



**Rutgers** Center for  
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*The Institute for Health, Health Care Policy and Aging Research*

**Fiscal Challenges to a Strong Home and  
Community-Based Long-Term Care System:  
Oregon's Fight to Maintain Leadership**

**Roger Auerbach**

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This document was prepared by Roger Auerbach of Auerbach Consulting, Inc., available at: rogerauerbach@yahoo.com.

Prepared for:



**Rutgers** Center for  
State Health Policy

Leslie Hendrickson



Robert L. Mollica

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Rutgers Center for State Health Policy  
55 Commercial Avenue, 3rd Floor  
New Brunswick, NJ 08901-1340  
Voice: 732-932-3105 - Fax: 732-932-0069  
Website: [www.cshp.rutgers.edu/cle](http://www.cshp.rutgers.edu/cle)

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# **Challenges to a Strong Home and Community-Based Long-Term Care System: Oregon's Fight to Maintain its Leadership**

Roger Auerbach

May 2008

## **Summary**

This paper analyzes the 2003 cuts to Oregon's Medicaid long-term care (LTC) system, the impact of those cuts on a well-developed home and community-based services (HCBS) system, how the state has responded, and lessons that could be learned from its response.

Oregon has been a leader in developing home and community-based long-term care services (HCBS) for individuals with disabilities of all ages. It began a state-funded HCBS program for older adults in 1975 and it was the first state in the country to apply for a federal Medicaid HCBS Waiver in 1981. The state has had a philosophical and programmatic commitment to delivering long-term care (LTC) services to people at home or in community settings and avoiding unnecessary institutionalization.

Oregon's HCBS program for older adults and adults with physical disabilities grew steadily throughout the 1980s and 1990s. It promoted consumer-directed in-home services, adult foster homes, specialized care facilities, and assisted living, and the number of Medicaid enrollees served in these settings increased. By the end of 2002, Oregon led the country with 59.2% of its total Medicaid LTC expenditures going to HCBS.<sup>1</sup> Although comparators are not available, Oregon was serving 83.4 % of its older adult and adults with physical disability populations with HCBS.<sup>2</sup> This percentage was certainly one of the highest, if not the highest, in the country.

## **The Budget Cuts of 2003**

Oregon encountered revenue shortfalls that began in 2001. After five (5) Special Sessions were held to balance the budget in 2002, the Legislature referred a temporary income tax rate increase ballot measure to the state's voters. The ballot measure was defeated in a January 28, 2003 Special Election.

In order for the state to balance its two-year budget for 2001-03, the Seniors and People with Disabilities Division (SPD) in the Department of Human Services was mandated to reduce LTC spending by nearly 30%.<sup>3</sup> SPD sent letters to 9,590 LTC clients, 29% of its clients, notifying them of the benefit cuts. In addition, clients who had income above the regular Medicaid financial eligibility limit and only received medical benefits because they needed LTC services (where income limits were higher) were

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<sup>1</sup> Burwell (2004)

<sup>2</sup> SPD data (2003a)

<sup>3</sup> Congressional Research Service (2003)

informed that they would also lose their medical coverage. In the end, 3,231 clients lost LTC benefits effective February 1, 2003, and another 1,643 lost benefits effective April 1, 2003.<sup>4</sup>

SPD also had to notify all licensed LTC facilities about the cut in services for clients and that state regulations required certain actions for involuntary move-out, discharge or transfer.<sup>5</sup> Hospitals, home health agencies, physicians, and health plan medical directors also received notices about upcoming service cuts for LTC clients and the potential loss of their primary and acute care benefits, and they were warned about potential emergency room utilization, delays in hospital discharge, and problems in care coordination. Physicians were warned about potential clinical deterioration of clients who would lose assistance with medication management or activities of daily living.<sup>6</sup>

### **Clients who Lost LTC Services**

Oregon developed a Survival Priority Level System (now called Service Priority Level) using a standardized statewide assessment instrument for individuals seeking LTC services well before the first cuts to its LTC system in 1991. The assessment data gave them the ability to compare individuals statewide across all program categories. Policy makers had decided that if cuts were required, they should be made based on need for services, not on income levels. Without this assessment data, reductions would more likely be made by reducing services, provider payments or the number of people served, without regard to delivering services to individuals who needed the most assistance. The 1991-93 budget had eliminated Survival Priority Level 18, but Levels 1-17 were funded until 2003.

