to include responsibility for additional types of public benefit programs, new functions such as licensing and certification, and other target populations. The following highlights some of those changes.

- Eligibility determination for state SSI supplementation and food stamps for older people became part of the single entry point roles of area agencies on aging—1984.

- Responsibility for licensing nursing homes, adult foster homes and residential care facilities was transferred to the Senior Services Division—a change pursued by the Division since it frequently clashed with the licensing agency over philosophical differences in approaches to overseeing supports provided in non-medical residential facilities. By integrating the licensing and financing of community residences with in one agency, the state sought to achieve a more coherent policy direction—1987.

- Assisted living was added to the Division's oversight responsibilities when state rules established it as a licensed facility—1989.

- Long term support programs for adults with physical disabilities were transferred to the Division and were fully integrated at the state level with programs serving older people. The state agency became the Senior and Disabled Services Division (SDSD) to reflect its expanded population focus—1989.

- Area agencies on aging that were already managing Medicaid long term care programs for older people were given the option of becoming the single entry point for adults with physical disabilities and assuming all related management functions. About one-half did; in the rest of the state, local offices of state government continue to be the entry point for adults with physical disabilities—1989.

- The Department of Human Services consolidated responsibility for long term supports for persons with developmental disabilities with the existing functions of the Division of Senior and Disabled Services to form the Seniors and People with Disabilities division. Locally, long term supports for people with developmental disabilities continue to be managed by county governments—2002.

Evolution of self-directed supports—The vast majority of older people and adults with physical disabilities who receive in-home services through the HCBS waiver program directly employ an individual provider—less than two percent of in-home service payments are made to agencies. Years before the self-direction movement took hold nationally, Oregon's "Client Employed Providers" became the state's predominate provider type, influenced by three factors.

First, the blueprint for a new long term care system developed by Oregon's stakeholders embodied the principle of "people having free choice in planning and managing their lives". Enabling program participants to have control over hiring and directing their own providers was viewed as one way of upholding that value. Second, Oregon set very ambitious targets for a rapid start-up of its home and community based services waiver program, with legislators expecting to quickly see the savings in nursing home spending they had been promised. Relying on independent workers was the fastest way for the state to build its community provider capacity. Third, the state's legislation charged the new long term care system with providing services at the "least cost". Bypassing agency overhead costs and fringe benefits for workers saved money.

As its HCBS waiver program matured, Oregon adopted new policies and programs that enhanced the availability and scope of self-directed supports. They are described in greater detail in other sections of this report and include:

- Oregon Spousal Pay Program, used in limited instances where the Medicaid prohibition against paying spouses as providers would likely result in institutional placement—1984

- Amendments to the Oregon Nurse Practice Act that provided an expansive definition of nursing tasks that can be delegated to an unlicensed provider—1987

- Contract RN Service, created to systematically incorporate nurse delegation into Oregon's publicly funded community based programs—1994

- Independent Choices Demonstration, which by cashing out the value of a person's long term care benefit, provides the maximum amount of self-direction—2001

- The Home Care Commission, established by voter referendum to be the employer of record for purposes of collective bargaining on behalf of self-directed workers—2001

Single Entry Points: Streamlining Program Access

Oregon's single entry points have truly become a "one stop shop" where older people and adults with physical disabilities can obtain information on a wide range of topics including community services, health care, financial assistance, housing, transportation, public benefits, and other general resources useful to any person living in the community. Extensive outreach and public information efforts have made their information and assistance services widely known and available all persons, not just those seeking publicly funded services. Most single entry point agencies have established satellite offices in order to have a visible community presence in multiple locations.

More in-depth benefits counseling is available to help people select Medicare health plans, supplemental policies, and enrollment options available under the Oregon Health Plan, the state's Medicaid managed care program. Crisis intervention is provided through the entry point's adult protective services program and through after hours on-call support provided as part of the information and assistance service.

Single entry point roles, however, go far beyond information and counseling to include determining an individual's eligibility for Medicaid, food stamps, home and community based services, and nursing home care. After conducting an assessment to determine if an individual meets the criteria for receiving long term supports, the single entry point's case managers the program participant design a service plan and authorizes the services to be provided.

Ninety percent of the state's population resides in regions where area agencies on aging are the single entry point for older people. In the remaining regions, entry point roles are divided between two organizations, with area agencies providing information and assistance and managing Oregon Project Independence and the Older Americans Act and local offices of state government managing Medicaid long term care services. Most adults with physical disabilities access supports through the same entry points as older persons. However, if an area agency has chosen to only be an entry point for older people, local offices of state government serve adults with physical disabilities.

