

---

# **A History of Oregon's Unique Long-Term-Care System**

A publication of



---

May 2013

---

**For information about obtaining electronic  
or printed copies of this document,  
please contact [SeniorForums@frontier.com](mailto:SeniorForums@frontier.com)  
or (503) 682-5767.**

---

# **A History of Oregon's Unique Long-Term-Care System**

## **Table of Contents**

Acknowledgements .....	i
Introduction .....	ii
Important Notes .....	iii
Section 1: An Overview of the Creation of the System	
Factors Leading to the New System.....	1-1
The State's Response .....	1-2
The Reasons for Oregon's success .....	1-4
Section 2: A Description of Oregon's System	
How the System Works .....	2-1
Components of Oregon's Long-Term-Care System .....	2-2
Section 3: Major Steps in Creating the System	
The late 1960s: The First High-Level Advisors on Senior Issues.....	3-3
1975: Oregon Project Independence .....	3-3
1977: A New State Agency.....	3-5
1978 - 79: The Long-Term-Care Ombudsman and Nursing Facility Patient's Bill of Rights .....	3-6
1979-80: Joint Demonstration Grants and the First Attempt at Reform .....	3-7

### Section 3: Major Steps in Creating the System *(continued)*

1981: Passage of Senate Bill 955 .....	3-9
Creation of the Pre-Admission Screening Program.....	3-13
Obtaining the Federal Medicaid Waiver .....	3-15
1982: Development of the Assessment System and Community Resources .....	3-17
Relocation of Nursing-Home Patients.....	3-19
1984: The Negotiated Investment Strategy.....	3-20
The Battle for Renewal of the Waiver .....	3-22
1985: The Controversy Continues .....	3-25
1987: “Nurse Delegation,” Development of Assisted Living and the “Health-Division Transfer” .....	3-26
Throughout the Life of the New System:	
Advocacy Plays a Critical Role .....	3-29
Governor’s Conferences on Aging .....	3-32
White House Conferences on Aging .....	3-34

### Section 4: Epilogue

Recent Additions.....	4-1
Results Attained Under the New System .....	4-2
Duplicating Oregon’s System .....	4-3
The Future.....	4-5

Source Documents .....	5-1
------------------------	-----

---

---

## Acknowledgements

This history would not have been possible without the work of many people who were part of the creation of the state's unique long-term-care system. Oregon Senior Forums very much appreciates their time and effort.

Much of the information (and all of the "sidelight" quotes) came from responses to a questionnaire developed by Oregon Senior Forums. We would like to thank the following people for their hard work in responding to the long list of questions:

Don Bruland	Aileen Kaye	James Wilson
John DeGroot	John Mullen	Bob Zeigen
June Hughes	Doug Stone	

We also held in-depth conversations with people who were an integral part of the process of implementing the new system. Our sincere thanks to Susan Dietsche, Ruth Shepherd, Lucille Pugh, Cindy Hannum, Sharon Miller and Jane Ellen Weidanz.

Georgena Carrow, one of Dick Ladd's top administrators throughout the formation of the Senior Services Division and many years after, was an excellent source of information as well as the coordinator of the entire history project.

The board members of Oregon Senior Forums provided a great deal of valuable insight. They are:

Dolores Hubert, Chair	Eunice Dutton	Remona Simpson
Georgena Carrow, Secretary	Don Butsch	Estill Dietz
Lee Hazelwood, Treasurer	Chris Flammang	

In addition to those already listed above, the following people participated in the document's review process:

Aileen Kaye	Vickie Gates	Ore. Dept. of Human Services
Jim Davis	Cindy Hannum	Joy Parker
Scott Deshong, Ph.D	Marlene Haugland	Doug Stone
Susan Dietsche	June Hughes	James Wilson
Tyson Dutton	Sharon Miller	Bob Zeigen
Anne Flammang, Ph.D	John Mullen	

Writer and editor on the history project was Marki Maizels of MMC Communications.

---

## Introduction

This look at the history of Oregon's pioneering efforts to better serve its senior citizens was produced by Oregon Senior Forums, a non-profit group formed in 1989. The group's goal is to promote educational opportunities, conferences and forums that encourage the sharing of information, ideas and concerns affecting seniors and people with disabilities.

The organization's board consists of seven members who were active in the advocacy efforts to establish Oregon's long-term-care system and continue to have an interest in senior issues.

Recently, the Senior Forums board determined that an important way to educate the people of Oregon and other states in the future would be to compile a history of how Oregon developed its unique system. This document is the result of that initiative. Its guiding principles were "*cherish the past, celebrate today, commit to the future.*"

As the nation faces a growing senior population and the need to effectively provide the services they require, it is hoped this history will be a useful educational tool for generations to come.

---

## **Important Notes**

### **What is “Long-Term-Care?”**

Long-term-care refers to the support services that enable the elderly and people with disabilities to perform necessary activities of daily living. Types of long-term care range from services provided in the home (such as housekeeping, medication management or bathing assistance), to live-in facilities (such as assisted living or adult foster care) to institutional care in traditional nursing homes.

Long-term care provided outside of institutions is often referred to as home-and community-based services (HCBS). In this document, we have chosen to refer to non-institutional long-term care as “alternative” or “community-based” living situations and services.

### **The History’s Time Frame**

This document concentrates on the actions that allowed Oregon to design, create and implement its pioneering long-term-care system for low-income seniors. It begins in the late 1960s, when senior issues moved into the state’s awareness, and continues through the late 1980s. By that time, the majority of the innovative changes had been put in place.

### **The Population Covered in the History**

This document concentrates on the development and implementation of a new system to serve Oregon senior citizens who need long-term care.

Oregon Senior Forums recognizes there is a close connection between the long-term-care needs of senior citizens and members of the disability community of all ages. However, because the organization’s focus is on senior citizens, the Oregon Senior Forums board has chosen to restrict this document to the long-term-care system for the elderly population.

## **Accuracy**

Senior Forums relied on many sources to create this history, including: the recollections of a wide range of people who were involved in creating and developing the long-term-care system; documents prepared by the Oregon Department of Human Services; and outside research papers.

In some cases, these sources disagreed about specific topics, and sadly, a number of the key players are no longer alive or are unable to provide their input. We have attempted to produce the most accurate overview possible within this challenging scenario. We welcome comments and corrections from readers.

## **Agency Names**

Like many government agencies, Oregon's human-services department seems to regularly change its name and the names of its divisions (or clusters, as they were once referred to.) Here are some notes to help the reader navigate the names used in this document:

- ◆ The Department of Human Resources (home to the division that serves seniors) changed its name to the Department of Human Services in 1997.
- ◆ The division that handles senior programs originally was known as the Senior Services Division (SSD). In 1989, it became the Senior and Disabled Services Division (SDSD). Its name again changed in 2001, to Seniors and People with Disabilities (SPD). In 2011, the division became Aging and People with Disabilities.

In this document, we have attempted to refer to the department and its divisions by the name used during the time we are writing about, though in some instances that was not appropriate and we have used the current names.



## **Acronyms Used in the Document**

AAA – Area Agency on Aging

AFC – Adult Foster Care

AFS – Adult & Family Services Division of the Oregon Department of Human Services

ALF – Assisted Living Facility

APD – Aging & People With Disabilities Division of the Oregon Department of  
Human Services

DHR, DHS – Oregon Department of Human Resources, Oregon Department of Human  
Services (see “Agency Names” on page iv)

FIG – Flexible Intergovernmental Grant

HCFA – Health Care Financing Administration (now known as the federal Centers for  
Medicare and Medicaid)

OAA – Older Americans Act

OCBNHC – Oregon Coalition for Better Nursing Home Care

OEA – Office of Elderly Affairs of the Oregon Department of Human Resources

OPI – Oregon Project Independence

PAS – Pre-Admission Screening Program

SDSD – Senior & Disabled Services Division of the Oregon Department of  
Human Services

SPD – Seniors & People with Disabilities Division of the Oregon Department of  
Human Services

SSD – Senior Services Division of the Oregon Department of Human Services



---

## **Section 1**

### **An Overview of the Creation of System**

Oregon has long been heralded as the national model for providing long-term-care services to low-income seniors. The primary characteristic that defines the Oregon system is its focus on alternative support-service and living options rather than on nursing-home care. It offers seniors a variety of choices to meet their differing needs.

Through its innovative system of serving low-income seniors, Oregon has been able to reduce its nursing-home population, lower the cost of services for seniors, expand the number of people who can receive state assistance, and perhaps most importantly, greatly improve the quality of life for its elderly citizens.

However, arriving at this outcome required an immense amount of work and dedication on the part of state agencies, senior advocates, lawmakers on the state and federal level, and the state's network of long-term-care providers.

#### **Factors Leading to the New System**

The environment that gave rise to the sea change in Oregon's senior services encompassed a number of factors.

In the mid-1970s many seniors, alarmed at the prospects that awaited them, became activists who drew attention to the deficiencies in the way the state served the low-income elderly. At that time, the primary way seniors could obtain state assistance was to enter a nursing home, regardless of the actual extent of their needs.

Though some types of alternative-care facilities (such as room-and-board facilities, residential care facilities and adult foster care settings) did exist, they were few in number and the state funds that could be spent on them were very limited. Even though most seniors strongly objected to entering nursing homes and often did not need the extensive care they provided, nursing-home placement was almost always the only choice available if a person needed financial help from the Medicaid program.

At the same time, instances of poor quality of care in some of the state's nursing homes became more visible. As advocates and activists brought senior issues into the limelight, the media began to pay attention to the examples of poor care and abuses within long-term-care facilities. For example, in 1978 a midnight vigil was held at a Salem nursing home that was planning to evict several Medicaid residents. And the newly formed Gray Panthers organization led a protest march in front of a poorly operated Portland facility.

Another equally pressing problem was the cost to the state. The number of seniors on Medicaid in nursing homes and the cost of their care were exploding in the late 1970s, threatening the state's ability to fund the program in the future. (The cost per case of nursing-home care doubled in the five years between 1974 and '79.)

In addition, it was felt that some nursing home operators were "gaming the system" to falsely increase the reimbursement amounts they received for Medicaid clients. At that time, reimbursement rates were supposed to be based on the costs "incurred by an efficient and economical facility," however, in reality, this was difficult to enforce and meant there were no practical limits on reimbursement.

## **The State's Response**

Recognizing the need for far-reaching changes, Oregon achieved the following between 1975 and 1987:

- ◆ Oregon created a state-funded program known as Oregon Project Independence (OPI) to provide in-home services to seniors. This, along with other demonstration projects, provided valuable data on the benefits of helping seniors avoid entering a nursing home.
- ◆ The state obtained permission, in the form of a waiver from the federal government, to use Medicaid money (formerly available only to cover nursing-home services) to pay for alternative living situations (such as adult foster care) and services (such as home health care). This waiver was crucial to Oregon's success and remains a model for the rest of the nation.

