

CRS Report for Congress

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A CRS Review of Ten States: Home and Community-Based Services — States Seek to Change the Face of Long-Term Care: Oregon

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Summary

Demographic challenges posed by the growing elderly population and demands for greater public commitment to home and community-based care by persons with disabilities of all ages have drawn the attention of federal and state policymakers for some time. Spending on long-term care in both the public and private sectors is significant. In 2001, spending for long-term care services for persons of all ages represented 12.2% of all personal health care spending (almost \$152 billion of \$1.24 trillion). Federal and state governments accounted for almost two-thirds of this spending. By far, the primary payor for long-term care is the federal-state Medicaid program, which paid for almost half of all long-term care spending in 2001.

Many states have devoted significant efforts to respond to the desire for home and community-based care for persons with disabilities and their families. Nevertheless, the financing of nursing home care, chiefly by Medicaid, still dominates most states' spending for long-term care today. To assist Congress in understanding the issues that states face in providing long-term care services, CRS undertook a study of 10 states in 2002. This report, which will not be updated, presents background and analysis about long-term care in Oregon.

Oregon is a recognized leader in home and community-based care and has more than 20 years of experience in moving long-term care clients from institutional settings to home and community-based settings. In 2002, 82% of Oregon's Medicaid long-term care clients were served in the community. Additionally, Oregon was the only state in the nation whose spending for institutional care was less than half of the state's total Medicaid long-term care spending in 2000, with only 37.2% spent on institutional care compared to the national average of approximately 70%.

In 1981, a clear preference for home and community-based services was established by the state legislature in Senate Bill 955. This legislation streamlined the administrative structure and established a clear vision for a long-term care system that embodies the values of independence, dignity, privacy, and choice. It also mandated that any cost-savings from reductions in institutional spending be reinvested into a system that promotes home and community-based care. The various functions of Oregon's long-term care system are administered by a single division (Seniors and People with Disabilities) housed within a single state agency (the Department of Human Services). This centralized administration shares a common vision to promote care in the community over institutions.

Oregon officials recognize that with the aging population and increasing costs, they may need to rethink the design of their current system. They hope to incorporate a concept of "bounded choice" where a person's wishes are considered within the boundaries of service capacity and fiscal constraints.

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Preface

Demographic challenges posed by the growing elderly population and demands for greater public commitment to home and community-based care by persons with disabilities of all ages have drawn the attention of federal and state policymakers for some time. Spending on long-term care by both the public and private sectors is significant. In 2001, spending for long-term care services for persons of all ages represented 12.2% of all personal health care spending (almost \$152 billion of \$1.24 trillion). Federal and state governments accounted for almost two-thirds of this spending. By far, the primary payor for long-term care is the federal-state Medicaid program, which paid for almost half of all U.S. long-term care spending in 2001.

In FY2001, federal and state Medicaid spending for long-term care was about \$75 billion, representing over one-third of all Medicaid spending. Over 70% of Medicaid long-term care spending was for institutions — nursing homes and intermediate care facilities for the mentally retarded (ICFs/MR). Many believe that the current federal financing system paid through Medicaid is biased toward institutional care. State governments face significant challenges in refocusing their long-term care systems, given the structure of current federal financing. In this regard, many states have devoted significant efforts to expand home and community-based services for persons with disabilities and their families. Nevertheless, financing of nursing home care — primarily through the Medicaid program — still dominates most states' spending in long-term care today.

While advocates believe that the federal government should play a larger role in providing support for home and community-based care, Congress has not yet decided on whether or how to change current federal policy. One possibility is that Congress may continue an incremental approach to long-term care, without major federal involvement, leaving to state governments the responsibility for developing strategies that support home and community-based care within existing federal funding constraints and program rules.

To assist Congress in its consideration of options for any future federal policy, and to assist policymakers in understanding issues that states face in the development of long-term care services, the Congressional Research Service (CRS) undertook a study of 10 states in 2002. The research was undertaken to review state policies on long-term care as well as trends in both institutional and home and community-based care for persons with disabilities (the elderly, persons with mental retardation, and other adults with disabilities). The research included a review of state documents and data on long-term care, as well as national data sources on spending. Interviews were held with state officials responsible for long-term care, a wide range of stakeholders and, in some cases, members or staff of state legislatures.

The 10 states included in the study are: Arizona, Florida, Illinois, Indiana, Louisiana, Maine, Oklahoma, Oregon, Pennsylvania, and Texas. States were chosen according to a number of variables, including geographic distribution, demographic trends, and approaches to financing, administration and delivery of long-term care services.

This report presents background and analysis about long-term care in Oregon and is one of a series of CRS state reports on long-term care.

A CRS Review of Ten States: Home and Community-Based Services — States Seek to Change the Face of Long-Term Care: Oregon

Introduction: Federal Legislative Perspective

States choosing to modify their programs for long-term care face significant challenges. Financing of nursing home care has dominated long-term care spending for decades. The federal financing structure that created incentives to support institutional care reaches back to 1965. A number of converging factors have supported reliance on nursing home spending. Prior to enactment of Medicaid, homes for the aged and other public institutions were

financed by a combination of direct payments made by individuals with their Social Security Old Age Assistance (OAA) benefits, and vendor payments made by states with federal matching payments on behalf of individuals. The Kerr-Mills Medical Assistance to the Aged (MAA) program, enacted in 1960, a predecessor to Medicaid, allowed states to provide medical services, including skilled nursing home services, to persons who were not eligible for OAA cash payments, thereby expanding the eligible population.¹

The Social Security Amendments of 1965, which created the Medicaid program, required states to provide skilled nursing facility services under their state Medicaid plans, and gave nursing home care the same level of priority as hospital and physician services.

“Section 1902 (a) A State plan for medical assistance must provide for inclusion of some institutional and some noninstitutional care and services, and, effective July 1, 1967, provide (A) for inclusion of at least . . . (1) inpatient hospital services ...; (2) outpatient hospital services; (3) other laboratory and X-ray services; (4) skilled nursing home services (other than services in an institution for tuberculosis or mental diseases) for individuals 21 years of age or older; (5) physicians’ services” P.L. 89-97, July 30, 1965.

In 1965, when Kerr-Mills was transformed into the federal-state Medicaid program, Congress created an *entitlement* to skilled nursing facility care under the expanded program. The Social Security Amendments of 1965 required that states provide skilled nursing facility services, and gave nursing home care the same level of priority as hospital and physician services. Amendments in 1967 allowed states to provide care in “intermediate care facilities” (ICFs) for persons who did not need

¹ CRS Report 83-181, *Nursing Home Legislation: Issues and Policies*, by Maureen Baltay. Archived and available from authors upon request.

skilled nursing home care, but needed more than room and board. In 1987, Congress eliminated the distinction between skilled nursing facilities and intermediate care facilities (effective in 1990). As a result of these various amendments, people eligible under the state's Medicaid plan are *entitled* to nursing home facility care; that is, if a person meets the state's income and asset requirements, as well as the state's functional eligibility requirements for entry into a nursing home, he or she is entitled to the benefit.

These early legislative developments were the basis for the modern day nursing home industry. Significant growth in the number of nursing homes occurred during the 1960s — from 1960 to 1970, the number of homes more than doubled, from 9,582 to almost 23,000, and the number of beds more than tripled, from 331,000 to more than one million.² Today there are about 17,000 nursing homes with 1.8 million beds.³

During the latter part of the 1960s and the 1970s, nursing home care attracted a great deal of congressional oversight as a result of concern about increasing federal expenditures, and instances of fraud and abuse that were becoming evident. Between 1969 and 1976, the Subcommittee on Long-Term Care of the Senate Special Committee on Aging held 30 hearings on problems in the nursing home industry.⁴

Since its inception, Medicaid has been the predominant payor for nursing home care. In 1970, over \$1 billion was spent on nursing home care through Medicaid and Medicare. Federal and state Medicaid payments accounted for almost all of this spending — 87%. Medicaid spending for nursing home care grew by 50% in the 3-year period beginning in 1967.

In FY2001, Medicaid spent \$53.1 billion on institutional care (for nursing homes and care in intermediate care facilities for the mentally retarded).

Home care services received some congressional attention in the authorizing statute — home health care services were one of the optional services that states could provide under the 1965 law. Three years later in 1968, Congress amended the law to require states to provide home health care services to persons entitled to skilled nursing facility care as part of their state Medicaid plans (effective in 1970). During the 1970s, the Department of Health, Education and Welfare (now Health and Human Services, (HHS)) devoted attention to “alternatives to nursing home care” through a variety of federal research and demonstration efforts. These efforts were undertaken not only to find ways to offset the high costs of nursing facility care, but also to respond to the desires of persons with disabilities to remain in their homes and

² U.S. Congress, Senate Special Committee on Aging, *Developments in Aging*, 1970, Report 92-46, Feb. 16, 1970, Washington, cited from the *American Nursing Home Association Fact Book, 1969-1970*.

³ American Health Care Association, *Facts and Trends 2001, The Nursing Facility Sourcebook*, 2001, Washington. The number of nursing homes is for 1999-2000 and number of beds is for 1998. (Hereafter cited as American Health Care Association, *The Nursing Facility Sourcebook*.)

⁴ U.S. Congress, Senate Special Committee on Aging, *Nursing Home Care in the United States: Failure of Public Policy*, Washington, 1974, and supporting papers published in succeeding years.

in community settings, rather than in institutions. However, it was not until 1981 that Congress took significant legislative action to expand home and community-based services through Medicaid when it authorized the Medicaid Section 1915(c) home and community-based waiver program.

Under that authority (known then as the Section 2176 waiver program), the Secretary of HHS may waive certain Medicaid state plan requirements to allow states to cover a wide range of home and community-based services to persons who otherwise meet the state's eligibility requirements for institutional care. The waiver provision was designed to alter the fact that the Medicaid program had emphasized institutional care rather than care in home and community-based settings. Services under the Section 1915(c) waiver include: case management, personal care, homemaker, home health aide, adult day care, habilitation, environmental modifications, among many others.⁵ These services are covered as an *option* of states, and under the law, persons are not entitled to these services as they are to nursing facility care. Moreover, states are allowed to set cost caps and limits on the numbers and types of persons to be served under their waiver programs.

Notwithstanding wide use of the Section 1915(c) waiver authority by states over the last two decades, total spending for Medicaid home and community-based services waivers is significantly less than institutional care — about \$14.4 billion in 2001, compared to \$53.1 billion for nursing facility care services and care for persons with mental retardation in intermediate care facilities (ICFs/MR). Despite this disparity in spending, in many states the Section 1915(c) waiver program is the primary source of financial support for a wide range of home and community-based services, and funding has been increasing steadily. Federal and state Medicaid support for the waiver programs increased by over 807% from FY1990 to FY2001 (in constant 2001 dollars).

The home and community-based waiver program has been a significant source of support to care for persons with mental retardation and developmental disabilities as states have closed large state institutions for these persons over the last two decades. Nationally, in FY2001, almost 75% of Section 1915(c) waiver funding was devoted to providing services to these individuals.

States administer their long-term care programs against this backdrop of federal legislative initiatives — first, the *entitlement* to nursing home care, and requirement to provide home health services to persons entitled to nursing home care, and, second, the *option* to provide a wide range of home and community-based services through waiver of federal law, within state-defined eligibility requirements, service availability, and limits on numbers of persons served.

⁵ States may waive the following Medicaid requirements: (1) statewideness — states may cover services in only a portion of the state, rather than in all geographic jurisdictions; (2) comparability of services — states may cover state-selected groups of persons, rather than all persons otherwise eligible; and (3) financial eligibility requirements — states may use more liberal income requirements for persons needing home and community-based waiver services than would otherwise apply to persons living in the community. For further information, see CRS Report RL31163, *Long-Term Care: A Profile of Medicaid 1915(c) Home and Community-based Services Waivers*, by Carol O'Shaughnessy and Rachel Kelly.

A CRS Review of Ten States: Report on Oregon

In the late 1970s and early 1980s, Medicaid expenditures for long-term care in Oregon's nursing homes were skyrocketing. From 1974 to 1979, the number of Medicaid clients being served in nursing facilities increased by more than 30%, while the population aged 75 and older was increasing by only 14%.⁶ The rate of inflation for institutional long-term care was more than 100% annually.⁷ Although the Oregon Department of Human Services (DHS) was created in 1971 to unify a fragmented service delivery system in the state, the offices responsible for long-term care continued to have separate budgets and administrative leadership.

In order to address these concerns, Oregon's state legislature decided to drastically reshape its Medicaid long-term care program. In 1981, the state legislature combined the state's unit on aging and its Medicaid long-term care program. This new division within DHS was charged with containing the costs of long-term care, while at the same time promoting the option of home and community-based care over nursing facility care. Over the last 20 years, state officials have strived to create a coordinated system of long-term care where nursing homes are the placement of last resort.

The number of Medicaid clients receiving home and community-based services has been steadily rising. In 2002, 82% of Medicaid long-term care clients were receiving home and community-based care, compared with only 40% of clients in 1985-86.⁸ This dramatic increase is due, in part, to the diverse home and community-based care options provided by the state. These options include a range of supported housing arrangements such as: assisted living facilities, residential care facilities, adult foster care, as well as in-home care where clients may select their own caregivers.