A total of 3,231 clients in Service Priority Levels 15-17 (assessed with lowest need for services) lost their LTC services effective February 1, 2003. Although 133 were not identified as to services being received, 87%, 2,701 of those identified, appear to have been living at home, 11% lived in residential care, and 2% in nursing facilities.<sup>7</sup> Some had their need level reassessed and continued receiving services; some lost LTC Waiver services, but continued receiving Medicaid State Plan services including some limited personal care, and some were admitted to nursing facilities.

Between February 2003 and November 2006, the number of people receiving no services increased from 33% of the total to 43%.<sup>8</sup> Since such a large percentage, 87%, were identified as living at home, individuals may have continued to live at home and received LTC supports from unpaid sources. The large majority received medical coverage from Medicare and could have used that source for their sole medical coverage.

People reassessed and eligible for LTC services increased during the first two years after the initial cut, from 13% to 25% of the total, but remained about the same over

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<sup>4</sup> SPD Report (2007a)

<sup>5</sup> SPD Executive Letter (2003g)

<sup>6</sup> SPD Executive Letter (2003h)

<sup>7</sup> SPD Data (2003b)

<sup>8</sup> SPD Report (2007a)

the next two years. Additionally, there was a small percentage increase in the number who received services in nursing homes as compared to HCBS.

The number of persons who received only medical coverage decreased significantly by 603 persons over the first two years, but only decreased slightly over the next two years.<sup>9</sup> Analyzing this high-level data, it appears that these people were either reassessed and began receiving LTC services again or dropped medical coverage, possibly due to the addition of a Part D Medicare benefit.

### **Level 12-14 Clients**

There were 1,643 clients in Service Priority Levels 12-14 (see Appendix A for definitions) who lost LTC services effective April 1, 2003.<sup>10</sup> Of the clients receiving cut-off notices (2,182), 54% appeared to have been living at home, 41% were in residential care, and 5% lived in nursing facilities.<sup>11</sup>

Clients in levels 12 and 13 may only have lost benefits for three months since the Legislature restored funding for those levels as of July 1, 2003. However, between April 2003 and November 2006, the number of people receiving no services almost doubled in number from 408 to 754.<sup>12</sup> Since 54% of the total that lost LTC services were identified as living at home before the cut, they may have continued to live at home and received LTC supports from unpaid sources. The large majority received medical coverage from Medicare and could have used that source for their sole medical coverage.

The number of people reassessed and eligible for LTC services stayed about the same during the first two years after the initial cut, but decreased over the next two years. Additionally, the number of individuals reassessed and receiving nursing facility services was initially much larger than the numbers in levels 15-17, but then decreased over the four-year period.<sup>13</sup> The increase in nursing facility services could be explained by the higher assessed need levels in this group.

People who received medical coverage only decreased significantly, from 498 to 276, over the first two years and only slightly over the next two years.<sup>14</sup> Analyzing this high-level data, it appears that these people dropped medical coverage, possibly due to the enhanced Medicare benefit.