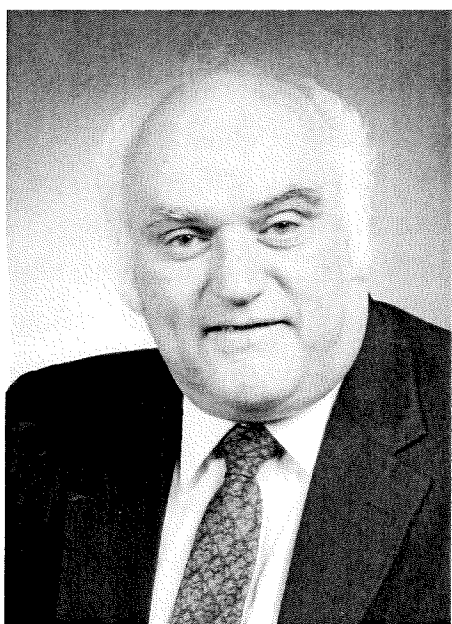
- ◆ Oregon codified in statute a policy on aging that stresses independence, dignity and choice, and requires that services be provided in the least-restrictive setting possible. The law also requires the state to use funds from the federal Older Americans Act and Oregon Project Independence to help keep seniors in their homes as long as possible.
- ◆ A single state agency (the Senior Services Division of the Department of Human Resources, or SSD) was created and charged with overseeing policy, budget and eligibility for all long-term-care programs.
- ◆ SSD set up an intake system for seniors that presented them with an array of options (in-home services, community-based care and long-term-care facilities) and allowed the individual to decide which is best, if at all possible.
- ◆ SSD also created a standardized assessment tool for use with all seniors who requested services. This tool allowed the collection of meaningful data about who is being served and their degree of need. Oregon also modified the pre-admission screening process required by the federal government so it helps determine proper levels of care needed by seniors.
- ◆ The state supported the creation of home- and community-based resources to meet the demand created by the new system; it recruited adult-foster-care providers, regulated residential-care facilities and set up pilot projects for a new type of facility known as assisted living.
- ◆ Oregon passed a law to allow people who are not registered nurses to provide certain kinds of medical services if they receive training and are under the supervision of an RN. This allows more seniors who require medical services to live at home or in alternative-care settings.

Section 3 of this document contains a chronology of the specific milestones achieved on Oregon's road to its new system and gives additional details about many of the topics discussed here and in Section 2.

## The Reasons for Oregon's Success

Oregon's ability to accomplish far-reaching changes in services for low-income seniors is often described as a "perfect storm" by those involved in it. Many factors converged that allowed a number of parties with diverse interests to overcome their differences and reach agreements that, in turn, have meant a better quality of life for countless seniors in Oregon.

Before we list those factors, it's vital to recognize the most influential component in the process: Richard (Dick) Ladd, a visionary whose involvement with the Oregon



system began in 1979 with research and implementation of the Flexible Intergovernmental Grant (FIG), and later transitioned to leadership of the newly formed Senior Services Division in 1981.

Those who worked with Ladd praise his sound intellect, clear vision, strong research skills, seemingly limitless energy and bias for risk taking. He was "by far the major player and the moving force behind the efforts" to change the Oregon system for the better.

His commitment to the dignity of seniors and the superiority of community-based care spurred his efforts to bring feuding parties together and insist that agreements be reached. His own ideas about how he, himself, wanted to be taken care of as he aged — with a nursing home being the last resort — drove him to ensure that others had such options as well. He staunchly opposed any system of care built upon other people making decisions about what is best for a senior.

Charley Reed, Ladd's counterpart in Washington State from 1987 through '96, relates that he and Dick often discussed quality-of-life issues around long-term care, sometimes using their own experiences as guides (for example, one major tenet of community-based living had to be that no one was required to have a roommate they did not know or want).

Ladd did not lead from a distance; staffers recall “long business meetings and late-night discussions, sharing our complementary and sometimes conflicting views and interests.”

One manager relates, “During the fall of 1984, Dick Ladd coached me one-on-one for a week to change my orientation and outlook from a service-delivery system to a program-monitoring system. His focus was to look at client outcomes to see if they were receiving the most appropriate, cost-effective, least-restrictive service.”

He was described by one manager as “a combination of a scientist, dreamer and a realist, who loved to prove people right or wrong through science and research. He loved math and working with statistics” (in which he had a bachelor’s degree). Another manager referred to him as the “General Patton of long-term care” because of his intense style.

Ladd’s former career as a truck driver was often cited when describing that straightforward and “in your face” style, and there are legends in the halls of the department about how this sometimes manifested itself. Perhaps the most famous centers on Ladd either punching or pulling the tie of a nursing-home lobbyist who insulted him. Though he was suspended for two weeks, division staff and senior advocates gave him a hero’s welcome upon his return.

Another manager recalls a time when the director of the Health Division called Ladd to complain that the manager was attending meetings of the Oregon Coalition for Better Nursing Home Care. The manager recalls that Dick informed the caller that, “since the meetings were at night and on my own time, I could attend the meetings, and furthermore I could go nude to them if I wanted.”

Dick Ladd died in 2003. As part of the memorial set up to him in the Human Services Building, people who knew and worked with him were asked to give their impressions of Ladd. Here is a sampling of those quotes:

“He was a visionary who also could produce results.”

“He proved he could change bureaucracies and bring special interests and politics together for the good of the most frail and needy citizens.”

“Dick knew how to get under the hood and make the engine run, and that has made all the difference.”

“Maybe more than any single individual, Dick has moved this country in the direction of home care for the elderly. In that sense, tens of thousands of Americans who never heard the name Dick Ladd are sleeping in their own home because of him.”

***Ladd’s vision and commitment took advantage*** of a number of other factors in Oregon during the late 1970s and throughout the `80s that were favorable to change. These included:

**The right players....**

- ◆ Oregon’s governors, beginning in the late 1960s, took an active interest in senior issues. Tom McCall, in office from 1967 to `75, convened a special task force in 1971 in response to legislative concerns, federal inquiries and citizen complaints about nursing-home care. Victor Atiyeh, Oregon’s governor during most of the creation of the new system (1979 to `87) had a strong interest in senior issues, and consulted with and accepted recommendations from advisors and commissions working on senior issues.
- ◆ The existence of entities such as the State Office on Aging and a succession of governor’s advisory committees and commissions on senior issues meant that senior concerns did not get “lost in the shuffle.” The advisory groups often numbered as many as 30 people and were active not only in advising governors and their staffs, but also in advocacy efforts at the state Legislature.
- ◆ The director of the Oregon Department of Human Resources between 1979 and `86, Leo Hegstrom, helped develop the vision of a new system and convey it to the governor. In addition, Hegstrom had a financial, rather than a social-work background, that allowed him to communicate effectively with lawmakers and legislative staff about cost savings and efficiencies.
- ◆ Oregon’s Legislatures during the 1970s were primarily bi-partisan and contained a number of members who were champions for seniors.



- ◆ Oregon had strong leaders in the U.S. Congress and Senate who could help when federal agencies blocked Oregon's efforts. Senator Mark Hatfield (a former Oregon governor) was chair of the Senate Appropriations Committee in the early '80s; Senator Robert Packwood sat on the Senate Finance Committee. Then-Representative Ron Wyden was a long-time senior advocate in Oregon. In addition, the staff of these lawmakers did much of the work that allowed Oregon officials to gain access to federal policymakers.
- ◆ Activist seniors in the state created organizations such as the Gray Panthers and the Oregon Coalition for Better Nursing Home Care (OCBNHC) during the 1970s and '80s. These joined forces with the existing Oregon State Council of Senior Citizens and United Seniors to become a powerful force supporting seniors. Members of all these groups developed effective advocacy methods, proving themselves to be invaluable in the efforts to gain legislative support.
- ◆ Supporting the senior advocates in Salem was an exceptionally strong grass-roots organization across the state that played a significant role in influencing the Legislature. Local advocates were called upon frequently to connect with lawmakers in their home district around specific issues. The key organizers of grass-root efforts were the advisory councils to the local Area Agencies on Aging; in a time before voice-mail or e-mail, they deserve credit for being able to quickly and effectively rally local senior citizens.
- ◆ There were people in the private-provider community who wanted to see change. One of the most notable was Keren Brown Wilson, who was committed to finding a way to provide home-like care in a positive environment. She worked with Dick Ladd to create the first two pilot assisted-living facilities and continued to be active during the evolution of care settings that meet seniors' needs for support in tasks of daily living.
- ◆ The state's Long-Term-Care Ombudsman's Office was invaluable in identifying quality-of-care issues in emerging options for seniors such as adult foster care and assisted living. In its work on behalf of seniors experiencing problems with all types of long-term care, the office was often the first to recognize the need for increased licensing, regulation or other oversight.

- ◆ Multnomah County's Legal Aid Program was pivotal in the success of one type of alternative care: adult foster care. Two of their attorneys crafted bills relating to certification of facilities and training of staff, helping to protect the general public as well as Medicaid clients.

#### **The right state laws and programs:**

- ◆ Oregon Project Independence, established as a state-funded program in 1975, provided services designed to allow senior citizens to stay in their homes. The program's outcomes demonstrated that care could be provided effectively and efficiently in locations other than nursing homes at a far lower cost.
- ◆ Senate Bill 955, passed in 1981, codified in statute a philosophy of dignity, choice and independence that guides decisions around senior care. It mandated that services be provided in the least restrictive and most cost-effective manner.
- ◆ The Nurse Delegation provision of the Nurse Practice Act, passed in 1987, allows certain types of medical care to be provided by people who are not registered nurses, but have been trained and are under the supervision of an RN. This has saved a considerable amount of money and expanded the number of people who can be cared for in community-based settings.
- ◆ Many other pieces of consumer protection legislation on a wide array of subjects affecting seniors were passed, which enhance and support the community-based-care system as well as protect seniors from abuse.

#### **The right approaches:**

- ◆ Requiring collaboration between all major stakeholders greatly helped the process of creating the system. From the outset, Dick Ladd and other leaders were committed to working as long as it took to find solutions, insisting that it was possible to reach agreement in spite of all the disparate opinions and interests. ("You can't have a balanced system without going to war with someone," says one participant in negotiation sessions.)

- ◆ Ladd's conviction that innovations could be instituted "before everything is perfect" prevented discussions and negotiations from continuing "ad nauseum" in search of an ideal. In his view, you began with your best effort and made changes continuously. A Senior Services Division manager who spent a great deal of time in the 1980s and '90s consulting with other states wanting to replicate Oregon's success notes that one recurring roadblock to their progress was an unwillingness to proceed until every detail had been agreed upon (which, she said, never happened).
- ◆ Consolidating the administration of all long-term-care programs in a single state agency (known originally as Senior Services Division or SSD) brought a number of benefits. It made it easier to maintain a unified vision among the various programs and avoid turf battles. It also enhanced the state's success in opposing pressure from nursing-home lobbyists.
- ◆ The decision to use local Area Agencies on Aging to deliver services avoids the problems faced by seniors in many other states, where people may have to deal with multiple agencies. Oregon's partnership with AAAs not only provides a single point of access for seniors (in many parts of the state), it improves the decision-making process for clients because of the AAA's knowledge and management of local resources.
- ◆ Creation of a common assessment tool to obtain information from seniors who come to an AAA or state senior-service office has been another very important factor in Oregon's success. That universal assessment form has provided vital information about who is being served, their degree of need and the options they select. It has allowed preparation of reliable reports for the state Legislature as well as the department's budget and policy experts.
- ◆ Recognizing that high-quality community-based-care options would be crucial to the success of the system, the state encouraged the development of facilities offering different levels of service. It also used varying levels of reimbursement to encourage creation of the types of facilities that were needed.