In 2001, the state legislature directed the state's principal long-term care agency (Seniors and Disabled Services Division) to administer programs for persons with developmental disabilities. This new agency (Seniors and People with Disabilities) plans to increase the availability of home and community-based care for persons with developmental disabilities by expanding one of the state's Medicaid Section 1915(c) home and community-based waivers.

State officials acknowledged that many of the barriers that have inhibited other states' attempts to develop comprehensive home and community-based service options were not felt as acutely in Oregon. Initial opposition from the nursing home industry was overcome by legislative and advocacy support; citizens and advocate groups in Oregon worked collaboratively for increased home and community-based

⁶ Seniors and People with Disabilities, *The Oregon Model*, Dec. 2001. [www.sdsd.hr.state.or.us/about/oregon_model.htm].

⁷ Ibid.

⁸ Barry Donnenfeld, *The Economic Downturn and Its Impact on Seniors: Stretching Limited Dollars in Medicaid, Health, and Senior Services*, Testimony for the United States, U.S. Senate Special Committee on Aging, Mar. 14, 2002.

options; and the state legislature has continued to be involved in shaping the direction of the state's long-term care system.

Over the last two decades, researchers and state officials have documented many of the innovative policies the state has instituted in the development of its long-term care system. A number of reports have concluded with similar findings. Among other things, Oregon's success in moving clients to home and community-based settings can be attributed to:

- the legislative mandate to reinvest any cost-savings from reductions in institutional care into the development of a system that promotes home and community-based care;
- the centralization of administrative responsibility in providing long-term care services;
- the use of public funds for services that are appealing to consumers, such as assisted living facilities, adult foster homes, and in-home services where clients may select their caregivers;
- the level of involvement of community-based area agencies on aging (established by Title III of the Older Americans Act) in the local administration of long-term care programs and their promotion of home and community-based services through consumer-friendly websites and telephone hotline services; and
- state legislation that allows unlicensed caregivers to be trained by nurses to provide certain medical services to long-term care clients.

In spite of Oregon's achievements in reorienting its long-term care system, officials recognize that with the aging baby boom population and increasing costs of long-term care, they may need to rethink the design of their current system to meet the challenges ahead.

This report provides an analysis of Oregon's long-term care system and is one in a series of 10 CRS reports on state long-term care systems.

Summary Overview⁹

Overview

- Oregon, a recognized leader in home and community-based care, has over 20 years of experience in shifting state resources from institutional long-term care to home and community-based care. A clear preference for promoting home and community-based services over institutional care was established by the state legislature in 1981.
- Oregon’s guiding principles in long-term care are to “embody the human values of independence, dignity, privacy, and choice.”

Demographic Trends

- An aging population poses challenges for the state. Its population age 85 and older — the group in greatest need for long-term care services — grew by 48% from 1990-2000, ranking 18th highest in the nation. Persons aged 85 and over with two or more limitations in activities in daily living (ADLs) are estimated to grow by 38% by 2010.
- Oregon’s population age 65 and older is expected to increase to 24.2% of the state’s population by 2025, compared to 18.5% in the total United States population.

Administration of Long-Term Care Programs

- Unlike most other states, the various functions of Oregon’s long-term care system are administered by a single division (Seniors and People with Disabilities (SPD)) and housed within a single state agency (the Department of Human Services). This centralized administration shares a common vision to eliminate any bias towards institutional care.
- Area agencies on aging (AAAs) have been given a strong leadership role in Oregon’s long-term care system. AAAs can choose to administer long-term care programs for the elderly and younger people with disabilities.

Trends in Institutional Care

- Over the last two decades, the state has developed a number of methods to control nursing home utilization. These include: a certificate of need program, which requires nursing facilities to

⁹ Information based on Oregon data and documents, national data, and interviews with state officials. This report does not discuss programs for persons with mental illness. It also generally excludes discussion of programs for infants and children with disabilities, other than those serving persons with mental retardation and developmental disabilities.

obtain permission from SPD before new facilities are built or old facilities are expanded; a pre-admission screening program for both private and Medicaid clients; extensive use of the Medicaid Section 1915(c) home and community-based waivers; and a state-funded program (Oregon Project Independence) that encourages the use of home and community-based services.

- As a result of Oregon's strategies to control nursing home utilization, state officials indicate that the disability levels of nursing home residents have increased dramatically. This is attributed to a greater use of home and community-based services that delay entry into nursing facilities.
- Since the state first implemented its home and community-based services waiver in 1981, the utilization of nursing homes for Medicaid clients has steadily declined. Between 1996 and 2001, there was a 17.2% decrease in the number of nursing home residents, and a 10% decline in the nursing facility occupancy rate.

Trends in Home and Community-Based Care

- In 2002, approximately 82% of Oregon's Medicaid long-term care clients were served in the community, up from 53% in 1990.
- Oregon administers a wide range of home and community-based services through a single Medicaid 1915(c) home and community-based waiver for seniors and adults with disabilities. Services include: adult foster care; assisted living facilities; residential care facilities; and in-home services which allow residents to remain in their homes and select their caregiver.
- The state has made extensive use of the Section 1915(c) Medicaid waiver program to provide home and community-based services to persons with developmental disabilities. As of June 2001, there were only 50 clients with developmental disabilities being served in the state's only intermediate care facility for persons with mental retardation (ICFs/MR).
- Oregon has developed a unique state-funded home and community-based service program, Oregon Project Independence (OPI), which provides services to persons who cannot afford the full cost of home and community-based care and are not enrolled in Medicaid. The program is designed to delay entry into the state's Medicaid program.

Long-Term Care Spending

- In FY2000, Oregon spent over \$712 million on Medicaid long-term care. Unlike most other states, Oregon spent approximately two-thirds of these dollars on home and community based services, and only one-third on institutional services.
- From 1990 to 2001, Medicaid spending for home and community-based services increased by almost 560% in constant dollars, whereas spending for institutional care increased by only 105%.

- In 2001, only 1% of Medicaid long-term care spending went to intermediate care facilities for persons with developmental disabilities compared with almost 14% for the U.S. as a whole.
- Unlike many other states where nursing home expenditures represent a significant portion of both Medicaid spending as well as Medicaid long-term care spending, in Oregon, spending for nursing home care is significantly less, representing about 20% of Medicaid spending and about one-third of Medicaid long-term care spending in FY2000.

Issues in Financing and Delivery of Long-Term Care

- In Oregon, many of the staffing shortages experienced by other states are ameliorated by the state's nurse delegation program and the client employed provider program. Nurse delegation allows licensed registered nurses to delegate certain nursing tasks to unlicensed caregivers. Through the state's client employed provider (CEP) program, individuals may select a caregiver with no formal long-term care training. The caregiver is then trained to administer the client's care plan. In spite of the success of this program, state officials are concerned about potential staffing shortages of frontline long-term care personnel in the future.
- Waiting lists for services for persons with developmental disabilities have been a persistent problem in Oregon. Recent litigation resulted in a settlement agreement which requires the state to increase funding for home and community-based services for persons with developmental disabilities by a cumulative total of \$350 million by 2007.
- Recent state budget cuts have greatly impacted Oregon's long-term care system. Long-term care spending was reduced by nearly 30% for the current state fiscal year. As of April 2003, over 4,792 persons were no longer eligible to receive Medicaid long-term care services (over 16% of total program participants), with potentially more cuts needed in the future. In addition to reducing the number of people eligible for Medicaid, the state also eliminated in-home supports for 3,800 seniors who were not eligible for Medicaid; reduced reimbursement rates to Medicaid long-term care providers by 15% to 30%; and eliminated the state's medically needy program for 8,757 individuals.
- Oregon administrators recognize that with the aging population and increasing costs of long-term care, they may need to rethink the design of their current long-term care system. They hope to incorporate a concept of "bounded choice" where an individual's wishes are considered within the boundaries of service capacity and fiscal constraints.

Demographic Trends

Oregon has a relatively small population of 3.4 million people, but ranks tenth in the nation in terms of land area. Approximately 70% of its residents live in the Willamette Valley between Portland and Eugene, an area that covers less than one-third of the state from the Pacific seaboard to about 300 miles in-land. Much of the rural, eastern area of the state is sparsely populated. In 2000, 12.8% of Oregon's residents were over the age of 65, only slightly above the national average of 12.4%.

From 1990-2000, Oregon's total elderly population grew by 12%, but its population age 85 and older, those in greatest need for long-term care services, grew by 48%. The proportion of Oregon's population aged 85 and older is the 18th largest in the nation. From 1990 to 2000, the state experienced a 26% increase in the population aged 75 to 84, those at near risk of needing assistance with daily tasks (see **Table 1**).

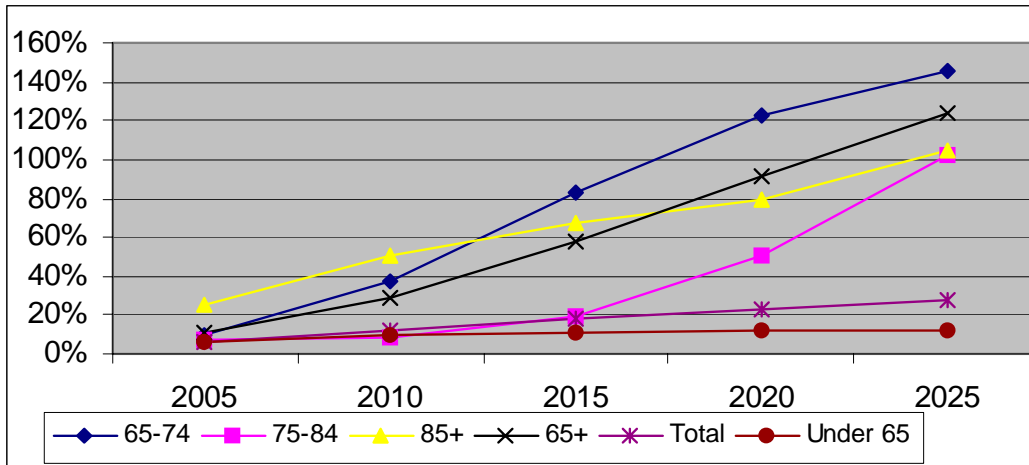
Table 1. Oregon Population Age 65 and Older, 1990 and 2000

| Age | 1990 | | 2000 | | 1990-2000 percent change | 2000 population rank in U.S. (based on percent) |
|--------------|------------------|-----------------------------|------------------|-----------------------------|--------------------------|---|
| | Number | Percent of total population | Number | Percent of total population | | |
| 65+ | 391,324 | 13.8 | 438,177 | 12.8 | 12.0% | 25 |
| 65-74 | 224,438 | 7.9 | 219,342 | 6.4 | 2.3% | 35 |
| 75-84 | 128,071 | 4.5 | 161,404 | 4.7 | 26.0% | 18 |
| 85+ | 38,815 | 1.4 | 57,431 | 1.7 | 48.0% | 18 |
| Under 65 | 2,450,997 | 86.2 | 2,983,222 | 87.2 | 21.7% | 27 |
| Total | 2,842,321 | | 3,421,399 | | 20.4% | 28 |

Source: United States Census Bureau. *Profile of General Demographics for Oregon: 1990-2000* [<http://www.census.gov/census2000/states/or.html>].

Like most states, Oregon will face a significant increase in its aging population over the next 25 years. Between 2000 and 2025, Oregon's 85 and older population is expected to increase by 124% (see **Figure 1**). In 2025, 24% of Oregon's population will be 65 years or older, compared to 18.5% for the nation (see **Table 2**).

Figure 1. Percent Population Increase in Oregon, 2000-2025



Source: Congressional Research Service (CRS) calculations based on data from the U.S. Census Bureau Projections at [http://www.census.gov/population/www/projections/st_yrby5.html]; analyzed data from State Population Projection: Every Fifth Year.

Table 2. Elderly Population as a Percent of Total Population, Oregon and the United States, 2025

| Age | Proportion of total population, Oregon | Proportion of total population United States |
|---------------------|--|--|
| 65+ | 24.2% | 18.5% |
| 65-74 | 13.3% | 10.5% |
| 75-84 | 8.0% | 5.8% |
| 85+ | 2.9% | 2.2% |
| Under 65 population | 75.8% | 81.5% |

Source: Congressional Research Service (CRS) calculations from census projections released in 1996. See **Appendix 2** for information about projections, their methodology and limitations.

Need for Long-Term Care

Table 3 presents estimates of the number of persons aged 18 and over who have limitations in two or more activities of daily living (ADLs) in Oregon. These estimates were derived from data generated by The Lewin Group and combine national level data on persons with disabilities with state-level data from the U.S. Census Bureau on age, income, and broad measures of disability. Persons aged 85 and over with two or more limitations in ADLs are estimated to increase by 38%

from 2002 to 2010. This growth will place pressure on public and private long-term care resources.