Assessment of Individual Needs

People seeking long term supports receive a comprehensive assessment conducted by a case manager employed by the single entry point. Over the past several years the Seniors and Disabled Services Division invested significant resources to develop a new automated tool, the

Client Assessment and Planning System (CA/PS), that is now being used to determine eligibility for the state's long term supports programs. Case managers use laptop computers to directly record an individual's responses during the assessment, while being guided to collect additional information by triggers built into the system.

The assessment documents a person's abilities and limitations in areas of personal care, mobility, toileting, communications, mental status and household management. It also collects information about living environments, personal characteristics and preferences, and medical status including chronic disease, medications, current treatments, pain episodes and general health history.

This enhanced focus on identifying medical needs grew out of a realization that increasing numbers of persons with complex health needs are receiving supports in the community rather than in nursing homes, and as a result, the HCBS waiver program needed to address participant's chronic health conditions. Certain participant responses to the tool's health-related assessment questions automatically trigger a referral to a registered nurse for a health care assessment. Examples of these responses include the use of five or more medications, need for pain management, certain medical treatments and the need for full assistance in cognition. A nursing assessment is intended to more completely identify an individual's health needs and develop a health care plan that in part serves as the basis for determining nursing tasks that could be delegated to a home care worker under the provisions of the state's Nurse Practice Act.

Eligibility Determination

Once a needs assessment has been completed, the Client Assessment and Planning System calculates an individual's priority for receiving services according to a seventeen level scale, based upon the degree of assistance an applicant requires with specific activities of daily living. Whether persons in specific priority levels are eligible for long term supports depends on the size of the program budget. Because the Seniors and People with Disabilities division complies data weekly on the number of persons currently receiving services, the cost of their authorized service plans, and their assessed priority level, the division is able to accurately project the amount of funds required to cover all people in each level of need.

Until January 2003, state funds have been adequate to enable persons in all seventeen priority levels to be eligible for community based services and nursing home care. Because of the state's current budget crisis, the legislature eliminated long term care eligibility for persons in priority levels 12-17. (The state's approach to implementing these program reductions is described in greater detail in this report's section on Future Directions.)

A couple aspects of Oregon's eligibility system are particularly noteworthy. First, the exact same criteria apply to program eligibility for both Medicaid HCBS waiver services and Medicaid financed nursing home services, determined through the same assessment instrument and procedure. Second, when funding is inadequate to support program eligibility for persons in certain priority levels, coverage for both nursing home care and HCBS waiver services is terminated. People do not have preferential access to nursing home care while being placed on a waitlist for community supports. Conversely, making all persons in a priority level eligible for

long term supports has the effect of creating a de facto entitlement to home and community based services.

Pre-Admission Screening

People seeking Medicaid funded nursing home services and those whose financial status would appear to make them eligible for Medicaid within 90 days of nursing home admission are required to participate in a pre-admission assessment. This assessment is performed by the single entry point using the Client Assessment and Planning System that also determines eligibility for community based services.

In addition, private pay individuals who are entering a Medicaid certified nursing home are required to receive an assessment prior to admission. This assessment entails considerably less information collection than the one conducted to determine Medicaid eligibility and is typically performed by hospitals or a "certified program" under contract with the state—usually a private individual.

Despite differences in scope and intensity between the two assessments, the goal is the same—to ensure that people are aware of the full range of available options so that nursing home admission is not a default path taken without adequate information. Some have argued that pre-admission screening's value as a deterrent to inappropriate nursing home placement has diminished since Oregon's home and community based services systems is so well developed and accessible to both persons eligible for Medicaid and private pay individuals. Others have commented that the state may be getting too lax in requiring pre-admission screening, at least for private pay individuals. In any case, nursing homes can be subject to a civil fine of up to $5,000 if residents are admitted without first being screened.

Person-Centered Services

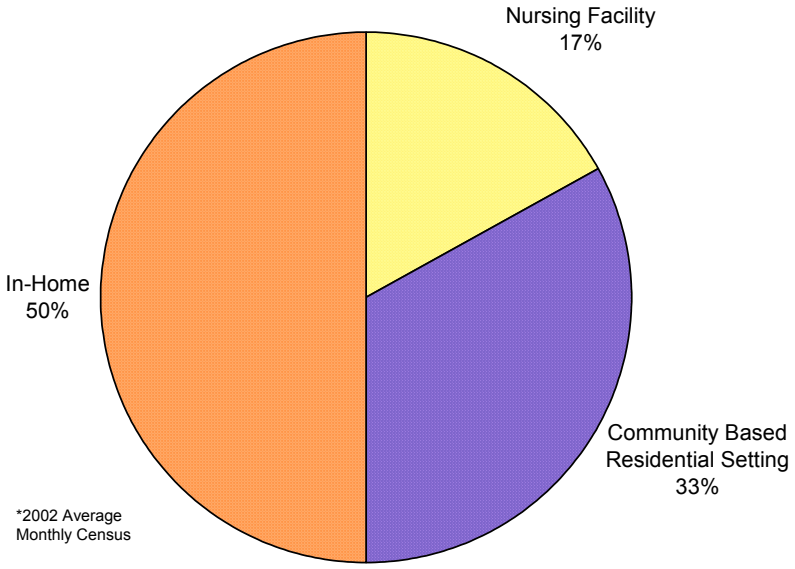
This series of case studies on state long term supports initiatives focuses on two primary components of systemic reforms. The first, as described in the previous section of this report, is single entry points, designed to be an identifiable organization where people can get information, objective advice and access to a wide range of community supports. The other essential component is a system of person-centered services that places participants, not services or providers, at the center of funding and service planning.