- ◆ At the outset, the need to control nursing-home placements was stressed to workers in the service-delivery system. Statistics were monitored by the SSD central office; distribution of those figures reinforced the importance of ensuring appropriate care settings. This was particularly important for SSD service-delivery staff, who, in the past, had not had a wide range of options to offer Medicaid clients.
- ◆ Relocating appropriate seniors out of nursing homes soon after receiving the Medicaid waiver helped control costs early in the life of the new system. SSD worked with nursing-home residents to determine who would benefit from being in community-based care and then helped accomplish those transfers, leading to early cost-cutting results.
- ◆ Oregon's priority has been to have its long-term-care program appeal to seniors and offer choices they actually want. Again, the guiding principles of choice, dignity and independence are key.
- ◆ Another important aspect is a focus on what appeals to the general senior population, not just Medicaid clients. The state encouraged development of high-quality facilities that would attract seniors who have the resources to pay, thereby helping ensure a facility could survive. This wider focus encouraged creation of new facilities, enhanced advocacy efforts and increased the level of knowledge about senior issues among lawmakers.

---

## Section 2

### A Description of Oregon's System

Years of effort went into creating a long-term-care system that was unique at its inception and remains one of the most progressive in the nation. This section gives a brief overview of the current functioning and components of that system.

#### **How the system works**

Low-income seniors can, in most parts of the state, visit a single office to have their social, medical and financial needs evaluated and learn about a range of options. They are no longer presented only with the option of entering a nursing home.

The political realities of passing the state's senior-service legislation (Senate Bill 955) in 1981 resulted in a somewhat complex system of offices that serve the elderly. Drafters of the legislation envisioned a decentralized system in which local Area Agency on Aging (AAA) offices handled client intake and case management.

That concept did not sit well with a number of AAAs, who either objected to taking on eligibility duties, did not want the responsibility of administering large and expensive programs, or did not want to handle low-income programs (perhaps fearing a "welfare stigma" being attached to senior services).

Compromises in the legislation gave AAAs three choices;

- ◆ they could remain the same, administering only the federal Older Americans Act and Oregon Project Independence, with the state handling the Medicaid program (these were known as Type A);
- ◆ they could administer Medicaid long-term-care programs by having the necessary funds and staff transferred to them from the state (Type B Transfer);

- ◆ they could supervise state employees and spend state funds through a contract with the state (Type B Contract).

The number of AAAs handling the Medicaid Program (Type B's) has decreased since the system was created. In 2013, there are only two Type B Contract agencies and four Type B Transfer ones. The remainder of the state's 17 AAAs are Type A agencies.

Regardless of the decision of the local AAAs regarding which programs to administer, the state requires that seniors have easy access to services, with as few trips to different agency offices as possible.

After their initial consultations with AAA or state senior-service staff, seniors also receive ongoing case-management services to ensure they are receiving necessary care in appropriate settings. Obtaining permission for case management to be a "billable" service under Medicaid was an important component of Oregon's waiver and contributed to the new system's success.

## **Components of Oregon's Long-Term-Care System**

It was not enough to affirm in state statute that nursing homes were the placement of last resort for seniors; a network of alternative-care settings and support services had to be available to accommodate people who did not need nursing-home care.

Therefore, at the same time the state was seeking permission to pay for alternative care, it was also planning and acting to ensure enough of those options would be available.

As a result, seniors in Oregon who qualify for Medicaid can choose from an array of residential settings and support services.

***Options in living situations for seniors*** include: 1) remaining in their homes with assistance from in-home service providers; 2) living in the community-based options of assisted living, adult foster care, and residential care facilities, or 3) entering a traditional nursing home.

***Assisted-Living Facilities (ALF):*** The concept of assisted living was "invented" in Oregon, through a partnership between the state and Keren Brown Wilson, a Portland

State University professor and community-care provider who wanted to develop a new model for senior-citizen residences.

Assisted-living facilities in Oregon must offer apartments with full bathrooms, a way to refrigerate and heat food and a locking apartment door. Residents receive only the supportive services they cannot provide for themselves. The intent is to provide residents with privacy, independence and dignity.

In the beginning, there was no state oversight or licensing of ALFs. As it became apparent that some people who chose to enter assisted living actually needed a much higher level of care, the state enacted rules governing assisted living, and established licensing and supervision of staff. Now, these facilities are required to be licensed, and provide a disclosure statement to potential residents that specifies the scope and degree of care it can provide.

Because it was recognized that most seniors favored assisted-living arrangements over foster care or other residential settings, ALF reimbursement rates were originally set at a higher level to encourage creation of facilities. However, in the early 2000s, a moratorium was implemented to stop unnecessary expansion of the ALF system. In 2009, that moratorium was repealed.

*Adult Foster Care (AFC):* Oregon's adult foster care providers serve people with a higher level of need than those in assisted living. They offer a homelike setting with caregivers who become familiar to residents.

Foster care can be provided by a relative (other than a spouse), through what is known as Relative Foster Care. Only one person can be cared for in this setting.

Non-relative adult-foster-care facilities can provide personal care, medication supervision and limited nursing services to a maximum of five residents. They must have a live-in manager who can arrange for needed medical services on-site or at another location. Local case managers are able to negotiate the rates paid for individual clients in non-relative AFC settings.

Adult foster care existed in Oregon prior to the Medicaid waiver being obtained; however there was a cap on the amount of money the state could spend to cover its

cost. When funds were exhausted, low-income seniors could no longer select adult-foster-care living arrangements.

*Residential Care Facilities:* Seniors who need moderate assistance with their physical care and medication monitoring can opt for a residential care facility. These homes are licensed to serve six or more residents. They may offer private rooms and, in specialized cases, limited on-site nursing services.

As with adult foster care, these facilities existed before the revamping of the Oregon long-term-care system, however funds for them were limited.

*Nursing Homes:* These traditional long-term-care facilities now serve only seniors with the highest level of need. Such facilities provide 24-hour nursing care or medical oversight, and may offer on-site physical rehabilitation and end-of-life care.

As alternative care has proved its popularity among seniors, many nursing homes are adding other options such as assisted living or adult foster care. These combined facilities can provide a way for seniors to obtain higher levels of care as their needs change without having to move to an entirely different facility.

***Services to support seniors living at home or in community-based settings include:***

***In-Home Services:*** Seniors can obtain services in their homes under the programs known as Client-Employed Provider, Independent Choices, In-Home Agency Services or Oregon Project Independence (specifically for people not on Medicaid).

The majority of seniors using in-home services do so under the *Client-Employed Provider Program*, which allows them to hire, supervise and fire their caregivers. In addition to covering the cost for services, the state also pays the caregiver's unemployment insurance and FICA costs. This avenue is chosen by most participants because of their desire to select and, if needed, change their caregivers.

When this program started, clients could hire relatives other than their spouse as a caregiver. A provision allowing spouses to be paid was added at a later time; it applies to individuals with needs that exceed the level of care that would normally be provided by a spouse.



The *Independent Choices Program* provides seniors on Medicaid with monthly cash benefits they spend on in-home services to meet their care needs. Participants must show they are in a stable living situation and have the ability to select and train their own providers. This program provides more flexibility for seniors to select the services they receive and set the amount paid to service providers than they have under the Client-Employed Provider Program.

*In-home Agency Services:* Approximately 10 percent of in-home clients receive services from home-care agencies that are under contract with the state. Rules limit agency-provided services to situations where they are the most cost-effective choice, or are necessary for interim or emergency services.

*Oregon Project Independence* serves people who are not eligible for Medicaid, or are eligible but choose not to enroll. It provides services that help seniors with activities of daily life, including household management (such as housekeeping, shopping and meal preparation), and personal assistance (such as help with bathing and dressing).

***Adult Day Services:*** This program offers a variety of health, social and other types of services and activities in a location away from the senior's home during the day. Activities can include music therapy, exercise, arts and crafts, games, outings and special events. Adult Day Services can be valuable in giving seniors interesting and challenging activities and interaction with others away from their usual living situation, and can provide a participant's family members with a respite from their care duties.

***PACE (Program of All-Inclusive Care for the Elderly):*** This program assigns an interdisciplinary team to each participant, which coordinates and continually evaluates the person's medical care, living situation, service needs and activities. It serves people living in their homes and in community-based care who ask to enter the program. Originally this program was only available in Multnomah County but expansion into Washington County is planned for 2013.



---

## Section 3

### Major Steps in Creating the System

This section looks at how the Oregon system came to be. The subsections form a timeline of the initiatives, programs and laws that, together, resulted in the state's unique long-term-care system.

The late 1960s: The First High-Level Advisors on Senior Issues .....	3-3
1975: Oregon Project Independence .....	3-3
1977: A New State Agency.....	3-5
1978 - 79: The Long-Term-Care Ombudsman and Nursing Facility Patient's Bill of Rights .....	3-6
1979-80: Joint Demonstration Grants and the First Attempt at Reform .....	3-7
1981: Passage of Senate Bill 955 .....	3-9
Creation of the Pre-Admission Screening Program.....	3-13
Obtaining the Federal Medicaid Waiver .....	3-15
1982: Development of the Assessment System and Community Resources .....	3-17
Relocation of Nursing-Home Patients.....	3-19
1984: The Negotiated Investment Strategy.....	3-20
The Battle for Renewal of the Waiver .....	3-22
1985: The Controversy Continues .....	3-25

1987: “Nurse Delegation,” Development of Assisted Living and the “Health-Division Transfer” .....	3-26
--	------

Throughout the Life of the New System:

Advocacy Plays a Critical Role .....	3-29
Governor’s Conferences on Aging .....	3-32
White House Conferences on Aging .....	3-34

---

## **The Late 1960s: The First High-Level Advisors on Senior Issues**

Oregon's focus on the needs of its senior citizens began earlier than in most states. In 1965, when the federal Older Americans Act (OAA) was passed, Governor Mark Hatfield created an Interagency Commission on Aging. Its role was to determine how best to obtain and provide OAA benefits to Oregon seniors.

During the terms of Tom McCall and Robert Straub (1967 to '79), the governor's senior advisory groups were known as committees, and in 1977 the Legislature replaced the committees with a Governor's Commission on Aging, to advise the newly formed Office of Elderly Affairs within the Department of Human Resources. In 1981, the state's pioneering senior-services legislation — SB 955 — created the Governor's Commission on Senior Services to advise the governor, Legislature and new Senior Services Division created by the law.

Throughout their existence, the state's senior-advisory bodies may have changed their names and makeup a number of times, however certain factors remained constant. The groups were at the highest level of state government, and governors, legislators, state agencies and public officials depended on the groups for information and advice about senior issues.

---

## **1975: Oregon Project Independence**

One of the most important components of Oregon's long-term-care system is Oregon Project Independence (OPI). In addition to its effectiveness in allowing seniors to stay in their homes, the early years of this program provided valuable evidence that was used to obtain Oregon's federal waiver, which, in turn, allowed the state to reinvent its entire long-term-care system.

OPI is an entirely state-funded program that offers housekeeping, home-health, personal-care and transportation services to seniors who are not eligible for or choose not to receive Medicaid, with the aim of allowing people to remain in their homes. It is administered by local Area Agencies on Aging (AAAs).

There are no income requirements for the program: eligibility is based on age and need. Seniors pay for services they receive based on a sliding income scale. Each AAA, as part of its planning process, determines the extent of services it can provide, allowing it to serve as many people as possible with its available funds.

The original idea for OPI is said to have come from Bertha Roth, a member of the Governor's Committee on Aging in the early '70s. The concept of providing in-home supportive services to people not receiving Medicaid also was supported by Marion Hughes, then director of the State Program on Aging in the Department of Human Resources.