Table 3. Estimated Number of Persons with Two or More Limitations in Activities of Daily Living (ADLs), by Poverty Status, in Oregon

| Percent of poverty | 2002 | | | 2005 | | | 2010 | | |
|--------------------|--|--------|-------|-------|--------|-------|-------|--------|-------|
| | Persons with 2+ ADLs by age and income | | | | | | | | |
| | 18-64 | 65+ | 85+ | 18-64 | 65+ | 85+ | 18-64 | 65+ | 85+ |
| Up to 100% | 1,960 | 2,128 | 847 | 2,040 | 2,308 | 964 | 2,126 | 2,650 | 1,165 |
| Up to 150% | 2,763 | 4,620 | 1,555 | 2,876 | 4,976 | 1,771 | 2,999 | 5,626 | 2,139 |
| Up to 200% | 3,405 | 6,202 | 1,986 | 3,546 | 6,671 | 2,262 | 3,698 | 7,525 | 2,732 |
| All income | 7,174 | 13,513 | 3,843 | 7,469 | 14,511 | 4,376 | 7,789 | 16,445 | 5,286 |

Source: Congressional Research Service (CRS) analysis based on projections generated by The Lewin Group through the HCBS State-by-State Population Tool, available on-line for subscribers at [<http://www.lewin.com/cltc>]. *The Lewin Group Center on Long Term Care HCBS Population Tool*, by Lisa M.B. Alexih, and Ryan Foreman (2002).

Administration of Long-Term Care Programs

State and Local Administration

According to state officials, a large part of the success of Oregon's long-term care system stems from its administrative structure. Oregon's system is one of the few in the country to consolidate all of the various administrative and service functions into a single state agency. The goal of state officials over the last 20 years (partially in response to several state legislative mandates) has been the creation of a seamless system for seniors and people with disabilities that favors care in community settings rather than in nursing homes or other institutions.

In 1981, on the final day of one of the longest legislative sessions in Oregon's history, the state legislature passed Senate Bill 955, drastically reshaping Oregon's long-term care system. The bill consolidated the state's unit on aging and its Medicaid long-term care program creating the Senior Services Division (which later became the Seniors and Disabled Services Division and is now Seniors and People with Disabilities). The new division was charged with containing the costs of long-term care, while at the same time creating a long-term care system that supported the preference of people with disabilities for home and community-based

services. A vision was articulated in the legislation for a long-term care system that embodies the “human values of independence, dignity, privacy, and choice.”¹⁰

In testimony to the U.S. Senate Special Committee on Aging in 1998, Roger Auerbach, the director of the Seniors and Disabled Services Division stated that, “the crisis Oregon faced was partially the product of the fragmentation and bureaucracy created by piecemeal legislative responses, without a clear vision of how a system should be built. The success we have to date is really proportionate to the clarity of our vision. That vision, which is now very clear, is one of a consumer-centered, individualized program delivered by a coordinated, accessible system.”¹¹

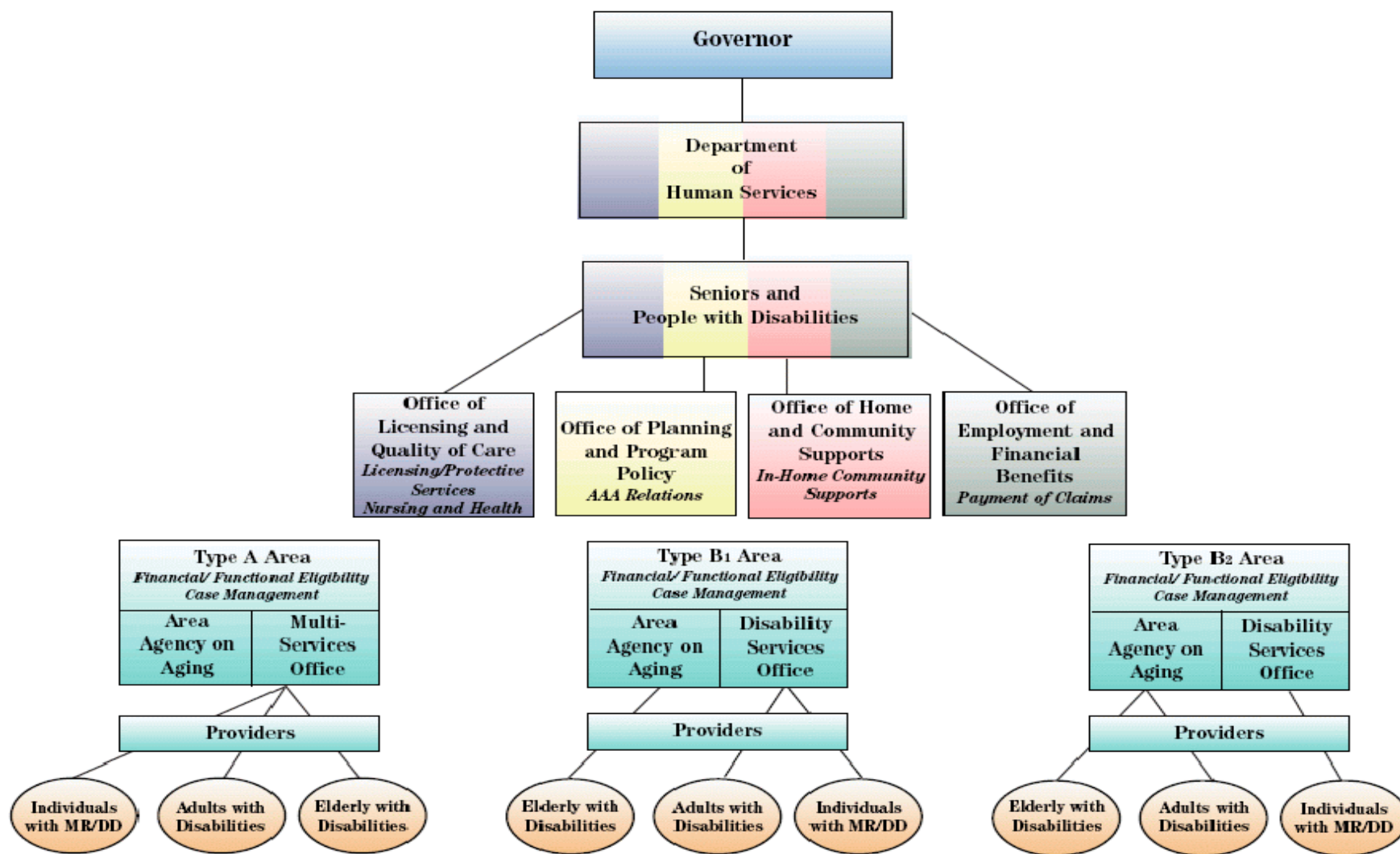
The most recent reorganization spearheaded by the legislature in 2001 consolidated all state long-term care functions into the single division of Seniors and People with Disabilities (SPD), one of seven divisions within the Department of Human Services. It is unique among long-term care systems in the United States in that it incorporates the state’s Medicaid agency, the state unit on aging, the state unit on developmental disabilities, and the long-term care regulatory agency under a single administrative structure and budget.

Figure 2 portrays the primary functions performed by SPD and local agencies that collectively make up Oregon’s long-term care system. Those functions are: financial and functional determination of eligibility; licensing and protective services; financial reimbursement; management of services for elderly and disabled persons; and the management of services for persons with mental retardation and developmental disabilities. Each of these functions is described in detail in the following sections.

¹⁰ Oregon State Legislature, Senate Bill 955, 1981.

¹¹ Roger Auerbach, *Reforming the Delivery System*, Testimony before the U.S. Senate Special Committee on Aging, Mar. 3, 1998

Figure 2. Oregon Long-Term Care System



Source: Chart prepared by the Congressional Research Service (CRS) based on Oregon's State Documents.

Management of Services for Seniors and Other Persons with Disabilities. At the state level, supervision of long-term care services for the elderly and persons with disabilities resides within the division of Seniors and People with Disabilities (SPD). SPD either contracts with area agencies on aging (AAAs) to provide these services, or uses state employees housed within the county offices of the Department of Human Services (DHS) to administer Medicaid and other long-term care programs. These offices serve as “single points of entry” for a variety of services available in state.

Local Administration. Oregon’s long-term care service delivery system is built on a diverse network of community organizations and state offices to provide care at the local level. The law creating the current long-term care system supported a strong role for the state’s area agencies on aging (AAAs) and allows for significant local control. SPD contracts with AAAs that wish to administer long-term care programs in the state. In areas where the AAA chooses not to provide services (primarily in the rural areas of Eastern Oregon), state employees within the county human services office administer long-term care services and programs. The result is that local service providers and administrators can choose the most appropriate administrative structure for their localities. There are three types of service delivery models in Oregon — *Type A*, *Type B1*, and *Type B2*. Each type of delivery system is described below:

- *Type A* — In this service delivery model, the AAA administers programs and services funded by the Older Americans Act and the state-funded Oregon Project Independence (OPI) program for seniors aged 60 and over. In a *Type A* area, the state operates a local multi-service office (housed within the county human services office) to administer Medicaid for long-term care clients. State employees develop care plans, provide ongoing case management, and license and monitor long-term care facilities for seniors and adults with physical disabilities. There are 19 *Type A* areas in Oregon.
- *Type B1* — In this service delivery model, the AAA administers programs and services funded by the Older Americans Act, the state-funded OPI program for persons 60 and older, *and* the state’s Medicaid long-term care program for seniors 65 and over. It does not provide Medicaid services to people with physical disabilities who are under the age of 65 or to individuals with developmental disabilities. In a *Type B1* area, the state operates a local Disability Service Office (housed within the county human services office) to administer Medicaid and other state programs for long-term care clients not served by the AAA. There are seven *Type B1* areas in Oregon.
- *Type B2* — This service delivery model administers all of the same programs that *Type B1* agencies may administer, but also serves adults aged 18 to 64 with physical disabilities. People with developmental disabilities are served in the Disability Service Office. There are eight *Type B2* areas in Oregon.

For the last several decades, Oregon's Department of Human Services has attempted to integrate its service delivery systems throughout the state. Oftentimes, clients with complex needs were forced to visit multiple social service offices and provide the same information to multiple case workers. In order to make it easier for clients to navigate the social service system in Oregon, the Department has developed a "no wrong door" approach to service provision. A client should be able to walk into any area agency on aging or county DHS office to determine initial eligibility for a variety of programs, such as Medicaid, food stamps, TANF, and state-funded programs such as OPI. Oregon has attempted to utilize the structure of the area agencies on aging to serve as an information center for a variety of social service programs in the state.

Management of Services for Persons with Developmental Disabilities. In 2001, the state legislature mandated that SPD administer programs for persons with developmental disabilities. At the local level, county DHS offices employ staff to provide case management services. Other services are subcontracted to local providers which typically specialize in serving individuals with developmental disabilities.

Licensing. SPD is responsible for licensing long-term care facilities and ensuring that quality care is delivered in both nursing homes and home and community-based settings. Oregon's licensing process includes inspection, reporting on inspection outcomes or complaint investigations, and sanctioning deficient facilities. In spite of these regulatory responsibilities, officials in the Office of Licensing and Quality of Care (housed within SPD) have attempted to move away from a strictly punitive approach, and adopt a model that offers technical assistance and problem solving to encourage continuous quality improvement.

Protective Services. SPD is responsible for adult protective services for seniors and people with disabilities in home and community settings and licensed facilities. State laws provide for mandatory reporting of elder abuse. Local Area Agency on Aging and state office personnel complete investigations and provide needed protection. SPD is also responsible for abuse prevention and statewide educational activities to strengthen awareness and partnerships for community interventions.

Case Management. Case managers are critical to implementing Oregon's preference for home and community-based care over nursing home care. Case managers take on a variety of roles in the state's long-term care system. In addition to managing clients' care plans, performing pre-admission screenings, and determining client eligibility for Medicaid, case managers also monitor nursing facilities and community-based care facilities.

Because home and community-based care requires more rigorous oversight by case managers to ensure the best placement of clients, SPD regulates the number of individuals a case manager can serve depending on the type of care he or she is receiving. In nursing facilities the staffing ratio is one case worker per 130 clients; in adult foster care, the staffing ratio is one case worker per 79 clients; in residential care facilities and assisted living facilities, the staffing ratio is one case worker per 100 clients; and for in-home services, the staffing ratio is one case worker per 69

clients. Depending on the type of service area where a client resides, case managers are employed by either the local area agencies on aging, the disability service office, or the multi-service office.

Financial and Functional Eligibility Determinations

Information about financial eligibility for Medicaid and other state programs is gathered at the local level by caseworkers in the area agencies on aging, the disability service office or the multi-service office. Although initial decisions on financial eligibility are made locally, state officials within SPD make the final eligibility determination.

Functional eligibility is also determined at the local level. In order to assist case managers in making eligibility determinations, SPD has developed a number of automated tools to streamline the process. The Client Assessment and Planning System (CA/PS) is a computer system that assists caseworkers in determining eligibility and assigning service priority levels. A service priority level is a number between 1 and 11 that identifies an individual's long-term care needs, based on limitations in activities of daily living (ADLs). A caseworker will make a number of assessments about a client's need for assistance, input information into the computer system, and CA/PS will automatically return a decision about eligibility, and if appropriate, assign a service priority level. To be considered functionally eligible for Medicaid services a client must be assigned a service priority level (**Table 4**). Once the assessment is complete, case managers work with the client to determine the most appropriate setting, incorporating a variety of factors such as informal supports and client wishes. A service plan is developed and periodically changed to meet the needs of the client. CA/PS also provides caseworkers with assistance in developing service plans that are appropriate for each priority level.