Person-centered services systems, as presented in the following sections of this report, have two key features. First by financing a wide range of support options, they enable persons to make meaningful choices about their living arrangements, types of supports they receive, and the manner in which services are provided. Second, by designing person-centered quality management and payment systems, the state's ability to achieve intended participant outcomes and program goals is enhanced.

Oregonians needing long term supports can choose among an array of services provided either in their own homes or in a range of community based residential settings. The single entry points' case managers help participants determine which support arrangements best fit their needs and

preferences. As the chart that follows illustrates, one-half of all older people and adults with physical disabilities receive supports in their own homes, while only seventeen percent reside in nursing homes. Thus, the vast majority of Oregonians who meet the criteria for nursing home admission receive their supports in other settings.

Percentage of Older Persons and Adults with Physical Disabilities Receiving Supports in Each Setting*



Source: Seniors and People with Disabilities

Individual Service Plans

From a participant's perspective the transition from assessment to service planning is seamless, with the same case manager guiding both phases, often during a single home visit. After the Client Assessment and Planning System (CA/PS) has calculated an individual's program eligibility, the participant and the case manager discuss service options. If the person decides to live at home, CA/PS electronically generates an in-home services authorization plan reflecting state regulatory limits on in-home service hours based on a participant's need for assistance with each activity of daily living and self management. For example, a person could receive 60 hours of services a month based on needing substantial assistance with mobility (15 hours), full assistance with bathing and personal hygiene (25 hours) and minimal assistance with eating (5 hours). Additional services such as such as transportation, minor home modifications and home delivered meals that could be included in service plans are individually authorized.

For participants who choose to live in community residential settings, CA/PS authorizes the setting, but not a service plan, which is developed together by the participant, the case manager and the residential facility staff. The Client Assessment and Planning System does, however,

calculate a payment amount within a multi-tiered rate structure that links provider payment to an individual's need for assistance.

Most case managers serve people living in the community who are financially and functionally eligible for publicly funded supports. A relatively small number of case managers have different roles. Risk intervention case managers help individuals who are in high risk situations but do not meet long term care financial eligibility criteria gain access to other community resources.

Relocation case managers identify Medicaid eligible persons entering a nursing home who have a high potential for returning to the community and help them make the transition. In the early 1980's Oregon hired large numbers of relocation case managers and aggressively developed services to facilitate transitions. Now considerably less emphasis is placed on relocation outreach since state officials believe most people who enter Oregon's nursing homes are either there for post-acute rehabilitation and therefore have every intention of returning home or are there for end of life care.

Self-Directed Supports

Client Employed Providers—Almost all of Oregon's home care services (equivalent to personal assistance in other states) are delivered by "Client Employed Providers". Of the $115 million spent in 2002 on in-home services under the HCBS waiver, 98.5 percent was for self-directed services. This high proportion is mostly due to program participants' preferences to receive supports from workers who are often known to them and who frequently work for them exclusively. Of Oregon's 13,000 client employed providers, only about 2000 work for more than one person at a time. The other factor influencing the high proportion of self-directed in-home services is state rules that limit the use of agency provided services to instances where they are either the "most cost efficient in meeting the needs of the client or necessary to meet interim or emergency service needs while more cost-effective solutions are sought and procured."

To support program participants in their employer roles, the Seniors and People with Disabilities division has developed an "Employers' Guide to the Client-Employed Provider Program" that advises participants about hiring and evaluating a worker, their responsibility to maintain employee records and check the accuracy of their provider's invoice, and the role of protective services in dealing with abuse. A similar guide has been prepared for providers. Program participants can also get help from their case manager in locating a provider from lists they maintain of persons who have previously been home services workers. The Department of Human Services is the fiscal intermediary, issuing the worker's check based upon an invoice signed by the participant, withholding the employee's share of Social Security taxes from wages, and paying the employer's portion of Social Security and Unemployment Taxes.