During the 1973-75 legislative interim period, a joint Committee on Aging was appointed. Its work resulted in the introduction of HB 2163 in the 1975 session, which created Oregon Project Independence.

The OPI bill was sent to the House Committee on Aging, chaired by Representative Ralph Groener, a strong supporter of services to seniors. During its consideration by the Legislature, the AAAs and the emerging senior-advocacy community actively worked toward its passage.

Current U.S. Senator Ron Wyden worked with Lane County Legal Aid at that time and was instrumental in organizing local seniors into an effective lobbying group. The Oregon State Council of Senior Citizens also sent its executive director, Hal Evenson, to lobby lawmakers.

Part of the lobbying effort was a Senior Day at the Legislature, which included a rally on the Capital steps that garnered considerable media coverage and put a spotlight on the problem of forcing seniors into nursing homes even if they required only a small amount of assistance in daily living.

The bill, which ended up including \$1 million for services during the 1975-77 biennium, passed by unanimous votes and became effective July 1, 1975.

In practice, Oregon Project Independence was designed to minimize paperwork and bureaucracy: “It operated from the principle of a light touch” one administrator wrote. Not everyone on OPI required ongoing, intensive contact or service coordination; resources could therefore be directed to those who did.

In one Oregon county, the OPI administrator took advantage of the local community college’s Displaced Homemaker Program, hiring women who “turned out to be excellent homemakers, housekeepers and personal-care aides. While we could only pay minimum wage, we offered training and a flexible schedule,” according to the administrator. “Relationships with clients were very positive, with few exceptions.” Another county contracted with a local hospital’s home-health-care agency to provide homemaker services.

Throughout its existence, OPI has continuously demonstrated that providing even a limited range of services to seniors can allow them to remain in their homes, preserving their independence and dignity while saving the state considerable amounts of money.

Being funded totally by state general funds, OPI is a constant target for reductions when the state experiences budget problems. Because of efforts by senior advocates and the program’s proven effectiveness in keeping seniors out of costly nursing-home placements, it has continued to operate, though at reduced levels. In 1992, the program was able to serve 3,500 seniors; in 2012 that number had dropped to less than 1,500.

---

## **1977: A New State Agency**

Under a law passed by the 1977 Oregon Legislature, an important change was made in the state’s Department of Human Resources (DHR) that helped accomplish Oregon’s vision for senior services.

Two existing DHR units – the State Program on Aging and the Office of the Special Assistant for Programs on the Elderly – were combined to form the Office of Elderly Affairs, which was attached to the DHR Director’s office. Its role was to administer the Older Americans Act and Oregon Project Independence.

Though not officially denoted as such, the office became the focal point for senior advocacy. Seniors tried during the 1977 and '79 legislative sessions to have the office raised to the status of a division, which would give it additional budgeting and regulatory authority. Both efforts were unsuccessful, most likely because the unit's budget was considered too small to merit division status.

The Office of Elderly Affairs existed until 1981, when state law created a new division with broad powers over senior programs.

---

## **1978-79: The Long-Term-Care Ombudsman and Nursing Facility Patient's Bill of Rights**

***Long-Term-Care Ombudsman:*** Amendments to the Older Americans Act in 1978 required all states to establish an ombudsman program. Oregon's Long-Term-Care Ombudsman program began in 1978 within DHR's Office of Elderly Affairs and in 1981 became part of the Governor's office. In 1985, legislative action made it an independent agency.

The office began with only an ombudsman, Marty Lemke, who recruited volunteers to serve as ombudsman "designees" throughout the state. They would visit all types of long-term-care facilities and talk with residents. When a concern or complaint was heard, the ombudsman designee worked with staff and management to resolve it.

While traditional ombudsmen are supposed to remain neutral, long-term-care ombudsmen in Oregon advocate for residents and represent their interests. The Ombudsman's Office can lobby the Legislature on behalf of senior-related legislation and monitor the state's enforcement of laws governing all types of long-term care.

As the Oregon system of alternative care expanded, the Ombudsman's Office played a vital role in monitoring the quality of care provided by the newly created care settings. In its work with residents who were experiencing problems, the office could easily spot



the need for new or increased regulation or monitoring, and pass that information along to the appropriate governmental agencies.

***Nursing Facility Patient's Bill of Rights:*** In 1979, the Oregon Legislature passed what is known as the Nursing Facility Patient's Bill of Rights, which provided a wide range of requirements that long-term-care facilities must meet in serving clients.

This consumer-protection law specifies 16 areas in which residents are protected. Among its provisions, it mandates that people must be treated with dignity and respect; have the right to make informed choices about their care; have a right to privacy and access to their records; and have the ability to voice grievances.

---

## **1979-80: Joint Demonstration Grants and the First Attempt at Reform**

As data from Oregon Project Independence (OPI) continued to demonstrate the benefits of providing seniors with alternatives to nursing homes, the Department of Human Resources (DHR) set about gathering additional evidence to support the adoption of OPI principles throughout the entire system of long-term care.

DHR Director Leo Hegstrom, who had an extensive financial background, recognized the need to collect data that could demonstrate the dollars-and-cents benefits of various approaches to any new system.

Hegstrom commissioned Dick Ladd, a researcher at Oregon State University, to research, design and operate different models of controlling inappropriate nursing-home usage, as well as devise ways to develop new home- and community-based resources to meet seniors' needs.

Ladd's work led to obtaining two federal joint demonstration grants: One, a "Flexible Intergovernmental Grant" (FIG) from the Administration on Aging's Model Projects

Program, allowed Oregon to test options for accessing the long-term-care system and delivering services.

The second was a Section 1115 Long-Term-Care Studies and Demonstration Grant from the Health Care Financing Administration (HCFA), which provided three-year waivers to Medicaid regulations, though it awarded no extra funds to the state. The waivers allowed Oregon to use Medicaid funds for home- and community-based services and the development of non-institutional resources.

The resulting demonstration project was commonly known as FIG, which continued from 1979 through 1981. Four counties were selected to participate, with each testing a different approach.

One county implemented a multi-faceted strategy that included new methods of accessing services, assessing the needs of clients, integrating services and sharing information. Another county tested only financial changes (using Medicaid funds to provide services outside of nursing homes). A third county used both strategies and the fourth, none of them.

The results of the four pilots made it clear that simply enacting financial changes (spending money on community-based services rather than nursing homes) was not successful in reducing the cost of care or avoiding inappropriate nursing-home placements. The change in spending needed to be accompanied by:

- ◆ a uniform method of intake into the system and assessment of client needs;
- ◆ increased coordination between service providers;
- ◆ shared data about clients, to identify duplication or gaps in service, and over- or under-utilization; and
- ◆ a local advisory board to develop policies.

***The first attempt at reform:*** In early 1980, separate from the FIG project, DHR developed a proposal for a revamped long-term-care system that used state-controlled branch offices. This plan was formulated without input from local officials and senior advocates; upon its release, both of these groups voiced strong opposition. Seniors

protested that the plan was created without their input; local AAAs objected to their minor role in service delivery.

That opposition was conveyed to Governor Vic Atiyeh, who responded with a challenge to advocates and the Governor's Commission on Aging to develop an alternate proposal that was acceptable to all parties. The two groups took up that challenge and appointed an ad-hoc committee charged with developing a redesigned long-term-care system. This began the process that culminated in passage of Oregon's pioneering legislation and establishment of an entirely new long-term-care system.

---

## 1981: Passage of Senate Bill 955

Senate Bill 955 – Oregon's groundbreaking legislation that represented the first major step toward revamping its long-term-care system – was passed in 1981 by Oregon's Legislature, on the last day of what was then the longest session in the state's history.

The wide-ranging law contained provisions that:

- ◆ established a state policy on aging;
- ◆ created the Senior Services Division (SSD) within the Department of Human Resources (DHR) to administer formerly fragmented senior programs and funds;
- ◆ set up a new local service-delivery system;
- ◆ required the relocation of appropriate nursing-home residents to alternative-care settings.

***History of the legislation:*** As mentioned in the previous section, the state's initial effort at revamping its long-term-care system met with strong opposition, mainly because it was drafted by DHR without input from senior advocates or local officials.

After Governor Vic Atiyeh asked for creation of a collaboratively produced, widely supported version of that proposal, an ad-hoc committee representing consumers, providers, and state agencies was formed. The entire group numbered close to 125, but

a core group representing seniors, the Governor's Commission on Aging and the Area Agencies on Aging did the majority of the work of drafting a proposal over a period of 18 months, with a high level of support from DHR. That proposal went to the governor, who, after being lobbied by senior advocates, agreed to make the bill part of his 1981 legislative package.

***Raising support for the bill:*** "Very few people thought the bill had a prayer of a chance of being passed," according to one DHR official, so the department and senior advocates began a statewide effort to build support.

According to the head of DHR's Office of Elderly Affairs, without the support of Walt McGettigan, chair of the Governor's Commission on Aging, "it is highly unlikely that seniors would have supported SB 955 the way they did."

McGettigan was joined by Dick Ladd, Georgena Carrow and Bob Zeigen of DHR on "road trips" to every corner of the state, where they held meetings to explain the proposed system and gain support. These meetings included local legislators, who were able to have their questions answered and hear from their senior constituents, a strategy that significantly helped the bill's journey through the 1981 session.

***Controversial provisions:*** A number of key changes in the proposed system drew opposition. Obviously, the for-profit nursing home industry was very concerned about a system which stressed alternatives to institutional care for seniors. They raised the specter of nursing homes going out of business and "not being there when they were needed." (The not-for-profit nursing home association did not oppose the bill.)

However, according to one DHR official, there was a fair amount of skepticism among the industry that the state could "actually pull it off" – set up a system with adequate resources to meet the varied needs of seniors. This tempered the industry's efforts to stop the bill.

A considerable amount of controversy centered on provisions giving local control of the program to the AAAs, but not for the same reasons. State and federal officials were concerned about giving local governments the power to administer part of the federal Medicaid program, one of the largest budgets in the state. Conversely, some local governments did not want the responsibility of administering the programs.

Certain AAAs were unhappy about the added burden of determining eligibility for programs, and feared turning into “welfare agencies” because of handling programs for low-income seniors. They felt people should be entitled to services because of their age, not because of their income, and feared Older-Americans-Act programs would take a back seat to Medicaid. Also of concern to AAAs was a requirement that their governing body be made up of public officials if they administered the Medicaid program.

Within DHR there was also significant controversy. The bill contained a major reorganization of the department, something seldom embraced by employees. Labor unions representing state workers became involved because of the personnel issues that arose. The bill transferred the administrators and case managers who worked on senior programs from the Adult and Family Services Division (AFS) to SSD. In that process, some case managers would go to the AAAs, where they would become local-government employees. Questions about their salaries, health benefits and working conditions were voiced, and according to one manager, heated discussions between the department, employees and unions were frequent.

There was also a fear among some employees who worked on various senior programs that their particular senior issues would be diluted in a combined division. “I went kicking and screaming,” one person wrote. “I feared it would weaken the advocacy functions inherent in the separate Office of Elderly Affairs.”

***Legislative consideration:*** The 1981 Legislature had to deal with the effects of a severe economic recession, so proposals that included monetary savings were welcomed. “Had it been a ‘normal’ session,” one DHR official wrote, “I doubt if the bill would even have gotten out of committee.”