Changes in Functional Eligibility Requirements Due to Budget Reductions. After a state-wide ballot initiative to increase taxes was defeated by voters in January 2003, Seniors and People with Disabilities had to reduce its long-term care spending by nearly 30% for the current state fiscal year. SPD decided to cut funding for individuals who were assigned service priority levels of 12 through 17 (**Table 5**). As of April 2003, over 4,792 persons had lost Medicaid long-term care services (over 16% of total program participants), with potentially more cuts needed in the future.

Of the residents who lost Medicaid services, 3,834 were receiving in-home services; 765 were residing in community-based assisted housing arrangements; and 193 were residing in nursing facilities. SPD worked with the Centers for Medicare and Medicaid Services (CMS) to make changes to their current waiver to provide limited transitional services for those who no longer qualify for Medicaid.

Table 4. Service Priority Levels Eligible for Medicaid Services

| Service priority level | Description of service priority level |
|-------------------------------|---|
| Level 1 | Requires full assistance in all major activities of daily living |
| Level 2 | Requires full assistance in mobility, eating and cognition |
| Level 3 | Requires full assistance in at least one of the following activities of daily living: mobility, cognition or eating |
| Level 4 | Requires full assistance in elimination |
| Level 5 | Requires substantial assistance with mobility and eating and requires assistance with elimination |
| Level 6 | Requires substantial assistance with mobility and eating |
| Level 7 | Requires substantial assistance with mobility and assistance with elimination |
| Level 8 | Requires assistance with mobility and eating and elimination |
| Level 9 | Requires assistance with eating and elimination |
| Level 10 | Requires substantial assistance with mobility |
| Level 11 | Requires assistance with elimination and minimal assistance with mobility |

Source: Documents provided by Oregon Department of Human Services, SPD.

Table 5: Eliminated Service Priority Levels

| Eliminated service priority levels | Description of eliminated service priority levels |
|---|--|
| Level 12 | Requires minimal assistance with mobility and assistance with eating |
| Level 13 | Requires assistance with elimination |
| Level 14 | Requires assistance with eating |
| Level 15 | Requires minimal assistance with mobility |
| Level 16 | Requires full assistance in bathing or dressing |
| Level 17 | Requires assistance in bathing or dressing |

Source: Documents provided by Oregon Department of Human Services, SPD.

Oregon's Long-Term Care Services for the Elderly and Persons with Disabilities

Trends in Institutional Care

Since the state first implemented its home and community-based services waiver on December 21, 1981, the utilization of nursing homes for Medicaid clients has steadily declined. Between 1996 and 2001, there was a 17.2% decrease in the number of nursing home residents.¹² According to the DHS Performance Measurement Report, in June of 2001, only 22.1% of all seniors receiving Medicaid long-term care services and 9% of all adults (aged 18-64) with disabilities were served in nursing facilities.¹³

In 2001, there were 151 nursing facilities operating in Oregon serving approximately 9,444 persons.¹⁴ The number of beds per 1,000 elderly persons is considerably less than the national average. In 2000, there were approximately 31 beds per 1,000 persons aged 65 and older and 235 beds per 1,000 elderly persons aged 85 and older, as compared to 53 and 435, respectively, for the United States (**Table 6**). At the beginning of Oregon's efforts to expand home and community-based services in 1981, the number of nursing home beds per 1,000 persons aged 65 and older in Oregon was roughly equal to the national average.¹⁵ The occupancy rate for Oregon's nursing homes in 2001 was 72.8%, somewhat lower than the national average of 80.8% (**Table 6**).

Over the last two decades, the state has developed a number of methods to control nursing home utilization. These include: a certificate of need program, which requires nursing facilities to obtain permission from SPD before new facilities are built or old facilities are expanded; a pre-admission screening program for both private and Medicaid clients; and extensive use of the Medicaid Section 1915(c) home and community-based waiver. As a result of these strategies to control nursing home utilization, state officials indicate that the characteristics of nursing home residents have changed over the last 2 decades. Disability levels of patients have increased dramatically. This is attributed, in part, to a greater use of home and community-based services that delays entry into nursing facilities.

¹² Steven R. Gregory and Mary Jo Gibson. *Across the States 2002: Profiles in Long-Term Care — Oregon, 2002*, AARP Public Policy Institute, (Washington) 2002. (Hereafter cited as Gregory and Gibson, *Across the States 2002*.)

¹³ Department of Human Resources, *Performance Measurement Report*, fall 2001. At [http://www.dhs.state.or.us/publications/pm_reports/dhsfall2001.pdf].

¹⁴ Gregory and Gibson, *Across the States 2002*.

¹⁵ Robert Kane, et al., *Oregon's Long-Term Care System: A Case Study by the National Long-Term Care Mentoring Program*, at [<http://www.ilru.org/pas/ltc.htm>] 1996.

Table 6. Nursing Home Characteristics in Oregon and the United States
(data are for 1999-2000 unless otherwise noted)

| Characteristic | Oregon | United States |
|---|--------------|---------------|
| Number of residents | 10,205 | 1,490,155 |
| Number of facilities | 151 | 17,023 |
| Number of beds | 13,493 | 1,843,522 |
| Number of Medicaid beds | 5,440 | 841,458 |
| Number of total beds per 1,000 pop. aged 65 and older | 30.8 | 52.7% |
| Number of total beds per 1,000 pop aged 75 and older | 61.7 | 111.1 |
| Number of total beds per 1,000 pop aged 85 and older | 234.9 | 434.8 |
| Occupancy rate | 72.8% (2001) | 80.8% |

Source: Data comes from the following sources: Oregon's occupancy rate — AARP, *Across the States 2002: Profiles in Long-Term Care — Oregon*; all other information comes from the American Health Care Association (AHCA), *Facts and Trends: The Nursing Facility Sourcebook*.

Implementation of the Medicaid 1915(c) Waiver Program for Seniors and Adults with Physical Disabilities. In 1981, Oregon became the first state in the nation to implement a Section 1915(c) waiver program on a statewide basis. This waiver program resulted in decreased reliance on nursing homes, in part, because, state officials decided at the program's inception to offer residents equal access to home and community-based care, with no caps on the number of people who could be served by the waiver and no waiting lists for services.

Because area agencies on aging or state employees of SPD determine eligibility for both home and community-based services and nursing facility services, they are able to inform clients of all available long-term care options. According to state officials, case managers are encouraged to arrange care plans so that individuals who do not wish to enter a nursing facility are able to find suitable alternatives at home or in the community.

Pre-Admission Screening. In 1989, Oregon adopted a pre-nursing home admission screening program. Oregon requires all prospective nursing home residents to be screened before entering a nursing facility. A patient's level of impairment is evaluated, and home and community-based service options are discussed with the client and family members. Partially as a result of this screening process, the rate of hospital discharges directly into nursing homes is significantly lower than the national average.¹⁶

Certificate of Need. In the 1970s, Oregon instituted a certificate of need (CON) program to control and downsize the number of nursing facilities in the state.

¹⁶ Unpublished documents from the Oregon Health Care Association. 2002.

In order to build a new nursing facility or expand an existing facility, a provider must receive DHS approval for Medicaid beds. The state reviews an application from a provider on a case-by-case basis using the following criteria: nursing facility bed occupancy in the service area; availability of home and community-based services in the area; and economic and financial feasibility. This procedure is intended to complement SPD's goal of promoting home and community-based services over institutional care by controlling the number of nursing home beds that enter the market.

Trends in Home and Community-Based Care

According to state reports, between 1985 and 2000, the number of Medicaid clients in need of long-term care served in home and community-based settings increased by 224%.¹⁷ In 2002, approximately 81.5% of the state's Medicaid clients received home and community-based services, as opposed to only 18.5% in nursing facilities. Oregon supports a wide range of home and community-based services for the elderly and persons with physical disabilities which are primarily provided through a Medicaid Section 1915(c) waiver and a state-funded program — Oregon Project Independence — for persons who are not receiving Medicaid. While many states have multiple waivers targeted to specific eligibility groups, Oregon has a single waiver to fund all home and community-based Medicaid services for seniors and adults with physical disabilities.

The state has developed a variety of innovative policies that encourage home and community-based care under its waiver. Oregon was one of the first states in the nation to use its waiver to support services in assisted living facilities; it is one of the only states to develop a large adult foster care system; and its use of unlicensed caregivers (through its client employed provider program) has dramatically increased the number of individuals that can be served in their homes.

Medicaid 1915(c) Waiver for Seniors and Persons with Physical Disabilities. Oregon operates a single Medicaid waiver program for the elderly and adults with physical disabilities. In order to qualify for Medicaid services, persons must have income that does not exceed 300% of the Supplemental Security Income (SSI) level (\$1,656 per month in 2003) and must meet SSI's resource limit of \$2,000 for an individual.¹⁸ For some individuals who do not meet these requirements, the state operates a Miller Trust that permits additional income and resources to be recovered by the state, thereby allowing an individual to qualify for Medicaid services.¹⁹

¹⁷ Seniors and People with Disabilities, *The Oregon Model*, Dec. 2001, at [www.sdsd.hr.state.or.us/about/oregon_model.htm]

¹⁸ Certain items are excluded, such as an individual's home; up to \$2,000 of household goods and personal effects; life insurance policies with a face value of \$1,500 or less; an automobile with value up to \$4,500; and burial funds up to \$1,500, among other things.

¹⁹ For more information on Miller Trusts and Medicaid eligibility, refer to CRS Report RL31413, *Medicaid: Eligibility for the Aged and Disabled*, by Julie Lynn Stone.

Originally approved in 1981, this waiver has been the primary alternative to nursing home care for adults with physical disabilities. In 2001, the estimated average cost per client under the waiver was \$5,558 per year. Approximately 42,242 persons are expected to receive long-term care services under this waiver for state fiscal years (SFY) 2001 to 2003.

The waiver provides a wide range of home and community-based services including: respite care, adult day health, specialized medical equipment, environmental accessibility adaptations, transportation, home delivered meals, specialized living services, and in-home services. For individuals who are not served in their own homes, the waiver provides long-term care in community settings, including adult foster care, residential facility care, and assisted living facility care.

In 2002, 81.5% of Oregon's Medicaid long-term care clients received home or community-based services under this waiver (see **Table 7**). Of these clients, 46.6% were served in their homes; 17% were served in adult foster homes; 12% were served in assisted living facilities; and 6% were served in residential care facilities.

Client Employed Provider Program. The majority of Oregon's in-home services are provided through the client employed provider (CEP) program. The CEP program allows Medicaid clients to hire and supervise their own care providers. Clients may select their own caregiver (such as friends or relatives) or they can be assisted in their search for a provider by the local AAA or county DHS office. Although CEPs are self-employed, the state pays unemployment insurance and the social security FICA payments on behalf of the CEP. State officials indicate that this program, which allows unlicensed caregivers to provide long-term care services, has greatly expanded the state's ability to provide home and community-based services.

Nurse Delegation and Contract Registered Nursing Services. In 1987, the state legislature amended its Nurse Practice Act to allow licensed registered nurses to delegate certain medical tasks to unlicensed caregivers, such as client employed providers or workers in adult foster homes. As a result of this legislation, nurses may train caregivers in certain home and community-based settings to perform almost all nursing tasks except for certain types of injections. Once an assessment is made by the nurse to ensure that a client is in stable condition, a care plan is developed; hands-on training is provided to the caregiver; and nursing tasks are delegated in writing. The nurse delegate must periodically assess a client's health and review the care plan.

In 1994, the state developed a system of contract registered nursing services, which expanded the state's ability to use nurse delegates for its Medicaid home and community-based waiver program. There are currently 150 nurses under contract with SPD providing nurse delegation services for Medicaid long-term care clients around the state. State officials and providers maintain that the use of nurse delegation has been essential to the expansion of home and community-based care services in Oregon.

Table 7. Medicaid Long-Term Care Caseload by Setting, July 2002

| Setting | Total Medicaid long-term care caseload | Percent of total caseload |
|--|--|---------------------------|
| Total Medicaid Clients | 31,266 | 100% |
| Institutional Services | 5,782 | 18.5% |
| - Nursing Facilities | 5,782 | |
| Home and Community-Based Services (HCBS) | 25,484 | 81.5% |
| In-Home Care | 14,556 | 46.6% |
| - Adult Foster Homes | 5,399 | 17.3% |
| - Assisted Living Facilities | 3,662 | 11.7% |
| - Residential Care Facilities | 1,867 | 6.0% |

Source: Congressional Research Service (CRS) calculations based on *Seniors and People with Disabilities Data Sheets*, July 2002. Percentages do not sum to 100% due to rounding.

State Programs. Oregon Project Independence. Many state officials and advocates believe that the eligibility requirements for Medicaid, particularly the asset limits, are a barrier to persons in need of long-term care who want to live at home. State officials indicated that many people in need of home and community-based care do not feel comfortable depleting almost all of their liquid assets that may be needed for household expenses and emergencies. One of the ways that Oregon has addressed this concern is through a state-funded program, Oregon Project Independence (OPI). OPI offers home and community-based services to persons with income up to 200% of the poverty level with no resource or asset test.