Nurse Delegation—In 1987 amendments to the state's Nurse Practice Act were adopted that significantly increased the ability of nurses to delegate nursing tasks to unlicensed persons such as client employed providers. In part these changes grew out of the legislature's concern that with the rapid decline in nursing home utilization, people living in the community—particularly in adult foster homes—might have nursing needs that were not being met. It directed the Senior Services Division and the Oregon Board of Nursing to jointly study the issue. The Senior

Services Division saw this mandate as an opportunity to push for greater nurse delegation. Its efforts were bolstered by personal stories presented to the legislature by individuals who needed routine nursing services such as injected medications but could not receive them from their self-directed provider because family members were the only lay persons able to perform such tasks.

The resulting amendments to the Nurse Practice Act permit delegation of "special tasks of nursing", broad and largely unspecified functions that are limited by a few explicit exemptions. In order to delegate nursing tasks, a registered nurse must assess an individual's health care needs, determine that the individual's condition is stable, deliver one-on-one training to an unlicensed provider on specific nursing tasks to be performed for a specific individual, leave the provider written instructions, and periodically monitor the individual's health status. The Act protects a nurse from liability due to the actions of the unlicensed provider unless the provider is acting on specific instructions from the nurse or the nurse failed to leave written instructions.

Delegation is only permitted in settings where a registered nurse is not regularly scheduled and not available for direct supervision. As a practical matter, that means that nurse delegation in Oregon cannot take place in an assisted living facility or nursing home, but can be done in a private home or in an adult foster home.

Administration of prescribed oral medications is an example of a task that can be done by unlicensed providers through a process of assignment rather than delegation. Assigned "basic tasks of nursing" can be taught by a nurse to a group of unlicensed providers in contrast to tasks delegated to a specific provider of a specific person.

Contract Registered Nurse Service—Although Oregon's Nurse Practice Act permits a very broad application of nurse delegation, what is most noteworthy is the state's deliberate strategy to maximize nurse delegation in its publicly financed home and community based services programs, particularly in conjunction with client employed providers. Initially, nurses were reluctant to participate in delegation, primarily due to concerns about liability; using educational and technical assistance resources to reach out to the nursing community was only marginally successful. Only after the Senior and Disabled Services Division embarked on a structured effort to promote nurse delegation did it become an integral and routine component of its programs.

The Division created the Contract Registered Nurse Service to address program participants' chronic and/or maintenance health care needs and to provide a formal structure for incorporating nurse delegation within the HCBS waiver program. Persons whose assessment identifies them as potentially needing assistance with health care needs are referred to contract nurses for an assessments and development of a health care plan, which is reviewed with the case manager.

If the contract nurse determines that a participant's health care needs can be meet through delegation of nursing tasks, she develops a proposed nursing schedule for teaching the provider how to perform the nursing tasks being delegated and for monitoring and reassessing the participant's health status. After the case manager authorizes the number of hours required for the nursing schedule, the contact nurse trains the provider. Participants with nursing needs that cannot be met through teaching and delegation are referred for home health services provided under Medicare and the Medicaid state plan.

Currently the state has two-year contracts with 150 nurses, who are required to carry their own liability insurance. As skilled professional medical personnel, the contract nurses' activities are claimed at the enhanced Medicaid administrative match rate of 75 percent federal share.

Independent Choices— The Independent Choices Program represents the next generation of Oregon's efforts to create opportunities for participants to direct their supports. It extends beyond the self-direction of state's client employed provider program where participants control provision of their in-home services to establish participants' control of their entire service plan.

Modeled after the "Cash and Counseling Demonstration", Independent Choices cashes out the value of an individual's service plan and makes an electronic deposit to a designated bank account controlled by the participant. The payment amount is determined by the results of an assessment conducted by a case manager through the Client Assessment and Planning System, which calculates the maximum number of in-home service hours an individual can receive under the HCBS waiver program based upon specific identified needs. To provide comparability with amounts paid for a service plan using client employed providers, the state adds funds to the deposit to cover the employer's share of FICA and state and federal unemployment insurance taxes. On average, monthly payments are $1,200.

To enroll in the program, people must be functionally and financially eligible for Medicaid long term care services and have a demonstrated capability to direct and purchase their own supports, or have a surrogate who is willing to perform these functions on their behalf. Participants are required to complete a ten-hour training session and pass and exam to be authorized to handle payroll functions, which include paying providers and withholding the appropriate taxes. Participants who fail the test—so far a very small number—are required to use a fiscal intermediary, the cost of which is covered by the program. In contrast, if participants are able to handle the financial aspects of being an employer and instead choose to use a fiscal intermediary, the costs are the participant's responsibility.

Authorized as a Medicaid section 1115 demonstration, the program is operating in five counties with a ceiling of 300 enrollees. Almost all participants were previously enrolled in one of the state's other long term care programs and transferred to Independence Choice to have more control over their service plans, including the ability to pay spouses, which is not permitted by Medicaid rules governing the HCBS waiver program. An independent evaluation will examine among other things whether participant satisfaction is increased in comparison to the client employed program. Since the state did not randomly assign people to an intervention group and a control group, the demonstration results will be compared to a similar population in a non-demonstration county.