The bill’s trip through the legislative process was at times rocky. Some AAAs were actively opposing the bill, not wanting to take on the red tape that went along with federal programs. A compromise that allowed the bill to pass was fashioned, enabling AAAs to opt out of administering Medicaid programs if they wished.

The approved system set up a somewhat confusing mix of AAA options: some would administer only Older Americans Act programs and Oregon Project Independence (known as Type A); others would take on Medicaid long-term-care programs using staff transferred from DHR and funds transferred from the state (known as Type B Transfer);

and the third type would administer Medicaid programs by supervising state staff who work under a contract with the county, with the state paying for services and staff salaries directly (Type B Contract).

Though this was not the uncomplicated system envisioned by the bill's creators, it did allow the legislation to proceed. SB 955 passed with almost-unanimous support on the last day of the 1981 regular session.

The passage of SB 955 can be attributed to many factors. Foremost were the intense advocacy efforts by the well-organized senior lobby, and especially those of the Governor's Commission on Aging, United Seniors and the Oregon State Council of Senior Citizens.

In addition, the ad hoc committee that drafted the bill contained broad-based representation and the statewide "road trip" meetings demonstrated a high level of support among the people who would be served under the new law.

Also contributing to the bill's passage were a bi-partisan Legislature that year and support of the bill by the governor. Another plus: DHR Director Leo Hegstrom was a strong supporter of the new vision of senior services and, with his financial background, he was able to effectively communicate the fiscal impact of the bill. His advice and counsel throughout the process was critical in ensuring the governor's continued support and obtaining legislative approval.

Another positive factor was evidence from the successful FIG Waiver Project and Oregon Project Independence (OPI), which showed the proposed system could be successful in cutting costs, a prime consideration during those difficult economic times.

***Components of the law:*** SB 955 set down a state policy on serving senior citizens that would govern all programs and services for the elderly. The policy requires that services be provided in a coordinated manner, and that seniors receive necessary care and services at the least cost and in the least-confining situation, "making nursing home placements the 'last resort' rather than the first."

The law directs policy makers to focus funds from the Older Americans Act and Oregon Project Independence on keeping people in their homes as long as possible. The law

also affirms that the state should re-allocate the savings in nursing-home costs to support alternative types of long-term care.

A single state agency with jurisdiction over senior programs was established within DHR in October 1981. This Senior Services Division (SSD) merged the functions of various DHR agencies and offices that had managed Older Americans Act services, OPI and Medicaid long-term care.

Along with consolidation came responsibility for managing diverse state and federal funding for senior services. These included Social Service Block Grant (SSBG) funds previously administered by AFS, which were capped and funded only limited adult foster care, residential care and in-home services.

The actual creation of SSD took a number of years to complete because of the significant procedural and personnel issues that were involved. One high-level DHR employee recalls it was an “emotional and sometimes painful process” but one that was successful in the end.

As mentioned earlier, the law handed over responsibility for Medicaid eligibility and service delivery to the AAAs that were willing to accept it, which most did. The remaining counties chose to limit their responsibilities to providing services under the Older Americans Act and Oregon Project Independence, and let SSD handle all administration of Medicaid services.

---

## **1981: Creation of the Pre-Admission Screening Program**

One early and important finding from the FIG project was that efforts to ensure seniors receive services in the least restrictive, most cost-effective setting had to begin at their earliest contact with the long-term-care system.

Because of that, when the federal government required states to begin a program of Pre-Admission Screening (PAS) for Medicaid-eligible seniors who applied for assistance, Oregon decided to expand the scope of those initial screenings so they would also help determine proper levels of care for each person.

Federal regulations required only that states screen for mental illness and developmental disability. In Oregon, the Pre-Admission Screening procedure also gauges the level of care a person needs, making the screening process another tool in determining if a person actually requires nursing-home care or if home- or community-based services can adequately meet their needs.

Under Oregon's system, pre-admission screenings are conducted for all applicants who are eligible for Medicaid or are likely to become so within 90 days of entering a nursing home. The program also requires any person who will be paying for their care from other sources to have an assessment (albeit a less extensive one) before they enter a nursing home.

As part of the screening process, seniors receive information about their options and take part in the decision-making process. The screenings are conducted locally and are overseen by the Area Agency on Aging or local state senior-service office.

Originally the screening teams were made up of a social worker, a registered nurse and a caseworker, who evaluated the entire scope of a person's social and medical needs. The team would assess where and how those needs could be met, taking into consideration the person's personal, family and community resources. The team worked with the client, the family and the caseworker to develop a plan that met the client's wishes (to the extent possible). Later, it was demonstrated that accurate and efficient screenings could be done by an RN alone.

Instances of disagreement over the results of a pre-admission screening do occur, often because the senior citizen wants to remain in a living situation that cannot adequately meet his or her needs. In these cases, the final decision is made by the senior, not by the screener or the person's family.

In the early days of the program, tensions sometimes arose between local AAA offices and DHR central office, which was closely monitoring the rate of nursing-home



admissions. One instance, referred to as the “Cuban Missile Crisis” by a DHR manager at the time, occurred when officials of Senior Services Division wanted to talk with local PAS teams in the Portland area without the participation of AAA managers. This prompted strong opposition from AAA administrators that required the efforts of DHR Director Leo Hegstrom to defuse.

Though implementation of this program was described by one participant as “like the wild west,” it provides another example of the emphasis on collaboration and the commitment to problem solving that enabled Oregon to bring together people and governmental agencies with diverse priorities, in the name of better lives for seniors.

---

## **1981: Obtaining the Federal Medicaid Waiver**

Oregon was the first state in the nation to be granted a statewide waiver to Medicaid regulations, enabling it to use funds meant for nursing-home care to instead provide services to Medicaid-eligible seniors in non-institutional settings.

That waiver, by giving Oregon the freedom to direct money to alternative types of services and living arrangements, was the most important single factor in the successful redesign of the state’s long-term-care system.

The Medicaid waiver allows funding of housekeeping, limited medical care and other services that are delivered to seniors in their homes or in alternative-living settings, as well as the costs of living in such facilities. It also allows the state to use Medicaid funds to provide ongoing case management to seniors.

The waiver request was drawn up by the Department of Human Resources Senior Services Division (SSD), with Administrator Dick Ladd leading the effort. The primary challenge in gaining approval from the federal government was convincing the Health Care Financing Administration (HCFA) that the new system would be cost-neutral.

There was a very strong mindset within HCFA that the only appropriate option for seniors was nursing-home care. The system for paying nursing homes was already in

place and federal regulators felt there was maximum accountability within the nursing-home system. They had significant doubts that a home- or community-based system could be managed effectively or provide the desired accountability.

There were also fears that the new system would result in an explosion of people wanting to obtain services (known as the “woodwork effect,” in that low-income seniors would “come out of the woodwork” to take advantage of the system when they learned that going into a nursing home was no longer their only option). Ironically, this argument points out the major flaw in the existing system ... people avoided using it because it forced them into a place they did not want to be.

Dick Ladd, DHR Director Leo Hegstrom and DHR research staff worked with federal officials to show that the Oregon experiment could be cost effective. Data from the FIG demonstration project and Oregon Project Independence proved that the state could provide services to three people in their homes for the same cost as one person in a nursing home.

James Wilson, deputy administrator of SSD, relates two reasons for the relatively easy process of obtaining the initial waiver (a “cake walk” as he describes it). First, the FIG demonstration project had gone well and the national staff at HCFA were happy with the results.

And secondly, the nursing-home industry had not awakened to the “possibility of their ox being gored.” As we discuss later in this document, the nursing-home industry later became a powerful force in opposition to the renewal of the waiver in 1984.

The waiver (under Section 1915<sup>©</sup> of the Social Security Act) became effective December 21, 1981. The next step for the state was to set up the policies, procedures and resources that would make the new system a reality.

---

## 1982: Development of the Assessment System and Community Resources

***The assessment system:*** Development of a uniform, statewide system of assessing the resources and needs of seniors seeking assistance was a critical part of Oregon's success. The assessment process not only needed to provide information about the extent and types of services a person should receive, but allow the gathering of statistics that were invaluable to the Senior Services Division and were required by federal regulators.

In the Oregon Project Independence program there was initially no common assessment tool. Applicants were not "means-tested" (meaning they did not have to fall below a certain income level to qualify) and their assets were not considered when determining eligibility. (However their net income did affect the amount they paid for services, on a sliding scale.)

For the "Flexible Intergovernmental Grant" (FIG) pilots, an assessment tool known as the "180 Form" was developed, which included income information and expanded upon the existing, federally mandated pre-admission-screening protocol that Oregon had developed.

With the implementation of the federal Medicaid waiver, SSD revised the 180 Form and renamed it the "360 Form." It was believed that no such assessment instrument and procedure were used anywhere else in the nation at that time.

The 360 form evaluates an applicant's situation using a standardized model, and is used by staff at AAAs and state senior-service offices with every senior who comes in with questions or a request for services.

The standardized assessment procedure has allowed Oregon to establish a set of 18 "survival priority levels" that clearly outline a person's capabilities and impairments. Seniors are assigned a level when they come into the system, based on their ability to perform tasks of daily living and the availability of assistance. Assessments are performed again at regular intervals and whenever a need is indicated.

The list of survival priority levels continues to be used by the Legislature for budgeting purposes. Depending on available revenue, lawmakers choose to cut off eligibility at a certain priority level: those with fewer needs are not eligible for state assistance.

The statistics garnered from the uniform assessment tool are used by the state to understand the profile of the population it serves. They allow policymakers to determine if services are being provided consistently and to develop mathematical formulas that can predict future costs of care. Most importantly, the assessment data allows the division to create statistical profiles of the needs and resources of the people it serves, which is of great value in working with lawmakers.

***Developing community resources:*** Before Oregon received its long-term-care waiver, a small number of alternative-care options such as residential care facilities and adult foster homes did exist, but the budget for reimbursing these providers was very limited; when the funds for the biennium were exhausted, seniors on Medicaid could no longer select those options.

With the advent of the federal waiver and Senior Service Division's emphasis on alternative-care options, development of such resources became a priority.

SSD sent resource development specialists into communities around the state to help develop alternative-care facilities. They advertised and held community meetings to solicit new providers and supported efforts to establish new community-based facilities. The state also mounted an education campaign aimed at local residents, physicians, and hospital-discharge planners, to convince them that community-based care was a viable and safe alternative to nursing-home placement.

One type of care that could be developed quickly was adult foster care (AFC). SSD deployed a group of staff members across the state to work with potential foster-home operators, and it increased the amount of reimbursement that could be paid to them. Because of such efforts, the number of adult-foster-care homes in the state tripled between 1982 and 1992.

Pilot AFC projects pointed out the need for oversight and licensing, rather than simple registration. (The state was in a recession and according to one AAA leader at the time, becoming an adult-foster-care provider was seen by some as a way to generate income.)

Two Oregon counties, Multnomah and Clackamas, had passed local ordinances relating to adult foster care. However, *statewide* licensing ensuring the health and safety of residents was required before Medicaid money could be spent on adult foster care under the federal waiver.

With the help of Penny Davis and Terry Rogers of Multnomah County Legal Aid, two such statewide laws were drafted and passed by the Legislature. The first, in 1983, required certification for adult foster homes that served Medicaid clients.

Later, in 1986, the second law set up a licensing requirement and mandated training for staff. Legal Aid obtained a grant and worked with the Oregon State University Program on Gerontology to create a training manual and provide classes.