Funded entirely by state revenues, OPI provides long-term care services for Oregonians over the age of 60. Clients with net incomes between 100% and 200% of the poverty level (between \$8,869 and \$17,720 per year in 2002) pay a sliding scale fee for services based on income. Individuals with income over 200% of the poverty may still enroll in the program but will pay the full rate of services. Services provided by the program include: personal care, respite care, assisted transportation, homemaker/home care services, chore, home health, adult day care, case management, registered nursing services, home delivered meals, and other services as authorized by SPD.

Oregon's Long-Term Care Services for Persons with Mental Retardation and Developmental Disabilities

Overview

Services to persons with mental retardation and other developmental disabilities in the United States have changed dramatically over the last half of the 20th century as a result of a number of converging factors. These include the advocacy efforts of families and organized constituency groups, various changes to the Social Security law that provided payments to individuals through SSI and SSDI and to service providers through the Medicaid program, and significant litigation brought on behalf of persons with developmental disabilities.²⁰

Oregon's system of services for persons with developmental disabilities has been influenced by a number of significant factors. These include:

- the initiation of the Section 1915(c) Medicaid home and community-based waiver services option in 1981;
- the *Plan for Universal Access to Services for People with Developmental Disabilities* initiated by the Oregon State legislature in 1999;
- the 2000 settlement agreement of *Staley v. Kitzhaber* which requires the state to increase funding for developmental disabilities services by a cumulative total of \$350 million by 2007; and
- the incorporation of the Mental Health and Developmental Disability Services Division into the division of Seniors and People with Disabilities in 2001.

There are an estimated 15,500 persons of all ages that meet Oregon's definition of developmentally disabled.²¹ Of these, approximately 8,400 are adults and 7,100 are children. In FY2000, total spending for services for persons with developmental disabilities was \$354.7 million (**Table 13**). Spending for home and community-based services represented 90% of total expenditures. This is a dramatic shift from 1990 spending levels when only 41% of spending was devoted to community-based services.²²

²⁰ For a detailed history of the development of services for persons with developmental disabilities, see David Braddock, Richard Hemp, Susan Parish, and James Westrich, *The State of the States in Developmental Disabilities*, University of Illinois at Chicago. American Association on Mental Retardation (Washington) 1998. (Hereafter cited as Braddock, et al., *The State of the States in Developmental Disabilities*.)

²¹ Oregon Department of Human Services, *A Plan for Universal Access to Services for People with Developmental Disabilities*, 2000.

²² CRS calculations based on data presented in Braddock, et al., *The State of the States in Developmental Disabilities* (Fifth Edition), (Washington) 1998, American Association on Mental Retardation, p. 404 (for 1990 data). Unpublished data furnished by Richard Hemp, University of Colorado (for 2000 data).

Trends in Institutional Care

The early history of services to persons with developmental disabilities is characterized by large state institutions or training schools begun during the latter part of the 19th century and continuing through the first part of the 20th century. Between 1920 and 1967, institutions quadrupled in size and resident totals peaked at almost 200,000 individuals nationwide in 165 free-standing state-operated mental retardation institutional facilities.²³ Today, some states are still faced with the legacy of large state-operated institutions.

In many states and in Oregon, most state-operated institutions have been closed or downsized, a development that has often been prompted by litigation. In 1908, Oregon opened Fairview, its first state-funded institution to care for individuals with developmental disabilities and mental retardation. By the early 1960s, thousands of persons received care in three state-run institutions in Salem, Pendleton, and The Dalles.

Today, after a decades-long process of moving persons with developmental disabilities into community-based group homes and residential settings, there is only one remaining state-operated institution in Oregon — the Eastern Oregon Training Center in Pendleton — with 50 residents in 2001. (See **Appendix 2** for a list of the institutions that have been closed.) Persons living in large institutions with 16 or more persons declined from 37% in 1990 to just over 8% in 2000 (**Table 8**).

The Medicaid home and community-based services waiver option has allowed Oregon to focus on the development of small congregate care options. In 2000, over 90% of persons with developmental disabilities were living in group residential settings, with the majority (78.5%) living in residences of six or fewer persons (see **Table 8**).

²³ Braddock, et al., *The State of the States in Developmental Disabilities*.

Table 8. Persons with Mental Retardation and Developmental Disabilities Served in Residential Settings, by Size of Residential Setting, 1990, 1995, and 2000

| Persons served by setting | | | |
|---------------------------|-------------------------|------------------------|------------------------|
| | 1990 | 1995 | 2000 |
| Total | 4,168 (100%) | 4,239 (100%) | 4,562 (100%) |
| 16+ Persons | 1,556 (37.3%) | 904 (21.3%) | 384 (8.4%) |
| Nursing facilities | 443 | 300 | 180 |
| State institutions | 840 | 463 | 105 |
| Private ICFs/MR | 140 | 0 | 0 |
| Other residential | 133 | 141 | 99 |
| 7 - 15 Persons | 697 (16.7%) | 600 (14.2%) | 597 (13.0%) |
| Public ICFs/MR | 0 | 0 | 0 |
| Private ICFs/MR | 22 | 0 | 0 |
| Other residential | 675 | 600 | 597 |
| <6 Persons | 1,915 (45.9%) | 2,735 (64.5) | 3,581 (78.5) |
| Public ICFs/MR | 0 | 0 | 0 |
| Private ICFs/MR | 0 | 0 | 0 |
| Other residential | 1,915 | 2,735 | 3,581 |

Source: David Braddock, Richard Hemp, Mary C. Rizzolo, Susan Parish, and Amy Pomeranz. *The State of the States in Developmental Disabilities: 2002 Study Summary*, by Coleman Institute for Cognitive Disabilities and Department of Psychiatry, University of Colorado, June 2002.

According to data compiled by Braddock et. al., Oregon ranked seventeenth in the nation in its use of small facilities (residences of six or fewer persons) in 2000.²⁴ There is a recognition on the part of Oregon state officials and stakeholders that the use of larger facilities should be further reduced in keeping with the state's commitment to community-based care.

²⁴ David Braddock, ed., *Disability at the Dawn of the 21st Century and the State of the States*, American Association on Mental Retardation, (Washington), 2002, p. 86.

Trends in Home and Community-Based Care

Over the last two decades, Oregon has made significant use of Medicaid financing to reduce the number and size of intermediate care facilities for persons with mental retardation and developmental disabilities (ICFs/MR). As in many states, the Medicaid Section 1915(c) waiver program has been the chief source of revenue for home and community-based services for persons with developmental disabilities. In 1981, Oregon applied for and received a waiver that would serve as an alternative to one of the two state-run institutions. By 2001, the Fairview Training Center in Salem had been closed and only 50 individuals remained in the Eastern Oregon Training Center.

Unlike the waiver program for the elderly and physically disabled, where the state has no waiting lists for services, persons with developmental disabilities often face lengthy waiting lists due to limited resources. Since the focus of the 1981 waiver was to remove individuals from institutions, those who were not residing in one of the two state ICFs/MR often spent years waiting to receive community-based services.

In 2000, parents of individuals with developmental disabilities filed suit against the state to challenge the existence of the current waiting lists. In *Staley v. Kitzhaber*, the plaintiffs argued that Oregon violated federal Medicaid law and the Americans with Disabilities Act (ADA) for failing to provide individuals with developmental disabilities the option of home and community-based long-term care services with “reasonable promptness.”²⁵

The state and the plaintiffs settled the lawsuit in September 2000. The parties agreed that the settlement would apply not only to the plaintiffs named in the suit but also to “all other similarly-situated individuals with developmental disabilities under the federal Medicaid program,” thereby treating the lawsuit as a class action.²⁶ As part of the agreement, Oregon agreed to implement its *State Plan for Universal Access to Services for People with Developmental Disabilities* over a 6-year period between 2001 and 2007. The plan provides for improved access to supportive services, such as personal care, in-home care, respite care, and job coaching, so long as cost of services does not exceed \$20,000 annually per client.

By 2007, after the plan has been fully implemented, supportive services must be provided within 90 days after the individual is determined eligible for services. Comprehensive services — or services costing more than \$20,000 per year — will be offered to a limited number of individuals. This may include intensive in-home care, 24-hour group homes, adult foster care homes, and environmental adaptation services. Comprehensive services for about 50 adults per year will be phased-in over the next 6 years.

²⁵ National Center for Family Support at [http://www.familysupport-hsri.org/resources/r_medicaid_dd-1.html].

²⁶ Oregon Department of Health, SPD at [<http://oddsweb.mhd.hr.state.or.us/Pubs/settlement/settlement.htm>].

The agreement also requires the state to improve its service delivery infrastructure. Funding for case management will be increased so that caseloads will drop from an average of about one caseworker per 95 clients to one per 45 clients. Additional funding will also be used to improve the provider network at the local level.

In 2001, the state legislature approved the plan and agreed to fund the settlement agreement. The state will increase funding for developmental disabilities services by a cumulative total of \$350 million by 2007.

Medicaid 1915(c) Waivers.²⁷ Oregon operates two 1915(c) waivers for adults with developmental disabilities. Below is a brief description of each waiver's average costs and the types of services offered.

- *1981 Waiver for Developmentally Disabled Individuals.* For the 2002 waiver year, it is estimated that 5,762 persons with developmental disabilities received long-term care services under this waiver. Originally approved in 1981, the waiver was designed as an alternative to intermediate care facilities for the mentally retarded (ICFs/MR) with the goal of reducing the number of individuals in state-run institutions. A wide range of services are provided under the waiver including: respite care, day habilitation, prevocational services, supported employment, adult foster care, adult group homes, supported living services, specialized medical equipment and supplies, environmental accessibility adaptations, transportation, family training, in-home support services, crisis diversion services, and extended state plan services. This program addresses some of the most complicated cases to serve in community settings and is consequently the most expensive of Oregon's three waivers. For the 2002 waiver year, the estimated average cost per client under the waiver was \$49,274.
- *2001 Waiver for Developmentally Disabled Individuals.* This waiver came about in response to *Staley v. Kitzhaber*. Approved in 2001, 951 developmentally disabled individuals received long-term care services during the first year of the waiver's implementation. Average annual costs were \$6,371 per case. By the third year of the waiver it is estimated that 6,081 individuals will be served at an annual cost of \$11,691 per case. Services provided under the waiver include: respite care, supported employment, community living supports, specialized medical equipment and supplies, environmental accessibility adaptations, transportation, chore, homemaker, personal emergency response systems, family training, in-home support services, crisis diversion services, and extended state plan services.

²⁷ In addition to these waivers, Oregon operates two 1915(c) waivers for children with developmental disabilities under the age of 18, as well as an additional waiver for medically fragile children. This report generally excludes discussion of programs for infants and children with disabilities.

Financing of Long-Term Care in Oregon

In most states, Medicaid is the chief source of financing for long-term care. In addition to the state's matching of federal Medicaid funds, many states also devote significant resources to long-term care. In Oregon, the Medicaid program accounted for \$1 billion in long-term care spending in FY2001.

Medicaid Spending in Oregon

Medicaid is a significant part of state budgets. After elementary, secondary and higher education spending, Medicaid spending was the largest share of state budgets in 2001. According to data compiled by the National Association of State Budget Officers (NASBO), *federal and state* Medicaid spending represented 19.6% of state budgets for the United States as a whole in 2001.

In Oregon, Medicaid spending is the largest single category of *federal and state* spending. Of the state's \$17 billion budget in 2001, federal and state Medicaid spending represented 14.9%. Federal and state spending for Medicaid doubled as a proportion of the state's budget from 1990 to 2001, outranking spending for elementary and secondary education (**Table 9**).

State spending for Medicaid services in Oregon contributed from state funds *only* (excluding federal funds)²⁸ also increased during the 1990s. As a percent of spending for all categories of state spending, state Medicaid spending increased from 3.3 % in 1990 to 7.6% in 2001 (**Table 10**).

²⁸ Federal and state governments share the costs of Medicaid spending according to a statutory formula based on a state's relative per capita income (federal medical assistance percentage, or FMAP). In FY2001, the federal share for Medicaid in Oregon was 60%.

Table 9. Share of Federal and State Spending by Category, Oregon and the United States, 1990-2001

| Expenditure category | Oregon | | | | All states |
|--|----------------|----------------|-----------------|-----------------|--------------------|
| | 1990 | 1995 | 2000 | 2001 | 2001 |
| Total expenditure (in millions) | \$6,987 | \$9,937 | \$16,557 | \$17,033 | \$1,024,439 |
| Medicaid | 7.5% | 15.3% | 13.0% | 14.9% | 19.6% |
| Elementary and secondary education | 10.6% | 17.7% | 14.8% | 13.7% | 22.2% |
| Higher Education | 14.8% | 11.9% | 10.9% | 12.4% | 11.3% |
| Public assistance | 2.2% | 3.1% | 1.7% | 1.7% | 2.2% |
| Corrections | 2.2% | 2.8% | 4.4% | 3.6% | 3.7% |
| Transportation | 7.6% | 8.0% | 6.9% | 5.2% | 8.9% |
| All other expenses | 55.2% | 41.2% | 48.3% | 48.4% | 32.1% |

Source: Congressional Research Service (CRS) calculations based on data from the National Association of State Budget Officers (NASBO), State Expenditure Reports for 1992, 1997 and 2001. Data reported are for state fiscal years. Numbers may not sum to 100% due to rounding.