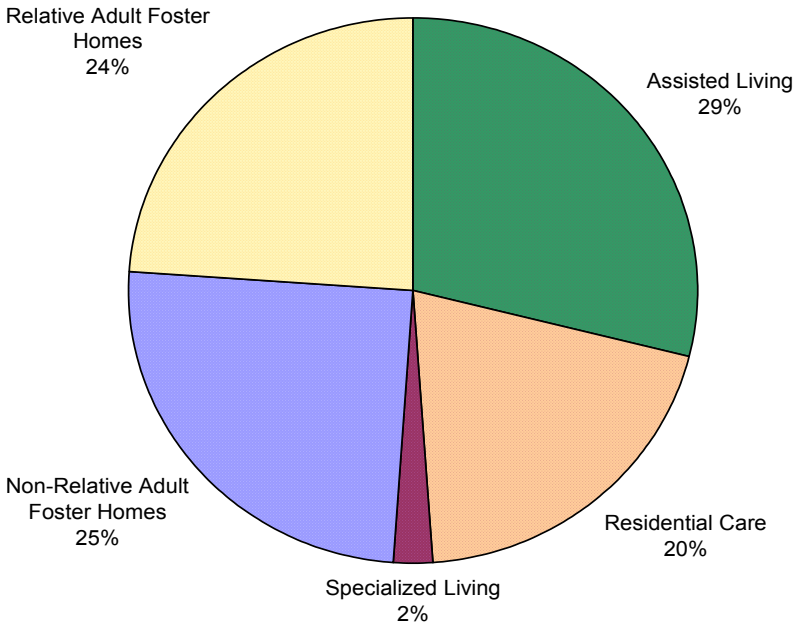
Community Residential Service Settings

One-third of older people and adults with physical disabilities who receive publicly funded long term supports in Oregon live in licensed residential settings. In comparison to other states, this proportion is relatively high, and over the years has generated positive and negative reactions.

Many states have been stymied in their efforts to address the housing needs of program participants and have admired the success Oregon has achieved in developing a broad array of residential options. Others have suggested that group residential settings provide participants with only marginally more independence than institutions and therefore should be used in limited and targeted ways. In Oregon, program participants as well as persons paying privately for their services have clearly embraced residential options as good places to receive supports. The state's efforts to foster the development of these service settings has increased their availability to persons who pay privately, who now comprise about one-half of adult foster home residents and two thirds of assisted living residents.

Residential options available to HCBS waiver program participants include adult foster homes, assisted living, residential care facilities and specialized living. The following chart illustrates the percentage of program participants living in community residential settings by type of facility.

Medicaid Waiver Participants Who Reside in Community Based Residential Settings by Type
(January 2003 Monthly Census)



Source: Seniors and People with Disabilities

While state rules governing the operation of each facility type vary, several state policies are common to all. First, payments provided under the HCBS waiver program cover participants' service costs; consistent with Medicaid rules, room and board charges are paid with participants' own funds, although the state specifies how much a facility can charge if the waiver program pays for a resident' supports. Second, residential facilities must provide a baseline level of assistance in order to participate in the program; beyond that, facilities must provide the service mix needed by their current residents. The state's multi-tiered rate structure pegs provider

payment amounts for each resident to service needs measured through CA/PS. And third, all facilities are licensed by the Seniors and People with Disabilities division.

Adult foster homes are the residential option most frequently used by waiver participants. In the early 1980s Oregon actively encouraged the development of adult foster homes for one of the same reasons it sought to expand the supply of client employed providers—it needed to quickly develop a provider capacity to implement its waiver program on a large scale. Adult foster homes were particularly important since, unlike other states that primarily focused on diverting people from nursing home admission, Oregon also targeted nursing home residents who could move to community settings. Most of those people needed housing as well as personal supports.

Already Oregon had been paying stipends to "relative adult foster homes" that provided support to a family member. After that program became somewhat more structured, it was included as a covered service under the HCBS waiver program. Today about one-half of program participants who receive supports in adult foster homes reside in relative adult foster homes. Non-relative adult foster homes are family-like residences that serve five or fewer persons. In contrast to residents of assisted living, residents of adult foster homes generally require more individual attention and have higher service needs, related in part to behavioral issues. One-half of non-relative adult foster home residents pay privately for their care.