The administrative rules drafted under the two laws were designed to allow a home-like setting while maintaining quality of care. According to one SSD manager, when the state started licensing adult foster care homes, private-paying clients were more likely to make use of them because the facilities were required to meet certain standards.

---

## **1982: Relocation of Nursing-Home Patients**

Senate Bill 955 required the newly formed Senior Services Division (SSD) to set up and implement a system to identify nursing-home patients who were likely to benefit from moving out of an institutional setting and into their own home or a community living arrangement.

To accomplish this, 25 staff from SSD, as well as staff from the Area Agencies on Aging that administered Medicaid programs, needed extensive training in selecting candidates for transfer and administering the moves so they caused the fewest detrimental effects.

Relocation out of nursing homes was offered as an option for residents, not a requirement. Those expressing interest were re-assessed within one to three months to ensure they still could benefit from such a move. If approved, residents without a home

they could return to began short visits to community-based residence options. When the person selected a residence, they went on increasingly longer visits to become accustomed to the new setting before making the permanent move.

The nursing-home industry, naturally concerned by the potential drop in their populations, worked to discourage the relocations, based on the likelihood of “transfer trauma” to the residents. SSD responded by adding procedures designed to decrease the risk.

At the time, Dick Ladd asserted that DHR research did not find instances of relocation trauma among the nearly 7,000 nursing home residents who were relocated during the first three years of the effort. He has admitted, however, that the state did not initially pay significant attention to the quality of care in some of the newly established community-based settings. That has been remedied by increased oversight and licensing requirements.

Nursing-home-relocation efforts continue today, with ongoing evaluation of nursing-home residents to determine if they still require and want the extensive services provided in nursing facilities. If the person agrees, they are given assistance in choosing another living option and making the move.

One AARP official wrote in a 2012 article that most seniors who went into a nursing home found they had crossed a “one-way bridge,” in that it was extremely difficult for the person to return to their home or a community-based living arrangement. In 1982, Oregon became perhaps the first state to provide a “two-lane bridge” that allowed nursing-home clients to return to a life outside of institutions, an approach that has since spread across the nation.

---

## **1984: The Negotiated Investment Strategy**

By 1984, the new system of local administration for long-term-care programs was experiencing significant problems, leading to ongoing dissatisfaction among the local Area Agencies on Aging (AAAs) and within the Senior Services Division (SSD).

Local AAAs wanted to manage the Medicaid program with the same flexibility and latitude they enjoyed under the Older Americans Act and Oregon Project Independence. But in order to comply with its federal waiver, SSD needed uniformity of procedures and a high level of accountability, the same as applied to its local staff who administered Medicaid in areas where the AAA had opted out.

Providers in the system had hoped for better rates of reimbursement from the system as well as fewer regulations, among other benefits. Advocates for seniors were alarmed by the ongoing struggles that threatened the new, far superior, approach to helping senior citizens.

In 1984, in the face of this deterioration, the AAAs urged SSD to bring in outside experts from Georgia to operate a “Negotiated Investment Strategy” process. Four five-member teams were formed, representing SSD, the AAAs, providers and participants in senior programs. Teams met twice a month for six months to discuss topics of contention, such as oversight, reimbursement systems and quality assurance.

This process gave the state an opportunity to convey to local administrators the realities of dealing with federal programs and the need to follow precise requirements in certain program areas. AAAs could voice their frustrations with administering the programs. These and many other issues were discussed and agreements between all the participants were hammered out.

The result of the discussions was a report entitled “Shared Roles and Responsibilities for Delivery of Services Through the Oregon Senior Services System.” It contained the agreements that had been reached and was signed by all the participants.

According to one source, the NIS process “cleared the air and put the system back on track.” It also allowed the vague directives of the state legislation to be translated into real-life policies and procedures that would govern the new long-term-care system.

Other NIS processes were used during the following years to address emerging issues. In the late 1980s, use of NIS was replaced with an ongoing Program Council within DHS, which continues to meet regularly with AAA and SSD managers to resolve issues before they reach a critical level.

---

## 1984: The Battle for Renewal of the Waiver

As the initial term of the federal waiver came to a close, the scenario had changed significantly since 1981. The nursing-home industry saw many potential clients opting for home- or community-based care and its powerful lobby set about working in Washington, D.C., to prevent a rush by other states to follow Oregon's lead.

In addition, budget reduction efforts put in place on the national level during the recession years of 1981-83 had given the Executive Office of Management and Budget (EOMB) a greater role in monitoring federal agencies. That office became another touchpoint where lobbyists could exert influence against Oregon's waiver.

James Wilson, who was brought into Senior Services Division (SSD) in 1984 –perhaps, he speculates, because of his past work for the federal Health Care Financing Administration (HCFA) – kept a detailed log of the division's exhaustive efforts to obtain renewal of the waiver and the roadblocks placed in its path. His work provides the bulk of the information in this section.

According to Wilson, the nursing home industry and EOMB put pressure on HCFA to look at data from 1970's demonstration projects known as "channeling grants." These dealt with home care for very frail elderly people (not typical of the seniors being served in alternative care in Oregon). Cost data from those grants showed that community-based care was not less expensive than nursing-home care, and, even though that conclusion did not apply to Oregon's system, the study was widely quoted, perhaps because it supported the "anti-home- and community-based care faction" within the government.

In addition, federal regulators became more fearful of the so-called "woodwork effect" discussed earlier: people flocking to the program because of its attractive options. Such alternative-care options had, in the past, been paid for by state governments; under waivers such as Oregon's the cost shifted to the federal level. The federal government wanted to impose limits on how many people could be served, first in Oregon and subsequently in other states that asked for or renewed similar waivers.



Oregon submitted its request for a three-year renewal of its waiver on June 1, 1984. What followed was a tale of intrigue, influence and many cross-country plane rides in an effort to keep Oregon's system alive. Wilson provided Senior Forums with a description of the steps involved in that process, which are highlighted below:

June 5, 1984 – Social-service officials from the state of Georgia informed SSD that waiver-renewal requests were being judged by a set of "draft" regulations which had never been published. At the division's request, Senator Robert Packwood's office requested the draft regulations from HCFA. HCFA denied that such regulations existed.

August 13-17, 1984 - HCFA, by law, had 90 days to provide feedback regarding Oregon's June 1 waiver-renewal request. Because SSD had heard nothing, SSD Administrator Dick Ladd, Wilson, and Jan Curry, Deputy Administrator of the Oregon Mental Health Division, traveled to Washington, D.C. They met with the undersecretary of the federal Department of Health and Human Services as well as the HCFA official in charge of waiver approval, and were told that "questions" had arisen about the renewal request, however they were not told what those questions were.

August 20, 1984 – The division received ten typewritten pages of questions about the renewal request. The questions required unduplicated counts of the number of individuals that Oregon expected to serve over the next three years. Since this was not the way caseloads were projected in the DHR budget process, SSD staff worked day and night answering the questions, which were mailed out on September 16<sup>th</sup>.

September 24-26, 1984 - Ladd and Wilson traveled to Washington to discuss problems related to the waiver renewal with Oregon's Congressional delegation and the staff of California Congressman Henry Waxman, the author of the legislation that allowed Medicaid waivers such as Oregon's. The discussions confirmed that HCFA was taking a much stricter approach to waiver approval than had been contemplated by Congress.

October 10-12, 1984 - Ladd and Wilson attended a conference on home- and community-based waivers in New Mexico, and were given a copy of HCFA draft regulations obtained from a HCFA regional office "under the table." This confirmed that Oregon was being asked to comply with regulations that had not met the federal rule stating regulations must be officially published for public comment in the *Federal Register* before being enforced.

October 17, 1984 – DHR Director Leo Hegstrom, Ladd and Wilson again flew to Washington, D.C., and met personally with then-HCFA Administrator Carolyn Davis. They were presented with a new list of conditions for waiver approval.

December 19, 1984 - Two days before Oregon's existing waiver was due to expire, Wilson received a telephone request from HCFA's Region X Office asking for additional assurances. He was told the waiver request would be denied if they were not provided. He was also told to withdraw the answers submitted to HCFA's ten-page request in August and to totally rewrite the waiver, incorporating all the assurances the state had been required to make. By that time, some of the pages in the waiver request have been rewritten and re-submitted to HCFA four times.

January 11, 1985 - In response to a request from HCFA's central office, Ladd and Wilson traveled to Baltimore to again meet with HCFA officials. They were told that the waiver could not be approved so long as Oregon expected to serve the number of individuals shown in its request.

During lunch at a Baltimore restaurant, a HCFA official wrote three numbers on a paper napkin. They were the number of individuals Oregon would be allowed to serve in each of the next three years of the waiver. The numbers were considerably lower than what had been requested. Seeing that Oregon had no other options, Ladd agreed to them. Upon returning to the HCFA official's office, a letter was drafted for Ladd to sign incorporating the newly "approved" numbers.

February 1, 1985 – SSD received a letter approving its waiver request for the next three years, which incorporated the new limits on the number of persons served.

March 13, 1985 – HCFA published its new home- and community-based-care waiver regulations in the *Federal Register*. They bore a striking resemblance to the (supposedly non-existent) draft regulations Wilson and Ladd had received in New Mexico.

According to Wilson, the lower numbers Oregon was forced to accept have long-since been replaced by more favorable federal laws and rules, "as the world finally accepts the fact that home and community-based care is a cost-effective and humane alternative to institutional care. However, the fight to get to the current situation went on for several years."

---

## 1985: The Controversy Continues

Oregon's success in obtaining a renewal of its home- and community-based-care waiver (albeit in a scaled-down size) did not stop the controversy and the efforts by the for-profit nursing-home industry to derail the system.

Between 1981 and '85, the state had been successful in moving clients away from nursing homes and into alternative types of care. (It's doubtful this involved a "hard sell," since so many seniors strongly fought the idea of institutional settings.) Nursing-home Medicaid populations declined by about 10 percent. In addition, seniors with the ability to pay were also opting for home- and community-based care, causing even more financial pain to the nursing home industry.

The industry retaliated with a formal complaint filed with the Health Care Financing Administration (HCFA) in 1985. The complaint asserted that Oregon was violating the terms of its waiver by forcing people out of nursing homes and not giving new clients a complete choice of care settings. The industry contended that many people who were placed in adult foster homes actually needed to be in nursing homes.

In response, HCFA began a formal investigation. At the same time, Senior Services Division (SSD) independently asked the Long-Term-Care Institute at the University of Minnesota School of Public Health to conduct its own review.

The two investigations came to the same conclusion: Oregon was not in violation of its waiver and the clients in its long-term-care system were generally satisfied with the way SSD handled their cases.

Many seniors were angered by the nursing-home industry's actions and publicly vented their disapproval by picketing the 1985 annual convention of the Oregon Health Care Association (the trade organization of for-profit nursing homes) in Portland. The protest garnered coverage on local and national news broadcasts.

According to a University of Minnesota research paper on the Oregon system, a spokesman for the nursing-home industry stated in the news coverage that the association was really only interested in "what was best for seniors." Picketers

responded that the seniors, not providers of care, should decide what constitutes “best for seniors.”

As time passed and the inevitability of the shift to non-nursing-home care became apparent to nursing-home operators, they have found ways to take advantage of the change. Institutions that formerly offered only intensive nursing-home options branched out to set up their own assisted-living or other types of alternative-care facilities. According to the Minnesota research, the industry has “decided to become a part of the state’s long-term-care philosophy,” providing environments that “emphasize privacy, dignity, choice and independence.”