Table 10. State Spending for Medicaid as a Percent of Total State Spending, Oregon and the United States, 1990-2001

| State spending | Oregon | | | | All states |
|--|----------------|----------------|-----------------|-----------------|------------------|
| | 1990 | 1995 | 2000 | 2001 | 2001 |
| Total state spending (in millions)^a | \$5,944 | \$7,569 | \$13,397 | \$13,580 | \$760,419 |
| State Medicaid spending (millions) ^b | \$194 | \$578 | \$819 | \$1,032 | \$85,141 |
| State Medicaid spending as a percent of total state spending | 3.3% | 7.6% | 6.1% | 7.6% | 11.2% |

Source: CRS calculations based on data from the National Association of State Budget Officers (NASBO), State Expenditure Reports for 1991, 1997 and 2001. Data reported are for state fiscal years.

^a Total state spending for all categories, excluding federal funds.

^b Includes local funds in FY1995; NASBO notes that local funds are a very small part of the program.

Medicaid Long-Term Care Spending in Oregon²⁹

Long-term care spending represented 33.2% of the \$2.1 million spent for Medicaid services in Oregon in FY2000,³⁰ down from 50.7% in FY1990. (**Tables 11 and 12**) Many state officials maintain that this decline is due, in part, to Oregon's commitment to home and community-based services and decreased reliance on expensive institutional care.

Institutional spending as a percent of total long-term care spending has also declined dramatically from FY1990 to FY2000. In 1990, almost 80% of long-term care dollars were spent on institutional care. This dropped to 37.2% in FY2000. During this same 10-year period, spending for home and community-based services increased from 22.1% in 1990 to 62.8% in 2000 (**Table 11**). Today, more than 80% of Medicaid clients receive long-term care in the community.

Medicaid long-term care financing in Oregon at a glance:

Long-term care spending represented almost 40% of Medicaid spending in FY2001, a decline from slightly more than half of all Medicaid spending in FY1990.

Unlike most other states, Oregon spends more on home and community-based services through Medicaid than for institutional care. In FY2000, almost two-thirds of Medicaid long-term care dollars were spent on home and community-based services, with only one-third of that spending devoted to institutional care.

Between 1990 and 2001, there was a 559% increase in state and federal Medicaid spending for home and community-based services.

According to state officials, these trends are due to a number of factors implemented at varying times during the 1980s and 1990s. These include a legislative mandate that called for a preference in providing community-based care over nursing home care; implementation of the state's pre-admission screening program to divert patients from nursing homes; implementation of Oregon Project Independence for persons who do not meet Medicaid financial eligibility requirements; significant use of Medicaid's Section 1915(c) home and community-based waiver services for persons with mental retardation; and closure of large state institutions for the developmentally disabled.

Note that between FY2000 and FY2001, spending for institutional care almost doubled, however, this is not representative of actual spending trends in Oregon (**Figure 4 and Table 12**). According to state officials, this increase is largely due to Oregon's use of Medicaid Upper Payment Limits. Under Medicaid provisions, states can be reimbursed by the federal government at the "upper payment limit" for nursing home services, while the providers in the state are reimbursed at a lower rate. States can use excess funds that result from the gap between the Medicare Upper

²⁹ This section discusses total Medicaid spending, both federal and state.

³⁰ Total Medicaid spending using National Association of State Budget Officers (NASBO) data differs from data shown in this table due to differences in data collection methods.

Payment Limit — the maximum Medicare rate paid to nursing homes — and the actual Medicaid reimbursement rate paid to providers. In Oregon, the difference between the upper payment limit and the state’s reimbursement rate to nursing homes was transferred back to DHS in 2001 and used to fund increases in the reimbursement rates to nursing facilities *and* community-based care facilities. Because of these transfers of state and federal funds, the 28% increase in institutional spending between 2000 and 2001 is not representative of actual spending trends. In 2001, the Centers for Medicare and Medicaid Services (CMS) tightened the regulations that apply to Medicaid Upper Payment Limits. Future budgetary documents may be more representative of spending trends for institutional and home and community-based services.³¹

Table 11. Medicaid Long-Term Care Spending In Oregon, FY1990-FY2000

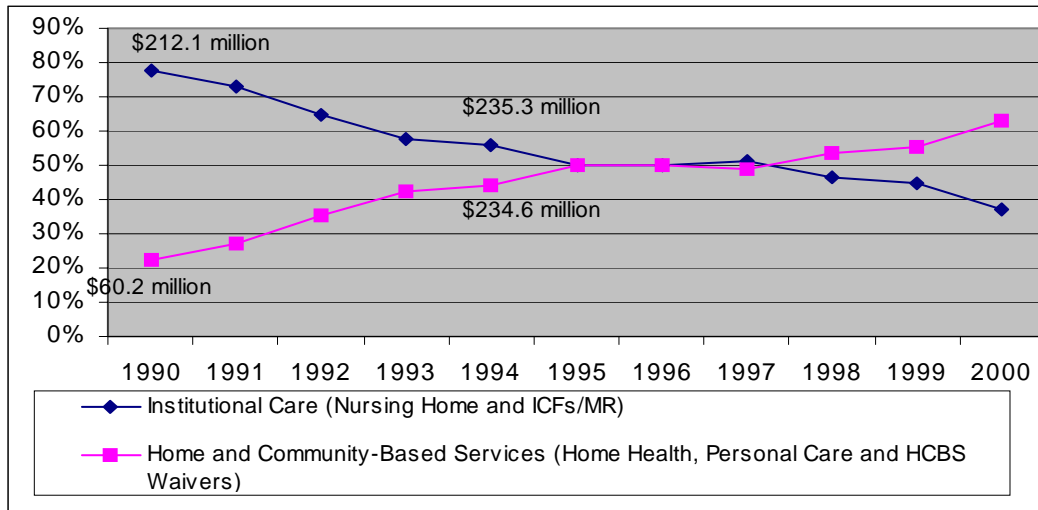
| State spending | 1990 | 1995 | 2000 |
|---|--------------|--------------|--------------|
| Long-term care spending as a percent of Medicaid spending | 50.7% | 32.7% | 33.2% |
| Institutional care spending as a percent of long-term care spending | 77.9% | 50.1% | 37.2% |
| Nursing home spending as a percent of long-term care spending | 42.3% | 34.0% | 33.7% |
| ICFs/MR* spending as a percent of Long-term care spending | 35.5% | 16.1% | 3.4% |
| Total home and community-based services spending as a percent of long-term care spending | 22.1% | 49.9% | 62.8% |
| HCBS waivers spending as a percent of Long-term care spending | 21.3% | 44.8% | 59.3% |

Source: Congressional Research Service (CRS) calculations based on CMS/HCFA 64 data provided by The Medstat Group, Inc. For 2000 and 2001, Brian Burwell et al., *Medicaid Long-Term Care Expenditures in FY2001*, May 10, 2002. For 1995, Brian Burwell, *Medicaid Long-Term Care Expenditures in FY2000*, May 7, 2001. For 1990, Brian Burwell, *Medicaid Expenditures for FY1991*, Systemetrics/McGraw-Hill Healthcare Management Group, Jan. 10, 1992. Total 1990 Medicaid spending, based on HCFA 64 data provided by Urban Institute, Washington, D.C.

*Intermediate care facilities for the mentally retarded.

³¹ For additional information on Medicaid Upper Payment Limits, see CRS Report RL31021, *Medicaid Upper Payment Limits and Intergovernmental Transfers: Current Issues and Recent Regulatory and Legislative Action*, by Elicia J. Herz.

Figure 3. Institutional and Home and Community-Based Services as a Percent of Medicaid Long-Term Care Spending in Oregon, 1990-2000



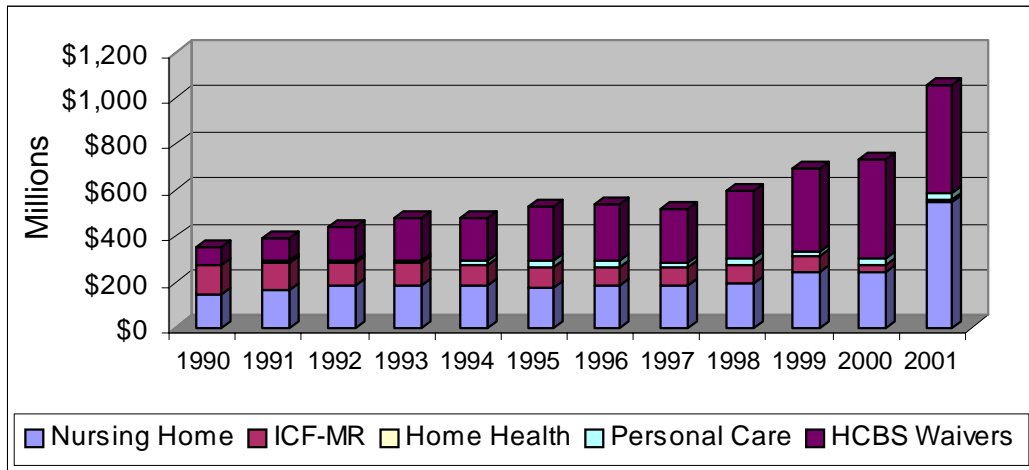
Source: Congressional Research Service (CRS) calculations based on Burwell, *Medicaid Expenditures FY1991-FY2001*.

Table 12. Medicaid Spending in Oregon, Total Spending and Long-Term Care Spending, by Category, and Percent Change, FY1990-FY2001
(dollars in millions)

| Spending category | 1990 | 1995 | 2000 | 2001 | Percent change 1990-2001 (in constant 2001 dollars) |
|--|----------------|----------------|----------------|----------------|---|
| Total Medicaid | \$536.6 | \$1,437.7 | \$2,144.1 | \$2,668.5 | 291.2% |
| Total long-term care* | \$272.3 | \$469.9 | \$712.1 | \$1,058.3 | 205.7% |
| Total institutional care | \$212.1 | \$235.3 | \$264.8 | \$554.0 | 105.4% |
| Nursing home | \$115.3 | \$159.7 | \$240.3 | \$542.8 | 270.2% |
| ICFs/MR** | \$96.8 | \$75.6 | \$24.5 | \$11.2 | -90.9% |
| Total home and community-based services | \$60.2 | \$234.6 | \$447.3 | \$504.3 | 559.0% |
| Home health | \$0.8 | \$1.8 | \$0.7 | \$0.7 | -31.2% |
| Personal care | \$1.5 | \$22.1 | \$24.0 | \$32.2 | 1613.7% |
| HCBS waivers | \$57.9 | \$210.8 | \$422.6 | \$471.4 | 540.5% |

Source: The Congressional Research Service (CRS) calculations based on Burwell, *Medicaid Expenditures FY1991-FY2001*. Total 1990 Medicaid spending, based on HCFA 64 data provided by Urban Institute, Washington.

Figure 4. Medicaid Long-Term Care Spending by Category in Oregon, FY1990-FY2001
(in constant 2001 dollars)

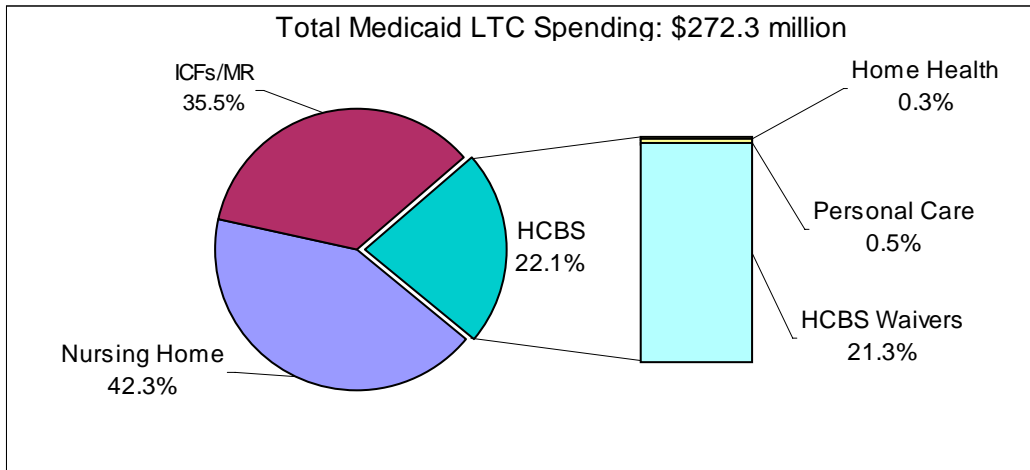


Source: Congressional Research Service (CRS) calculations based on Burwell, *Medicaid Expenditures FY1991-FY2001*.

Figures 5a and b depict changes in long-term care spending patterns from FY1990 to FY2000. In 1990, 35.5% of Medicaid long-term care spending was devoted to care for persons with mental retardation in ICFs/MR; this decreased dramatically to 3.4% in 2000. At the same time, nursing home spending decreased from 42.3% in 1990 to 33.7% in 2000.