Assisted living is distinguished from adult foster homes and residential care facilities by state standards that require private apartments with kitchenettes and individual bathrooms. As with its other residential options, Oregon sought to make assisted living available to people with differing levels of service needs. To ensure that potential residents know the level of support they can expect to receive from a facility—particularly as their care needs might increase—assisted living facilities are required to release a uniform disclosure statement that specifies in detail the scope and intensity of its services and staffing patterns. First covered as a HCBS waiver service in 1990, assisted living's popularity has grown with both HCBS program participants and private pay individuals. Concerned about its proliferation, the state placed a two year moratorium on licensing new facilities in 2001, which will sunset in 2003.

Specialized living services, added to Oregon's HCBS waiver in 1991, are primarily targeted to younger adults with brain injury or spinal cord injury who live in congregate housing apartments. Service components vary depending on the mix of participant needs in each location. State staff note that in addition to providing more specialized services than is typical under other options, some pooling of attendant supports through assisted living services makes emergency back-up services more readily available to participants.

Residential care facilities are comparable to board and care facilities in other states. As a facility type, they pre-date the waiver program and generally provide a lower level of support than Oregon's other residential options. Some newer facilities specializing in care for people with Alzheimer's disease are being built to meet the physical plant requirements of assisted living facilities but choose to be licensed as a residential facility.

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Person-Centered Management Systems

Oregon's long term care system is funded by a single budgetary allocation that can be flexibly used within a locally managed service delivery system for a broad range of services provided in a variety of settings. Ultimately, resource allocation decisions are driven by the needs and preferences of individuals as they move through the long term care system. These characteristics have created a system where "money follows the person". They also present significant management challenges.

Management Information Systems

To effectively manage such a flexible system, state and local officials need information systems that provide timely and critical data on the performance of the system, particularly on the number of persons currently receiving services and their authorized service costs. Locally, case managers have different information needs. Single entry points, either area agencies on aging or local offices of the Department of Human Services, perform a broad set of functions, including among others, individual needs assessments, service planning, service authorization, and eligibility determination for Medicaid and food stamps. In carrying out these functions, staff on the front lines need an efficient way to record all the individual data they collect.

Oregon's ACCESS system meets both needs. Originally developed to streamline eligibility determination and automate the completion of required forms and data entry, its most recent addition is the Client Assessment and Planning System (CA/PS) previously referenced in several sections of this report. It is an automated assessment tool with algorithms that assign an individual's need for assistance to service priority levels, automatically resulting in an eligibility decision. For participants who choose to receive supports in their own homes, CA/PS calculates the maximum number of in-home services hours that can be authorized in the service plan based upon assessed needs for assistance; for participants who choose to live in a community residential setting, CA/PS calculates the payment rate to be paid to the provider.

The Client Assessment and Planning System includes triggers that automatically generates a referral for a Contract RN assessment if certain health conditions are present and through its risk assessment feature recommends other referrals. Finally, it collects information and produces reports required for all of the service programs administered by the single entry point, including the Medicaid HCBS waiver program, Oregon Project Independence and the Older Americans Act. Information from the ACCESS system is merged with other databases to generate monthly reports used by senior managers to track the number of persons receiving services in each covered setting, their priority need level, the cost of their authorized services and other system performance measures.

Quality Management System

Oregon views its case managers and contract nurses to be critical vehicles for assuring that participants' needs are being met. Formal field reviews conducted by state staff to assess the performance of the single entry point agencies were put on hold during the past year due to the

intensive time commitments required to implement the program reductions necessitated by the state's budget crisis. When they are re-instituted later this year, they will follow the procedure used in the past, which includes reviewing a sample of assessments on-line, reviewing records on-site, and conducting assessments and interviews of participants in the sample to determine if state rules are being implemented and service plans match participants' needs and preferences. In the interim, Seniors and People with Disabilities generated a one percent sample of participant files and required local managers to conduct a review using a state developed protocol.

Concerns about quality have mostly related to Oregon's adult foster homes. In some respects they were easy targets for critics of the state's home and community based services system since they were the setting that was primarily used for persons transitioning from nursing homes to the community. Questions were raised about whether they had the capacity to serve persons with significant support needs. Some of the criticisms appeared to be valid, highlighted by several well-publicized instances of serious lapses in quality. After each of these instances the state established more rigorous standards and monitoring strategies to improve quality.

Several years ago, Seniors and People with Disabilities redesigned its quality approach to strengthen its licensing procedures, conduct random monitoring visits of community based facilities to supplement licensing visits, and to place a greater emphasis on helping providers achieve quality through technical assistance and training. In addition the state makes extensive use of adult protective services to conduct investigations of alleged abuse in all community based and institutional services settings.

Future Directions

As of this writing Oregon is confronting two new challenges. The first, budget reductions that threaten to significantly reduce the number of people that receive long term supports, is the most far reaching. The second challenge, negotiations with a newly unionized workforce of client employed providers, has the potential for increasing the home care workforce if higher wages and benefits are won through a new union contract, but the state's budget crisis will present challenges in funding any enhancements.