### **Impact on the LTC System**

Two commonly accepted measures of LTC success are the percentage of HCBS Medicaid expenditures compared to total LTC expenditures and the percentage of individuals served with HCBS compared with those served in institutions. In federal fiscal year 2002, the last full reported year before the 2003 cuts, Oregon spent 59.2% of

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<sup>9</sup> Ibid

<sup>10</sup> Ibid

<sup>11</sup> SPD Data (2003b)

<sup>12</sup> SPD Report (2007a)

<sup>13</sup> SPD Report (2007a)

<sup>14</sup> Ibid

its Medicaid LTC dollars on HCBS for its “aged and disabled” (Medicaid Waiver terminology) population. In federal fiscal year 2004, the first full year after the cuts, HCBS expenditures went down to 53.1%, and for the last publicly reported year, federal fiscal year 2006, they increased to 54.9%. That 54.9% had Oregon **ranked first in the country** in proportionate spending on its aged and disabled populations.<sup>15</sup>

Perhaps the more important measure is the number of Medicaid LTC enrollees who are served with HCBS compared with institutional services. These data are not generally available for comparative purposes, as states do not always track and report the number of people who receive Medicaid personal care at home and no waiver services. However, this is an important measure for states and it has been an especially important measure in Oregon Medicaid’s LTC history. Before the cuts, in December 2002, Oregon was serving 83.4% of its LTC older adults and adults with disabilities populations outside of institutions.<sup>16</sup> In July 2004, about 18 months after the first cuts, that percentage decreased to 80.5%.<sup>17</sup> In the latest available data, December 2007, that number was 80.8%.<sup>18</sup>

### **Continued Impact and Future Considerations**

Oregon has made major reductions in the number of people it serves in its Medicaid LTC system. It made those cuts based on assessed functional need for services rather than by changes in financial eligibility, but it retained the needed infrastructure to continue serving almost 81% of its enrollees in HCBS. Even though there has been reduced funding due to reduced numbers being served and workloads have increased,<sup>19</sup> the Area Agencies on Aging (AAAs) and the SPD offices continue to perform the same functions as they did before the reductions.

Inadequate staffing at the local and state levels could cause major issues for Oregon’s LTC system. Slower eligibility decisions could result in unnecessary institutionalizations. Higher case management workloads could result in slower detection of problems, which could also result in hospitalizations and institutionalizations. Fewer licensing and monitoring staff could lead to quality of care issues. In addition, smaller staffs likely result in less outreach to other community partners and the public.

### **Provider Concerns**

Budget problems not only affected the number of persons who could be served in Oregon’s LTC system, but also affected adequate payment for community-based care providers. Provider payment is a constant issue for Medicaid programs across the country and Oregon is no different in this regard. In October 2006, SPD saw an increase in the number of HCBS providers notifying the State that they wanted to gradually withdraw from Medicaid by not taking any new Medicaid enrollees.<sup>20</sup> By January 2008,

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<sup>15</sup> Burwell (2007)

<sup>16</sup> SPD Data (2003a)

<sup>17</sup> SPD Data (2004)

<sup>18</sup> SPD Data (2007b)

<sup>19</sup> Toews Interview (2008)

<sup>20</sup> SPD Paper (2008a)

45 facilities were on gradual withdrawal contracts, 31 of which were assisted living facilities, and 14 of which were residential care facilities serving clients with an Alzheimer's diagnosis. SPD warned that this lack of access meant restricted choice for consumers and increased, more expensive utilization of nursing facilities.<sup>21</sup>

In a 2008 Special Session, SPD proposed an increase of \$260 a month for all adult foster homes, residential care, and assisted living providers. This increase would narrow the gap between what providers receive from Medicaid and what they receive from the private pay market and make more community-based residential capacity available for Medicaid enrollees.<sup>22</sup> The Legislature approved the proposed HCBS provider increase beginning in July 2008.

### **Planning for the Future**

Addressing the needs of a system with fewer resources was an immediate focus, but in August 2005, the Oregon Department of Human Services (DHS) convened a Workgroup on the Future of Long-Term Care in Oregon. This Workgroup was comprised of representatives of state and local government, senior and disability advocacy organizations, and provider organizations, many of which had spent decades developing the existing LTC system.