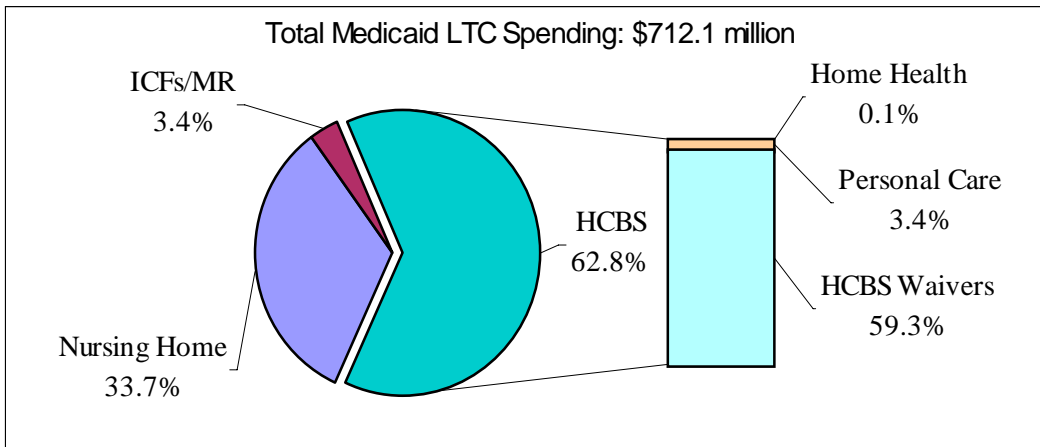
Between 1990 and 2000, spending on home and community-based services more than doubled as a share of long-term care spending, increasing from 22.1% in 1990 to 62.8% in 2000. This is primarily due to expansion of the Section 1915(c) waiver for persons with physical disabilities in Oregon. Waiver spending increased from 22.1% of long-term care spending in 1990 to 59.3% in 2000.

Figure 5a. Medicaid Long-Term Care Spending in Oregon by Category, FY1990



Source: Congressional Research Service (CRS) calculations based on Burwell, *Medicaid Expenditures FY1990-FY2000*.

Figure 5b. Medicaid Long-Term Care Spending in Oregon by Category, FY2000

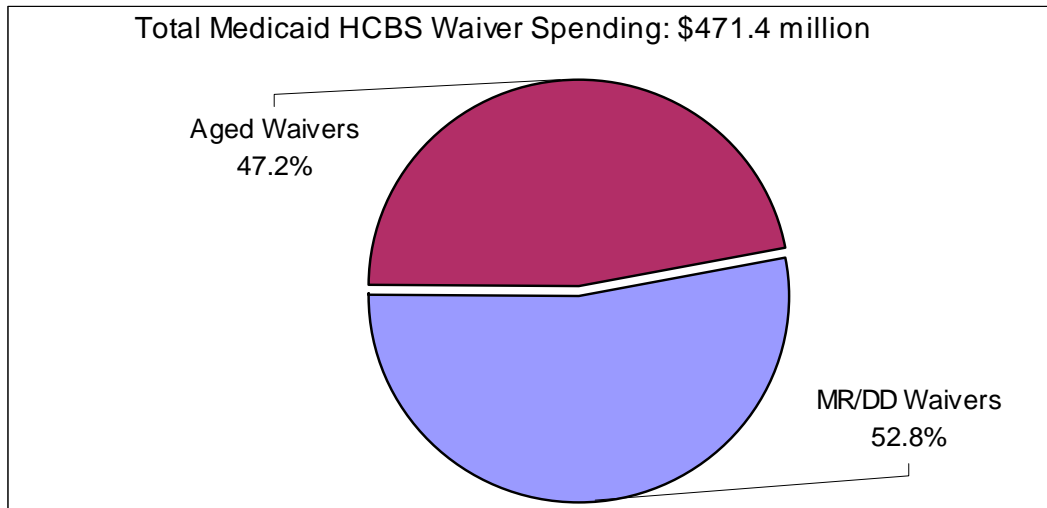


Source: Congressional Research Service (CRS) calculations based on Burwell, *Medicaid Expenditures FY1990-FY2000*.

In the nation as a whole, approximately three-quarters of Medicaid waiver spending is for persons with mental retardation and developmental disabilities. In Oregon, 52.8% of waiver spending for persons with mentally retardation and developmental disabilities, and 47.2% is devoted to spending on other disability groups (**Figure 6**). This is largely due to the commitment of state officials to ensure that no waiting lists exist for the elderly and physically disabled waiver, while allowing waiting lists to be used for persons with developmental disabilities. The waiver for the developmentally disabled initiated in 1981 was primarily used to remove individuals from Fairview and the Eastern Oregon Training Center. In 2001, the state legislature approved a plan to increase funding for a new MR/DD waiver.

The plan outlines the state's intent to increase funding for developmental disabilities services by a minimum of \$350 million by 2007.

Figure 6. Medicaid Home and Community-Based Services Waiver Spending by Target Population in Oregon, FY2001



Source: Congressional Research Service (CRS) calculations based on Burwell, *Medicaid Expenditures FY1990-FY2000*

Medicaid and State Spending on Services for Persons with Mental Retardation and Developmental Disabilities

In 2000, spending for home and community-based services made up 90% of total Medicaid expenditures for persons with developmental disabilities. This is a dramatic shift from 1990 spending levels when only 41% of spending was devoted to home and community-based services. These funds serve approximately 9,654 persons in a variety of community, residential, and institutional settings. Combined federal and state spending in Oregon for persons with developmental disabilities was \$354.7 million in 2000 (**Table 13**). This represented more than a 57% increase (in constant 2000 dollars) since 1990. Of total 2000 spending, a significant share — 45.5% — was contributed by the state.

The state has used the waiver to maximize federal Medicaid reimbursement for home and community-based services, while at the same time it has decreased federal spending for institutional services. Federal spending for institutional services decreased by 70.4% from 1990 to 2000.

Table 13. Federal and State Spending for Institutional and Community Services for Persons with Mental Retardation/ Development Disabilities in Oregon, 1990 and 2000
(millions in current dollars)

| | 1990 (current dollars) | 2000 (current dollars) | Percent of FY2000 total | Percent change (in constant 2000 dollars) |
|--|------------------------------|------------------------------|-------------------------------|--|
| Total funds | \$181.3 | \$354.7 | 100.0% | 57.7% |
| Congregate/institutional services | \$106.8 | \$34.5 | 9.7% | -74.0% |
| Federal fund | \$60.0 | \$22.1 | 6.2% | -70.4% |
| State funds | \$46.7 | \$12.4 | 3.5% | -78.6% |
| Community services | \$74.5 | \$320.3 | 90.3% | 246.3% |
| Federal funds | \$33.0 | \$171.2 | 48.3% | 318.4% |
| ICFs/MR funds | \$0.4 | \$0.0 | 0.0% | -100.0% |
| HCBS waiver | \$20.7 | \$113.6 | 32.0% | 342.6% |
| Title XX/SSBG funds | \$1.8 | \$0.0 | 0.0% | -100.0% |
| Other | \$10.0 | \$57.6 | 16.2% | 362.3% |
| State funds | \$41.5 | \$149.0 | 42.0% | 189.0% |

Source: Congressional Research Service(CRS) calculations based on data presented in *The State of the States in Developmental Disabilities* (Fifth Edition), by David Braddock et al. (1998) Washington, American Association on Mental Retardation, p. 404 (for 1990 data). Unpublished data furnished by Richard Hemp, University of Colorado (for 2000 data).

* Intermediate care facilities for the mentally retarded.

** Home and community-based waiver (Section 1915(c)) of the Medicaid statute.

*** Social Services Block Grant (Title XX of the Social Security Act).

Issues in Long-Term Care in Oregon

Oregon officials and stakeholders identified issues in the state's long-term care system in a series of reports over the years. The following discussion highlights selected issues identified in reports by researchers, task forces and advocacy groups, as well as issues that surfaced in CRS interviews with state officials, providers, and consumers.

Institutional Bias in Federal Funding and Oregon's Response. A recurring theme in discussions of long-term care with state officials is the view that the federal financing system is biased towards institutional care. This is largely due to the fact that nursing facility care is an entitlement under Medicaid for persons meeting its eligibility criteria. Financing of institutional care is a federal mandate; home and community-based care is not. Although states may choose to provide home and community-based services under various Medicaid options, state officials indicate that state funding constraints and the provider system that was created as a result of the institutional entitlement make it difficult to reorient the system. Although Oregon has been successful in providing the majority of its long-term care clients with home and community-based services, many officials believe that the federal system should equally support a consumer's choice to stay at home or in the community.

For most states, the impetus for heavy reliance on institutional care is embedded in the structure of the federal Medicaid system resulting in vast funding disparities between institutional care and home and community-based care. Over the last 20 years, Oregon has relied on a number of strategies to ameliorate the institutional bias embedded in that system. For example, rather than relying on providers to refer hospital patients directly into nursing homes, Oregon requires most residents to be screened before entering a nursing home. A patient's level of impairment is evaluated, and home and community-based service options are discussed with the client and family members. Partially as a result of this screening process, the rate of hospital discharges directly into nursing homes is significantly lower than the national average.

Another method to counter institutional bias is to control or downsize institutional capacity. Oregon controls its institutional capacity by requiring the approval of Medicaid beds through the Certificate of Need process (described earlier) and through limitation on reimbursements. Controlling the supply of state institutions for the developmentally disabled differs somewhat from that for nursing homes. The state has closed all but one intermediate care facility for persons with developmental disabilities over the past several decades, and as of 2001, fewer than 1% of persons with developmental disabilities were served in institutions. The state could do so because these facilities were operated by state government. Virtually all nursing homes in the state are privately owned and therefore controlling or downsizing institutional capacity is not as direct as in the case of state-operated facilities.

State officials indicated that federal entitlement to nursing home care should be changed so that nursing homes are an exception rather than the rule. In Oregon,

home and community-based care is considered first, and then, if services are judged to be inappropriate or unavailable, the alternative is an institutional placement.

Budget Cuts. Recent state budget cuts have greatly impacted Oregon's long-term care system. After a statewide ballot initiative to increase taxes was defeated by voters in January 2003, the state has been forced to make up its revenue shortfall with drastic cuts in a number of social service programs. Seniors and People with Disabilities (SPD) had to reduce its long-term care spending by nearly 30% for the 2003 state fiscal year (SFY). SPD decided to cut funding for individuals whose impairment levels fell within service priority levels 12-17 (**Table 5**). As of April 2003, over 4,792 persons had lost Medicaid long-term care services (over 16% of total program participants), with potentially more cuts needed in the future.

By choosing to restrict Medicaid enrollment through functional eligibility criteria (as opposed to caps on 1915(c) waiver spending, for example), Oregon was able to ensure that institutional services, as well as home and community based services, were effected by these budget reductions. Of the residents who lost Medicaid services, 3,834 were receiving in-home services; 765 were residing in community-based assisted housing arrangements; and 193 were residing in nursing facilities. SPD worked with the Centers for Medicare and Medicaid Services (CMS) to make changes to the state's current waiver program to provide limited transitional services for those who no longer qualify for Medicaid.

In addition to reducing the number of people eligible for Medicaid, the state also eliminated in-home supports for 3,800 seniors who were not eligible for Medicaid; reduced reimbursement rates to Medicaid long-term care providers by 15% to 30%; and eliminated the state's medically needy program for 8,757 individuals.

Medicaid Eligibility Requirements and Access to Services. A number of issues identified by state officials relate to Medicaid eligibility for home and community-based services. Persons needing long-term care services paid for by Medicaid must meet countable income and resource limits established by the state within federal requirements. States may allow persons with income up to 300% of the federal SSI level to become eligible for Section 1915(c) home and community-based waiver services. This level in 2003 is \$1,656 per month and is the level used by Oregon for its waiver programs. The resource level used by Oregon for the waiver programs is the same as that for nursing home care; that is, in order to qualify for Medicaid, a person may have resources that do not exceed \$2,000 for an individual and \$3,000 for a couple.³²

While these requirements limit the number of persons who may become eligible for Medicaid, they also act as a barrier to many persons in need of long-term care who live at home. For example, state officials indicated that persons in need of home and community-based care who live in their own homes do not feel comfortable

³² Certain items are excluded, such as an individual's home; up to \$2,000 of household goods and personal effects; life insurance policies with a face value of \$1,500 or less; an automobile with value up to \$4,500; and burial funds up to \$1,500, among other things.

depleting almost all of their liquid assets that may be needed for household expenses and emergencies.

Oregon, through its state-funded Oregon Project Independence program, has addressed some of these Medicaid financial eligibility issues. The Oregon Project Independence program allows persons with income up to 200% of the federal poverty level (up to \$17,720 per year in 2002) to become eligible for state-funded home and community-based services, with no resource or asset test. Individuals pay a sliding scale fee for each service based on income. This allows persons needing long-term care to receive services and gradually become eligible for Medicaid, rather than having to wait until all countable resources are depleted to the \$2,000 Medicaid level.