One important driver in that shift was Ed Sage, who served as the director of the Mid-Willamette Area Agency on Aging and then took a job as Executive Director of the Oregon Health Care Association. His insights, gained from helping seniors make choices about their care, gave him credibility in his work with nursing homes that were considering branching into other types of care.

---

## **1987: “Nurse Delegation,” The Development of Assisted Living and the “Health-Division Transfer”**

**Nurse Delegation:** In 1987, the Oregon Legislature took another major step toward the success of alternative care by including a so-called “nurse delegation” provision in the Nurse Practice Act. The addition allows licensed registered nurses to delegate many types of nursing care to unlicensed providers who receive training and can demonstrate their competence.

The need for the law became apparent during the six years after receiving the federal waiver: people who needed only simple, ongoing medical procedures such as injections either had to go into a nursing home, hire a home-health service to come to them or arrange travel to a medical facility. Many times, these seniors simply didn’t get the care they needed.

In addition, nursing regulations during that time allowed a relative to provide certain types of care but prohibited strangers from doing the same things. No valid justification could be found for that inequity.

In response to the problems that clients reported and the state's shortage of nurses, the Department of Human Resources proposed the nurse-delegation concept to the Legislature.

The bill was opposed by the Oregon State Board of Nursing and the Oregon Nurses Association, and a prolonged and often heated battle ensued. Nurses feared that care from non-nurses would endanger patients. The nursing-home industry opposed the change because it threatened to further reduce the number of people entering their facilities. In support of the bill were home-health agencies, who were facing a shortage of staff to provide all the nursing tasks required by their clients.

According to a Senior Services Division staff member at the time, it took intensive efforts by senior advocates to overcome objections and obtain passage of the law.

Decisions about which patients can receive medical services from delegated individuals and the types of medical procedures that can be performed are made by a registered nurse. The RN is required to assess the nursing needs of the client, teach the caregiver how to do the task, observe the task being performed and periodically evaluate the client outcomes. Oregon gives nurses a great deal of discretion in deciding which nursing tasks can be delegated, unlike most other states that have a prescribed list.

This law has had a major role in the success of alternative-living situations such as in-home care and adult foster care, by increasing the options for providing necessary medical services to seniors regardless of where they live. It has also been an important cost-control tool.

***Assisted living and the "Health-Division Transfer":*** Oregon is the birthplace of the assisted-living model of care. It is said that the idea came from Keren Brown Wilson, a professor of gerontology at Portland State University. She developed and opened a new type of care facility after a discussion with her mother about the kind of care she wanted as she aged. After the model of care proved successful, Wilson approached SSD about including it as an option under the Medicaid program.

In 1987, Wilson and Dick Ladd worked together to obtain approval for state-supported assisted-living prototypes in Portland. Two such facilities were created, and their quality of care and resident satisfaction were evaluated. The positive results from the prototypes enabled SSD to approve assisted-living facilities for reimbursement under Medicaid.

Setting up the first assisted-living facilities posed challenges that signaled the need for changes in the state's system of inspecting and licensing long-term-care facilities. At the time, those responsibilities rested with the Health Division of DHR.

Assisted-living facilities did not fall under any of the existing regulations covering nursing-home and residential-care facilities and the Health Division was not willing to make changes to accommodate the pilot project. One particular sticking point was the inclusion of stovetops in assisted-living apartments. While they would provide a valuable option for senior residents, they were strictly forbidden under existing rules and the Health Division would not allow them.

The solution to this roadblock was the transfer of responsibilities for licensing all long-term-care facilities to SSD, which was accomplished in July, 1987. SSD then had the ability to write new regulations that covered the special features of assisted-living facilities.

After Medicaid reimbursement to assisted-living facilities was approved, the concept gained popularity quickly, particularly as people who could pay privately discovered the option and chose to move in.

---

## **Throughout the Life of the New System: Advocacy Plays a Critical Role**

Despite the demonstrable success of Oregon's new long-term-care system, its continued operation depended on ongoing efforts by senior advocates and lawmakers who support senior issues. In virtually every legislative session since 1975, efforts to educate lawmakers and rally support have been vital to keeping programs alive and, in some cases, expanding the number of people who could be served.

Oregon Project Independence (OPI) is particularly vulnerable because it is completely funded by state general funds, which depend on the state's income taxes. During economic downturns, the state faces serious budget challenges and programs with no federal matching funds are usually targeted for reduction or elimination.

It has been the job of individual senior advocates and organizations to spend the countless hours needed to monitor legislation, meet with lawmakers, testify at hearings, attend (and sometimes participate in) committee work sessions and keep senior issues in the media spotlight. Advocates have supported not only the budgets of specific senior programs, but also the overall Department of Human Services budget and other senior-related bills.

Independent advocacy is crucial because DHS cannot advocate for increases in the budgets of senior programs; it is required to support the funding levels that governors put in their proposed budgets. The job of building support for changes to senior-program budgets therefore falls to the advocacy network.

Some of the advocates in the 1970s and '80s had past professional experience as lobbyists; many others were willing to "use shoe leather" to walk around the capital, talking with lawmakers and staff and "getting things done that no one else can." These advocates also can effectively bring the "consumer vision" to their communications with lawmakers.

Much of the advocates' work focuses on meeting with individual legislators to provide information about the value of senior programs, from the standpoint of both monetary

savings and quality of life for seniors. OPI has a particularly compelling argument in its favor: without help from this program, many seniors would have to go into other, more expensive care settings rather than staying in their homes. State government must often pick up much of the cost for that care.

The statewide advocacy network that was built up in the early years of the system has proven its value during legislative outreach: an individual from a lawmaker's district can be tapped to meet with the legislator, adding to the effectiveness of the visit.

Starting with the legislative sessions of the 1980s, advocates, the Governor's Commissions and Area Agencies on Aging organized "Senior Days" at the Legislature. As many as 300 seniors from across the state were bussed to Salem, where they would learn about the issues and how to lobby before meeting with their local legislators. There were often large rallies on the capitol steps featuring talks by the house speaker, senate president and governor.

Advocates also came up with unusual ways to make their points. For example, during one session when a senior meal delivery program was targeted for a 10-percent cut, advocates delivered lunches to legislators with 10 percent of the food left off.

Ron Wyden, now a U.S. senator, was one of the founders of the Oregon Gray Panthers as an outgrowth of his work in low-income legal services at the University of Oregon. One of his lobbying strategies: awarding the "Golden Bed Pan" award to legislators who did not support senior issues.

There are many names that need to be mentioned from the earliest days of advocacy efforts. Frank Armstrong, Hayes Beall, Don Butsch, Ken Cooper, Jim Davis, Hal Evenson, G.G. Goldwaithe, Bill Gordon, Ace Harmer, Lee Hazelwood, Phyllis Lissman, Walt McGettigan, Bess Probst, Phyllis Rand, Ruth Shepherd and Charlie Winters were especially active during legislative sessions of the '80s and '90s. Many found themselves at the capital every day and spent considerable amounts of time with DHS staff gathering information.

Cecil Posey and Bob Van Houte used their experience as former lobbyists for education services to become powerful and successful advocates during the creation of the system.



Both served as chair of the United Seniors group and were instrumental in the success of Senior Days at the capitol.

The governor's advisory commissions on senior issues (which have had a number of different names throughout the years) often have been at the forefront of advocacy efforts, aided by the Oregon State Council of Senior Citizens, United Seniors and AARP. The state's Area Agencies on Aging, along with their advisory councils, have also been very active and effective in an advocacy role.

Marty Lemke, an active senior advocate, teamed with Ron Wyden to travel the state, building support for the formation of the long-term-care ombudsman program. She became the state's first ombudsman and, after leaving that position, created the Oregon Coalition for Better Nursing Home Care.

Even though DHS could not engage directly in advocacy efforts, part of its job was to provide support to the governor's senior commissions. In that capacity, Senior Services Division staff assisted advocacy efforts by providing statistics, researching information, developing strategies and preparing testimony. Jane Ellen Weidanz, Jan Carlisle, Sherryll Johnson Hoar, Ruth Wilson and Georgena Carrow were key in those efforts.

Legislative staff members important to advocacy efforts include Jerry Brown of the Legislative Fiscal Office and Art Wilkinson, who staffed the Joint Ways & Means Committee.

After the Senior Services Division expanded to include people with disabilities, senior advocates joined forces to form the Advocacy Coalition of Seniors and People with Disabilities. This group was created after the passage of Ballot Measure 5 (a property-tax-limitation initiative that threatened funding for social services); its aim was "protecting and restoring human services for seniors and people with disabilities."

Original coalition co-chairs Candice Gottenberg and Ruth McEwen were powerful leaders who helped give a united voice to seniors and people with disabilities. The advocacy coalition has stayed together and has had success even during difficult economic downturns.

---

## **Throughout the Life of the New System: Governor's Conferences on Aging**

During the development of Oregon's long-term-care system, several statewide conferences on important senior issues were held. The significance of these events in the development of the Oregon system cannot be overstated.

Each was held at a strategic time, in order to define key senior issues and needs, and determine how best to address issues and meet those needs. A great deal of state legislative action resulted from these conferences, as well as influence on national legislation.

The key to the success of each conference was the wide range of participation from across Oregon, gained by holding local forums in advance where seniors and advocates could identify issues, outline solutions and establish priorities. Issues and resolutions were then taken to statewide conferences by representatives of the local forums.

The first conference was held in March, 1981, convened by Governor Vic Atiyeh. It was designed to discuss issues, develop resolutions, and select delegates to attend the 1981 White House Conference on Aging.

The community forums held across the state in advance of this conference attracted hundreds of participants. According to June Hughes, who helped plan the local forums, this first conference "filled a need and desire of seniors to gather in order to identify and discuss critical issues affecting their well-being."

Ten issue areas were discussed, including housing, transportation, education, employment, health, income and long-term care. From that, more than thirty resolutions were outlined for submittal to the White House conference.

The next Governor's Conference on Aging was held in 1988, during the term of Governor Neil Goldschmidt. The 108 local forums in preparation for the conference drew more than 2,000 participants.

The conference itself was attended by 205 delegates, along with 17 members of the Governor's Commission on Senior Services and 75 observers. Ten work groups addressed the top issues identified by the local forums, producing a list of 40 priority issues that were presented to Goldschmidt, the Legislature and Senior and Disabled Services Division (the new name for SSD).

Subsequent Governor's Conferences were held in 1990, 1992, and 1998.

The 1998 session, convened by Governor John Kitzhaber, was unique in a number of ways. It was jointly planned and sponsored by U.S. Senator Ron Wyden, the Governor's Commission on Senior Services, Oregon State University, Portland State University, the Area Agencies on Aging, the Department of Human Services and a number of senior organizations.

This was the first conference to be open to people of all ages, agency leaders, and state and federal legislators. It focused on the future impact of the increasing senior population in Oregon and the nation. The top recommendations from the conference included caregiver professionalism, housing partnerships and mental-health services for all.

The success of these conferences illustrated the value of meeting and discussing issues on a regular basis. To help ensure that such gatherings would continue to occur, in May 1989, the Governor's Commission on Senior Services, AAAs and other senior organizations incorporated a group known as Oregon Senior Forums to raise funds and plan for informational meetings and issue-related conferences. (The board of that group commissioned the creation of this document.)