Long Term Care Program Reductions

Oregon is facing a serious budget crisis that has already resulted in significant reductions in human service programs, with more possible by June 30, 2003, the end of the state's fiscal year. While almost all states are projecting shortfalls during this budget cycle, Oregon's economic situation is particularly severe.

Reductions to human service programs began in November when the state's revenue forecast indicated funds already appropriated for the current year would have to be cut in order to achieve a balanced budget in fiscal year 2003. In January, the legislature sent a ballot measure to the state's voters proposing a temporary tax increase. The state's voters, who under Oregon's constitution have the sole power to enact tax increases, rejected it. This outcome triggered another round of budget cuts for the current fiscal year while the governor and the legislature began negotiations over the next biennium's budget.

Among the programs or coverages already eliminated are general assistance, the medically needy program, and optional eligibility groups and some benefits of the Oregon Health Plan, the state's Medicaid managed care program that broke new ground in the early 1990's by limiting coverage of certain health care treatments in order to greatly expand the population covered.

Some older people and adults with physical disabilities have lost long term care services. Oregon Project Independence has so far survived proposals for elimination, but its funding has been reduced. However, the most significant long term care cut is the termination of program eligibility for approximately 4,800 people (15 percent of total participants) whose needs fell within service priority levels 12-17. Accompanying their loss of long term care services was loss of Medicaid eligibility unless they met the community income standard for financial eligibility. The following chart illustrates the needs of people in each priority level eliminated for funding.

Service Priority Levels Eliminated for Funding as of April 2003

Level	Participant Needs
12	Requires minimal assistance with mobility and assistance with eating
13	Requires assistance with elimination
14	Requires assistance with eating
15	Requires minimal assistance with mobility
16	Requires full assistance in bathing or dressing
17	Requires assistance in bathing or dressing

Seniors and People with Disabilities conducted extensive on-site and web-based training for staff of the single entry points across the state to keep them up to date on program changes and to emphasize the importance of following state procedures for accurately assessing and/or reassessing participants' needs. Seniors and People with Disabilities has issued new program rules that clarify the specific type of assistance in conducting activities of daily living that participants must need to qualify for service priority levels that are still being funded.

To help protect the health and safety of people who lost eligibility for the HCBS waiver program due to elimination of funding for service priority levels 12-14, the Centers for Medicare and Medicaid Services worked with Oregon to add to its waiver a new service—Community Resource Development Services. The service was authorized while participants were still enrolled in the waiver to cover specific transition costs incurred through June 30, 2003. The state contracted with a fiscal intermediary that service vendors billed for the provision of transition services.

Examples of allowable transition costs include teaching and training unpaid caregivers, home modifications, assistive technology, and for those transitioning from a community based residential setting, expenses required to set up a household. The maximum amount that could be authorized was a one-time payment of $800, except that persons who needed to pay a one-time rent or security deposit could have been authorized a payment of $1,200.

HCBS waiver program participants who lost program eligibility but meet Medicaid state plan financial criteria can receive Medicaid personal care services and continue to use a client

employed provider. Under the state plan, people are limited to receiving no more than 20 hours of personal care a month. Seniors and People with Disabilities also amended their Contract Registered Nurse Program to permit terminated HCBS waiver participants who receive Medicaid personal care to continue receiving contract nurse services.

As of this writing, Oregon's biennium budget has not been finalized. Long term care program cuts being considered include elimination of Medicaid long term care services for people in priority levels 10 and 11 and elimination of the entire budget for Oregon Project Independence.

Home Care Commission

Oregon's 13,000 Client Employed Providers gained collective bargaining rights in 2000 through the passage of a statewide ballot initiative—a vehicle frequently used in this independently minded state to enact state laws. It also created the Home Care Commission to be the employer of record of home care workers for the purpose of collective bargaining. In addition, the Commission is charged with setting worker qualifications, making training available, creating a statewide job registry and making referrals to interested employers. The Governor appoints the Commission members, a majority of whom must be older persons or persons with a disability who are receiving state funded home care services.

Persons covered by bargaining negotiations are home care workers hired by an older person or person with a disability to provide assistance with activities of daily living and whose pay comes from public funds. The statute explicitly affirms the right of individuals to hire and fire a home care worker, making it clear that the Commission is the employer of record only for the purpose of collective bargaining.

Home care workers voted to join the Service Employees International Union (SEIU), the labor organization that spearheaded the ballot initiative's passage. SEIU and the Oregon Department of Administration, which represents the Home Care Commission in labor negotiations, have come to agreement relatively easily on contract provisions related to conditions of work, but as of this writing have not resolved the central issues of wages and benefits.