Waiting Lists for Persons with Developmental Disabilities. Waiting lists for services for persons with development disabilities have drawn attention across many states and in Oregon. Despite the sizable amount of funding devoted to home and community-based services for persons with developmental disabilities in Oregon, waiting lists for services have been a persistent problem.

According to state reports, as of June 13, 2002, 4,773 individuals were waiting to receive home and community-based services. Of those, 750 had been on the waiting list for less than 2 years; 763 had been on the waiting list between 2 and 4 years; and 3,260 had been waiting for services for more than 4 years.³³ As a result of the Staley lawsuit, approximately 5,000 persons with developmental disabilities are to be removed from the waiting list and receive services by 2007.

Long-Term Care Staffing. Across the country, states are faced with the challenge of finding sufficient numbers of qualified staff to provide long-term care services. Many of the staffing shortages experienced in other states, however, are ameliorated in Oregon by the state's client employed provider (CEP) program and nurse delegation program. In 2001, approximately 20,000 individuals needing long-term care were served in their home by client employed providers. State officials indicate that this program, which allows clients to select unlicensed caregivers to provide long-term care services, has greatly expanded the state's ability to serve individuals in their homes. The state has also addressed issues of staffing shortages through its nurse delegation program. This program allows licensed registered nurses to delegate certain medical tasks of nursing to unlicensed caregivers. State officials and providers maintain that the use of nurse delegation has been essential to the expansion of home and community-based care services in Oregon.

In spite of the success of these two initiatives, state officials expressed concern about finding adequate numbers of direct care workers (defined as home health aides, nurse aides, personal attendants and personal care aides), particularly to serve persons with developmental disabilities in residential settings.

³³ Oregon Department of Human Services, *Seniors and People with Disabilities*. At [<http://oddsweb.mhd.hr.state.or.us/Pubs/CPMS/waitsum.htm>].

Centralization of Responsibility. Many states confront issues of fragmentation in the administration of long-term care programs. Oregon's system, however, is one of the few in the country to consolidate all of the various functions of its long-term care system into a single state agency. Many state officials credit the success of Oregon's long-term care system to the centralization of responsibility within a single administrative structure and budget. The goal of state officials over the last 20 years (partially in response to several state legislative mandates) has been the creation of a seamless system for seniors and people with disabilities that favors care in community settings rather than in nursing homes or other institutions.

Bounded Choice. State administrators recognize that with the aging population and increasing costs of long-term care, they may need to rethink the design of their current system. In the coming years, administrators hope to incorporate a concept of "bounded choice" into the system where an individual's preferences for services are considered within the boundaries of service capacity and fiscal constraints.

The Governor's Task Force on the Future of Services to Seniors and People with Disabilities made a number of recommendations for incorporating a concept of bounded choice in Oregon's long-term care system. The concept raises some difficult questions in light of the state's ongoing commitment to promoting a system that values consumer choice. The task force hopes to pursue changes in federal regulations and the state's waiver programs that would allow service packages to be designed within certain financial constraints.

Other Issues. Other issues raised by advocates, providers, and state officials are:

- *Consumer Choice.* In the fall of 2001, Oregon initiated a Medicaid pilot project — Independent Choices — to offer consumers the option of expanded control over their long-term care services. In this program, SPD authorizes clients to receive lump monthly payments in their bank accounts. Participants are then responsible for meeting their long-term care needs within that monthly allotment. Consumer-directed care of this kind — often referred to as "cash and counseling" programs — is not currently available on a larger scale in Oregon, although state officials expressed their ongoing commitment to expand consumer choice within their long-term care system.
- *Estate Planning and Avoidance of Estate Recovery.* State officials reported that although there may be a small number of people sheltering assets in order to qualify for Medicaid long-term care services sooner than they otherwise would, the number is growing. An increasingly popular way of sheltering assets in Oregon is to shelter assets in trusts (i.e., Pooled Trusts), annuities and other financial instruments that are deemed "not available" to the Medicaid applicant to pay for long-term care, or transferring assets to community spouses and other individuals. Particular concern was expressed about the use of special needs trusts among younger

individuals with disabilities. State officials also provided anecdotal evidence of increasing avoidance of Medicaid Estate Recovery requirements.

- *Provider Costs and Liability Insurance.* In Oregon, as in many states, nursing home providers were unanimous in their concern about the increasing costs of liability insurance and the absence of state caps on punitive damages. This issue was raised by many of the provider groups that were interviewed for this study.
- *Integration of Medicare and Medicaid.* Advocates and state officials expressed an interest in eliminating the administrative inefficiencies associated with using multiple payers and delivery systems in a poorly coordinated system between Medicare and Medicaid. One option might be to pool Medicare and Medicaid financing to promote financial and service integration, and revising program rules to promote administrative integration. This, advocates asserted, could help reduce incentives to use institutional care, improve the quality of care, and streamline administration and oversight.
- *Assisted Living as an Alternative to Nursing Home Care.* Some providers and advocates in Oregon expressed concern about an upward swing in the disability levels of clients in community-based settings in recent years. Anecdotal evidence suggests that this upward swing is particularly apparent in assisted living facilities in Oregon. Caring for persons with acute disabilities in potentially less regulated home and community-based settings raises concerns for some long-term care advocates and providers.

Appendix 1. Major Home and Community-Based Long-Term Care Programs for the Elderly and Persons with Disabilities in Oregon

| Program | Target group | Functional eligibility | | Financial eligibility | | Services | No. of persons enrolled/slots approved | Annual cost cap (aggregate/individual) | Admin. Oversight | Financial oversight |
|---|---|--------------------------------|---|---|---|---|---|--|--------------------------------------|--------------------------------------|
| | | Criteria | Determined by | Income/resource limits | Determined by | | | | | |
| <p>Home and community-based waiver for the elderly and physically disabled [1915(c)]</p> <p>Initiated statewide in 1981</p> | Seniors aged 65 and older with a disability and individuals aged 18 to 64 with a physical disability. | Nursing facility level of care | Area agencies on aging under contract with SPD or state employees in a Multi-Services Office or a Disability Services Office. | Individuals must have income at or below 300% of the federal SSI level (\$1,656 in 2003) and resources of \$2,000 or less per individual or \$3,000 per couple. | Area agencies on aging under contract with SPD or state employees in a Multi-Services Office or a Disability Services Office. | Personal care, respite care, assisted transportation, homemaker/home care services, chore, home health, adult day care, case management, registered nursing services, home delivered meals, and other services as authorized by Seniors and People with Disabilities. | 34,676 persons/2002 waiver year estimates | \$245,899,253/2002 waiver year (Aggregate cost cap) | Seniors and People with Disabilities | Seniors and People with Disabilities |

Source: Prepared by the Congressional Research Service (CRS) based on data provided by Oregon Department on Human Services.

| Program | Target group | Functional eligibility | | Financial eligibility | | Services | No. of persons served | Annual cost cap (Aggregate/individual) | Admin. Oversight | Financial oversight |
|--|--|--|---|--|---|--|---|---|---|---|
| | | Criteria | Determined by | Income/resource limits | Determined by | | | | | |
| <p>1981 waiver for developmentally disabled individuals as an alternative to an intermediate care facility for the mentally retarded or persons with related conditions</p> <p>(1915(c))</p> <p>Initiated statewide in 1981</p> | <p>Persons with developmental disabilities of all ages as an alternative to an intermediate care facility.</p> | <p>Applicants must be diagnosed with a developmental disability by a psychiatrist. In Oregon, a developmental disability is defined as having an IQ of 69 or less or an IQ of 75 or less with complicating conditions.</p> | <p>SPD employees housed within a Multi-Services Office or a Disability Services Office.</p> | <p>Individuals must have income at or below the federal SSI level (\$1,656 in 2003) and resources of \$2,000 or less per individual and \$3000 per couple.</p> | <p>SPD employees housed within a Multi-Services Office or a Disability Services Office.</p> | <p>Respite care, habilitation (day habilitation, prevocational services, supported employment, adult and child foster care, adult and child group homes, supported living services) specialized medical equipment and supplies, environmental accessibility adaptations, transportation, family training, in-home support services, crisis diversion services, and extended state plan services.</p> | <p>5,762 persons/2002 Waiver Year Estimates</p> | <p>\$255,479,779/2002 Waiver Year</p> <p>(Aggregate cost cap)</p> | <p>Seniors and People with Disabilities</p> | <p>Seniors and People with Disabilities</p> |

Source: Prepared by the Congressional Research Service (CRS) based on data provided by Oregon Department on Human Services.

| Program | Target Group | Functional Eligibility | | Financial Eligibility | | Services | No. of Persons Served | Annual Cost Cap (Aggregate/ Individual) | Admin. Oversight | Financial Oversight |
|--|--|---|--|---|--|--|--|---|--------------------------------------|--------------------------------------|
| | | Criteria | Determined by | Income/resource Limits | Determined by | | | | | |
| <p>2001 waiver for developmentally disabled individuals as an alternative to an intermediate care facility for the mentally retarded or persons with related conditions</p> <p>(1915(c))</p> <p>Initiated statewide in 2001</p> | Persons with developmental disabilities aged 18 and older who live on their own or with a family member as an alternative to an intermediate care facility | Applicants must be diagnosed with a developmental disability by a psychiatrist. In Oregon, a developmental disability is defined as having an IQ of 69 or less or an IQ of 75 or less with complicating conditions. | SPD employees housed within a Multi-Services Office or a Disability Services Office. | Individuals must have income at or below 300% of the federal SSI level (\$1,656 in 2003) and resources of \$2,000 or less per individual and \$3000 per couple. | SPD employees housed within a Multi-Services Office or a Disability Services Office. | Homemaker, respite care, habilitation (supported employment, community living supports, community inclusion) specialized medical equipment and supplies, environmental accessibility adaptations, transportation, chore, personal emergency response systems, family training, in-home support services, crisis diversion services, and extended state plan services | 951 persons/2002 Waiver Year Estimates | \$27,302,365/2002 Waiver Year (Aggregate cost cap) | Seniors and People with Disabilities | Seniors and People with Disabilities |

Source: Prepared by the Congressional Research Service (CRS) based on data provided by Oregon Department on Human Services.

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| Program | Target Group | Functional Eligibility | | Financial Eligibility | | Services | No. of Persons Enrolled/Slots Approved | Admin. Oversight | Financial Oversight |
|--|--|---------------------------------------|--------------------------------|--|--------------------------------|--|--|---|---|
| | | Criteria | Determined by | Income/resource limits | Determined by | | | | |
| <p>Oregon project independence</p> <p>State-funded program</p> <p>Statewide</p> <p>Initiated statewide in 1977</p> | <p>Aged 60 or older or patients with Alzheimer's or related conditions</p> | <p>Nursing facility level of care</p> | <p>Area agencies on aging.</p> | <p>Clients with net incomes between 100% and 200% of FPL pay a sliding scale fee for each service; individuals with income over 200% of FPL pay the full rate of each service; no resource caps. Cannot be receiving benefits from Medicaid, Medicare Beneficiary or Supplemental Low Income Medicare Beneficiary Program.</p> | <p>Area agencies on aging.</p> | <p>Personal care, respite care, assisted transportation, home maker/ home care services, chore, home health, adult day care, case management, registered nursing services, home delivered meals, and other services as authorized by Seniors and People with Disabilities.</p> | <p>4,538 persons/ State Fiscal Years (SFY) 2001-2003</p> | <p>Seniors and People with Disabilities</p> | <p>Seniors and People with Disabilities</p> |

Source: Prepared by the Congressional Research Service (CRS) based on data provided by Oregon Department on Human Services.

Appendix 2. Population in Large State Facilities for Persons with Mentally Retardation/Developmental Disabilities, Closure Date, and Per Diem Expenditures, 1960-2001

| Large state MR/DD facilities or units operating 1960-2001 | Year facility opened | Year closed | Residents with MR/DD on 6/30/01 | Average daily MR/DD residents FY2001 | Average per diem expenditures FY2001 (\$) |
|---|----------------------|-------------|---------------------------------|--------------------------------------|---|
| Columbia Park Hospital and Training Center (The Dalles) | 1963 | 1977 | | | |
| Eastern Oregon Training Center (Pendleton) | 1964 | | 50 | 50 | 540.10 |
| Fairview Training Center (Salem) | 1908 | 2000 | | | |

Source: Census information provided by the Office of Seniors and People with Disabilities. Average per Diem Expenditure data from: *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2001*. Research and Training Center on Community Living, Institute on Community Integration/UCEED. University of Minnesota (June 2002).

Appendix 3. About the Census Population Projections

“The projections use the cohort-component method. The cohort-component method requires separate assumptions for each component of population change: births, deaths, internal migration (Internal migration refers to state-to-state migration, domestic migration, or interstate migration), and international migration The projection’s starting date is July 1, 1994. The national population total is consistent with the middle series of the Census Bureau’s national population projections for the years 1996 to 2025.” **Source:** Paul R. Campbell, 1996, Population Projections for States by Age, Sex, Race, and Hispanic Origin: 1995 to 2025, U.S. Bureau of the Census, Population Division, PPL-47. For detailed explanation of the methodology, see same: at [<http://www.census.gov/population/www/projections/ppl47.html>].

Additional Reading

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