---

## **Throughout the Life of the New System: White House Conferences on Aging**

During the development of senior services across the country, White House Conferences on Aging were convened in order to help establish national priorities. There were White House Conferences in 1961, 1971, 1981 and 1995. Oregon participated in each of those by sending delegates, serving on national planning committees and holding local-issue forums.

The 1995 White House Conference was significant because it came at a time when the success of Oregon's unique long-term-care system was at its peak and interest in the Oregon story was at an all-time high. It was a powerful tool in shaping federal policy and encouraging other states to develop alternatives to nursing-home care.

Knowing the significance of national exposure, Oregon's governor and public officials held local forums in every community in the state prior to the conference. The forums were meant to identify issues and solutions that could be taken to the national conference as "resolutions for action." The forums also helped identify key leaders who would become delegates to the conference.

Oregon sent 30 delegates and about 20 other people who either provided staff support or were official observers.

Each state was given two minutes at the opening session to present their key issues. Oregon's statement "brought the house down" according to one observer, because "we were the only state in the nation serving more seniors in their homes or community settings than in nursing homes."

After that, Oregon delegates became the most popular participants in the issues sessions, with other state delegates always wanting to know "how did you do it?" or "what kind of services do you have?"

Delegates were stopped in the halls, while eating dinner and even in the bathrooms by others wanting information. The bright green badges shaped like the state that said

“We are Oreganized” got attention too – even Vice President Gore laughed and said “I love Oregon!”

Resolutions that were voted on during the conference had the stamp of Oregon’s experience. There were many who spoke about offering choice in services, establishing home-like living facilities in communities, adding mental-health services to long-term care and even some “senior friendly” tax-reform resolutions.

Oregon’s system had always been of great interest to other states and federal leaders, but after the conference awareness was heightened even further. Requests to visit the state and invitations for Oregon officials to visit other states poured in.

Oregon’s expertise was in great demand. Its success was “held in great esteem” according to Cindy Hannum, one of the Senior and Disabled Services Division managers responsible for responding to information requests. “We were doing consulting for the entire nation,” she recalls.



---

## Section 4

### Epilogue

Much has happened to the long-term-care system in Oregon since the 1990s. Budget realities have forced cutbacks in programs, and some in the senior community would assert that much of the “vision” behind the system has been lost or changed, something that could be expected with the exit of many of the original senior advocates, state officials and lawmakers.

Though one responder to the Senior Forums questionnaire lamented that “if we could bring Dick Ladd back for a day, he would probably blow a gasket at the way things have deteriorated,” another points out that many states still have not adopted the alternative-care approach that Oregon pioneered. Elderly, low-income Oregonians have more choices than the majority of their counterparts in the rest of the country, who are still forced into nursing homes as soon as they need even a small amount of help in daily living.

#### Recent additions

All of the components of the Oregon long-term-care system described in earlier sections of this document, such as pre-admission screening, use of an assessment tool and extensive community-based services, still operate in the state, though their policies and the extent of their services may have changed.

To help people navigate all their options, the state recently established a new online information system known as the Aging and Disability Resource Connection (ADRC).

This allows seniors, their families and caregivers to use the internet to learn about the range of choices that exist in support services and living situations. It connects the users to local community resources that can help them evaluate and obtain different options. The system benefits all seniors in the state, not only those on Medicaid.

A new advocacy group was formed in 2007 that brings together seniors, labor, businesses and other concerned Oregonians. Known as the Campaign for Seniors and

People with Disabilities, its aim is to preserve the parts of the Oregon system that have proven to be effective, strengthen the entire system and help ensure high-quality care for seniors. Formation of the group was the result of legislators telling key advocate groups that it was “hard to listen to so many advocates” and important messages may not be heard because of so many voices.

## Results Attained Under the New System

The changes made to Oregon’s long-term-care system have had a dramatic impact on where Medicaid seniors live and receive services. Far fewer are in nursing homes; many more stay in their own homes or are in community-based facilities.

The chart below illustrates that shift. Even though the state’s population of people over 75 years of age has continued to increase, there has been a steady, significant decrease in the number of Medicaid seniors in nursing homes.

<b>Year</b>	<b>Oregon’s Age 75 + Population</b>	<b>Medicaid Seniors in Nursing Homes</b> (monthly average)	<b>Medicaid Seniors at Home or In Community-Based Care</b> (monthly average)
1979	116,689	8,080	6,160
1986	144,873	7,590 <sup>1</sup>	9,734
2012	247,133 <sup>2</sup>	2,950	15,940

<sup>1</sup> This is estimated to be 24 % below the level projected if Oregon had not obtained its Medicaid waiver.

<sup>2</sup> 2011 figure

One of the most frequently asked questions about the Oregon system is how much money it saves state government. Unfortunately, that is a difficult question to answer accurately.

The primary reason is that constructing a formula would require knowing how long individuals will stay in a certain type of care facility, something that can’t be



accurately predicted. A number of other variables, such as whether people in community-living facilities end up in hospital emergency rooms more often than nursing-home residents, also cannot be predicted.

However, by looking at the cost of each type of long-term care, it is evident that the shift away from nursing homes would naturally bring significant savings: Oregon's average cost-per-case in a nursing home in 2012 was \$5,534 per month, in community-based care it was \$1,655 and for people living in their homes, \$1,258.

In its presentation to the 2013 Legislature, the Oregon Department of Human Services included another approach to quantifying its savings. DHS looked at Medicaid long-term-care expenditures in Connecticut, a state with similar demographics that has not accomplished a significant shift away from nursing homes.

The Connecticut model had 57 percent of Medicaid recipients in nursing homes, with 43 percent in home- and community-based settings. In Oregon's current system only 16 percent of Medicaid clients are in nursing homes, with 84 percent in non-nursing-home living situations.

DHS found that if Oregon's pattern of nursing-home usage followed Connecticut's, the state would spend \$2.58 billion a biennium instead of its actual budget of \$1.504 billion. (These figures include both seniors and people with disabilities.)

Oregon also enjoys other benefits beyond direct cost savings: its system allows the state to stretch the dollars it has and serve many more senior citizens in the kind of living arrangements that they favor.

Another advantage of the community-based system is seen when private-paying seniors use less-expensive alternative facilities and services rather than nursing homes. This prevents them from "spending down" their resources as quickly and then having to go onto Medicaid.

## **Duplicating Oregon's System**

Can other states replicate the Oregon system? Unfortunately, that is doubtful. Even in Oregon, if the same system had to be implemented now, it is not at all certain the efforts would be successful.

In 1992 Dick Ladd was lured to Texas to build an Oregon-type system there, as well as integrate all human services. After two years he walked away without making a great deal of headway. Even his commitment and powerful style couldn't overcome the entrenched systems and strong special interests that refused to change. Despite that, Oregon's experience and the research conducted around community-based care can provide guidance for those wishing to redesign their senior services.

In December 2006, under contract from the Centers for Medicare and Medicaid Services (CMS), Thomson Medstat published the "Technical Assistance Guide to Assessing a State Long-Term-Care System." Its intent was to provide states with a tool for analyzing their effectiveness in achieving a balanced long-term-care system.

Several key components were identified by researchers as important in realigning a long-term-care system. It's interesting to note how closely these 2006 findings line up with the changes that Oregon began putting in place nearly 25 years earlier.

- ◆ **Consolidated state agencies** – a single agency for both institutional and community services that coordinates policies and budgets;
- ◆ **Single access points** – a clearly identifiable organization that manages access to a wide variety of community-based alternatives, to ensure people understand the full range of available options;
- ◆ **Institution-supply controls** – mechanisms such as "Certificate of Need" requirements that enable states to limit or reduce the number of institutional beds;
- ◆ **Transition from institutions** – outreach to identify nursing-home residents who want to move and assistance with their transition to the community;
- ◆ **A continuum of residential options** – availability of support services in a range of living options, from single-family homes to integrated group settings;
- ◆ **Infrastructure development of community-based options** – recruitment and training that develops a sufficient supply of providers who have the necessary skills and knowledge;
- ◆ **Participant direction** – people who receive community-based care should have primary decision-making authority over their service providers and budget;

- ◆ **Quality management** – an effective system that measures whether the system achieves desired outcomes and identifies strategies for improvement.

The Oregon Senior Forums Board adds one very important component to the above list: establishment, in statute, of a policy that stresses choice, independence and dignity in senior services.

## **The Future**

Oregon is looking for new ways to help seniors remain as independent as possible. In 2013, DHS will be filing its “State Plan K Option” request with the federal Centers for Medicare and Medicaid Services. This new option will provide additional federal funds to support Oregon’s home and community-based care system. It will increase the availability of services and allow Oregon to explore the use of technology to support individuals in their homes.

Long-term-care systems in Oregon and other states may well see significant changes in the near future because of ongoing financial challenges and the new national health-care law. Oversight for long-term care might be folded into the new, overall health system and thereby lose the benefit of being operated by an agency that focuses specifically on senior needs. The programs themselves could shift to a managed-care approach and be turned over to for-profit corporations. Budget problems could severely restrict the number of people who are served.

*As budget cuts and other threats to community-based care arise, advocates will need to mobilize, as they did in Oregon in the 1970s, `80s and `90s, to remind the public and lawmakers of the far-reaching benefits of a system that allows services to be customized to an individual’s needs and which stresses independence, dignity and choice.*

The Oregon Senior Forums Board hopes that other locales will be able to harness the vision and leadership needed to successfully implement a new and better approach to senior services. We trust this document will prove valuable in those efforts.



---

## Section 5

### Source Documents

Interest in the Oregon system has been high since its early days, and a number of studies and articles have been produced about it. Documents consulted in the creation of this paper are:

*Caring for the Elderly: Oregon's Pioneers* George Washington University,  
November 2000.

*Consumer Directed Care and Nurse Practice Acts* Susan C. Reinhard, The Center for  
State Health Policy, Rutgers University, 2001

*A CRS Review of Ten States: Home and Community-Based Services – States Seek to  
Change the Face of Long-Term Care: Oregon* Congressional Research Service,  
October 2003

*Development of the Oregon LTC System (PowerPoint Presentation)* Richard Ladd,  
May 2002

*Final Report, Fig/Waiver Continuum of Care* Oregon Department of Human Resources,  
December 1981

*History White Paper* Senior & Disabled Services Division, Oregon Department of  
Human Resources, August 1992

*Long-Term Care In Oregon* Elizabeth A. Kutza, Ph.D., Portland State University  
Institute on Aging, 1994

*Oregon Long Term Care System Developments* Oregon Department of Human  
Resources, July 1993

*Oregon's Key to Independent Living* Susan Dietsche, 1994

*Oregon's LTC System: A Case Study By The National LTC Mentoring Program* Robert Kane, Richard Ladd, Rosalie Kane, Wendy Nielson, University of Minnesota, April 1996

*Presentation on Oregon's Long-Term-Care System* Jim McConnell, Multnomah County Aging & Disability Services, August 2002

*Promising Practices in Long Term Care Systems Reform: Oregon's Home and Community Based Services System* Diane Justice and Alexandra Heestand, U.S. Department of Health and Human Services, June 2003

*Technical Assistance Guide to Assessing a State Long-Term-Care System* Steve Eiken, Thomson Medstat, Inc., December 2006

*30 Years of HCBS: Moving Care Closer to Home* Generations: The Journal of the American Society on Aging, Spring 2012