Oregon's neighbors--states that have a large number of publicly paid independent home care workers--are also engaged in collective bargaining. In some of California's counties, public authorities with roles similar to Oregon's state level Home Care Commission have been negotiating labor agreements for several years. And in Washington state, a ballot measure almost identical to Oregon's was passed a year later in 2001. The outcome of labor negotiations in Oregon and Washington could significantly influence future efforts to establish bargaining rights for independent providers in other states.

Lessons Learned

Oregon's long term care system has leveled the playing field between spending for community based services and nursing home care, giving program participants choice over both the type of supports they receive and the location in which they are provided. Although the state's current fiscal crisis could reverse some of Oregon's accomplishments, the basic structure of its system

remains intact. Oregon's experiences can yield valuable lessons for other states as they seek to make supports provided in the community the norm rather than the exception. Some of these lessons are drawn from features of the system's initial design, others grow out of mid-course corrections, and others are attributable to the characteristics of the people who led the long term care system through its various stages of evolution.

State policy consolidation—By consolidating the administration and regulation of a broad package of long term care services provided in institutional, community residential, and in-home settings into a single long term care agency, Oregon was able to develop coordinated policies that promoted common goals across all programs. It was also able to avoid the wasted time and effort expended in many states negotiating ways to make competing programs fit together for program participants.

Integration of program budgets—Simply placing all related programs into one organization will not automatically result in a seamless delivery system. In Oregon, having a single budget encompassing services provided in all settings meant that resource allocations could be driven at the individual level by participant preferences rather than through program silos.

Equal access to institutional and community based services—Oregon's decision to establish service priority levels and give everyone who meets their criteria equal access to nursing home and community based services proved to be an essential design feature that in combination with a single long term care budget, permitted financing to truly follow the person.

Single entry points for service access—Consolidation of local program administration brought together in one place comprehensive information about a broad array of resources available to support program participants living in the community. Specifically, vesting the single entry point with the authority to authorize supports in all settings—in one's home, in residential facilities, and in institutions—enables program participants to make decisions about living arrangements with the assurance that they have been presented information on all options.

Quality management systems—Current and previous Oregon state officials have commented that they should have paid more attention to quality at the outset, especially for adult foster homes. To enhance the ability of adult foster homes to appropriately address the chronic care management needs of their residents, the state is channeling them to make greater use of consultations with contract nurses.

State leadership—An intangible factor that greatly contributed to the success of the Oregon long term care system is the quality of leadership that has been at the helm of the Senior Services Division and its successor organizations. Dramatically different in style and focus, each director has provided the type of leadership needed during each particular phase of the evolution of Oregon's system.

Bibliography

Auerbach, Roger. *Seniors and Adults with Disabilities Working Together: Putting the Puzzle Together*. Oregon Department of Human Resources, Seniors and Disabled Services Division, Salem: 1998.

Justice, Diane, et al. *State Long Term Care Reform: Development of Community Care Systems in Six States.* National Governors' Association, Washington, D.C.: 1988

Ladd, Richard C., *et al*. *Oregon's Long-Term Care System: A Case Study by the National Long-Term Care Mentoring Program*. University of Minnesota, School of Public Health; Minneapolis: 1996

Oregon. 2001. *Revised Statutes*. Chapter 410 §§ 1-990. Available online at http://www.leg.state.or.us/ors/410.html.

Oregon. 2003. Department of Human Services, Seniors and People with Disabilities, *Oregon Administrative Rules*. Chapter 411. Available online at http://arcweb.sos.state.or.us/rules/OARS_400/OAR_411/411_tofc.html.

Oregon. 2003. *Board of Nursing, Oregon Administrative Rules*. Chapter 851: Division 47. Available online at http://arcweb.sos.state.or.us/rules/OARS_800/OAR_851/851_tofc.html.

Oregon Department of Human Services, Seniors & People with Disabilities. *A Guide to Oregon Adult Foster Homes*. Salem: 2002.

Oregon Department of Human Services, Seniors & People with Disabilities. *The Client Employed Program: The Employers' Guide*. Salem: 2001.

Oregon Department of Human Services, Seniors & People with Disabilities. *The Client Employed Program: The Providers' Guide*. Salem: 2001.

Oregon Department of Human Services, Seniors & People with Disabilities. *Contract RN Service*. Salem: July, 2002.

Oregon Department of Human Services, Seniors & People with Disabilities. *Oregon Consumer Guide: Assisted Living and Residential Care Facilities*. Salem: 2002.

Oregon Department of Human Services, Seniors & People with Disabilities. *Testimony Before Joint Legislative Committee on Ways and Means*. Salem: April, 2003.

Oregon Legislative Fiscal Office. *Detailed Analysis 2001-2003 Legislatively Adopted Budget*. Salem: 2001.

Oregon Secretary of State. *Oregon Blue Book 2003-2004*. Salem: 2003.