The Workgroup issued a preliminary report in May 2006 that contained recommendations to:

- Promote healthy aging and implement evidence-based programs;
- Counsel broad and diverse groups on planning for long-term care and use sound financial tools to pay for expected care;
- Develop accessible and affordable housing, transportation, and disability-friendly communities;
- Strengthen care by friends and family,
- Strengthen information and referral systems navigation, and additional local resources;
- Develop a “tiered” approach to LTC focusing on delivering limited supports earlier to people who need them and delaying or avoiding full Medicaid services; and,
- Develop a pilot program of integrated care for persons who are eligible for both Medicare and Medicaid.<sup>23</sup>

The most recent iteration distributed by SPD includes an outline for the next draft of a Long Range Plan due for completion in July 2008. It includes interesting recommendations grouped in three areas, which could be the basis for proposed legislation for the 2009 regular session:<sup>24</sup>

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<sup>21</sup> Ibid

<sup>22</sup> Ibid

<sup>23</sup> DHS Workgroup (2006)

<sup>24</sup> SPD Paper (2008b)

1. Community Demographic Readiness: Developing strategies that will keep seniors and people with disabilities independent, healthy, and safe in their own homes and home communities, including enhanced information and assistance, caregiver support, and healthy living programs;
2. Realignment of Medicaid-Reimbursed LTC Services: Stabilizing Oregon's publicly-financed LTC system and preparing for the huge influx of new clients, which includes new institutional diversion and transition programs, focus on pre-Medicaid services, and provider rate incentives; and,
3. Protection of Vulnerable Adults: Increasing quality of care in long-term services, which includes increased licensing and regulatory staff, funding for workforce development and provider improvement, and creating an abuse registry.

## **Conclusion**

Oregon has arguably built the most successful home and community-based long-term care system in the United States. It built the needed infrastructure to support individuals outside of institutions, developing both strong community-based administrative support and strong community-based providers. It also built a standardized statewide needs assessment instrument which allowed it to better manage services across different programs and settings. That assessment system, supported by increasingly sophisticated computer software and hardware, allowed Oregon to make decisions to serve fewer in its Medicaid HCBS program based on individuals' need for services rather than their income. It also allowed all program services to continue, although serving fewer people, and its basic infrastructure to remain intact.

Today Oregon still serves over 80% of its older adults and adults with physical disabilities in home and community-based settings. Even as the state works to reinforce its administrative and provider infrastructures, it is planning additional initiatives to prepare for the long-term services and supports needs of the coming generations.

## Introduction

Oregon has been a leader in developing home and community-based long-term care services (HCBS) for individuals with disabilities of all ages. It began a state-funded HCBS program for older adults in 1975 and was the first state in the country to apply for a federal Medicaid HCBS Waiver in 1981. The state has had a philosophical and programmatic commitment to delivering services to people at home or in community settings and avoiding unnecessary institutionalization.

Oregon's HCBS program for older adults and adults with physical disabilities grew steadily throughout the 1980s and 1990s, except for a minor service reduction during the early 1990s economic downturn. It promoted consumer-directed in-home services, adult foster homes, specialized care facilities, and assisted living, and the number of Medicaid enrollees served in these settings increased. By the end of 2002, Oregon led the country with 59.2% of its Medicaid LTC expenditures going to HCBS.<sup>25</sup> Although comparators are not available, Oregon was serving 83.4 % of its older adult and adults with physical disability populations in HCBS.<sup>26</sup> This percentage was certainly one of the highest, if not the highest, in the country.

In 2003, due to major budget problems, Oregon cut the number of people it was serving in its Medicaid long-term care (LTC) program. Years before, policy makers had decided to assign "survival priority levels" to individuals qualifying for the HCBS Waiver based on the assessment of their ability to perform activities of daily living: mobility, eating, elimination, bathing, dressing, and grooming. This policy was driven by the belief that if service reductions were necessary, they should be made by level of need rather than by economic qualifications.

Recent data show that the number of people served in the waiver program and in nursing facilities has decreased over 20% since the cuts, and the number of people receiving waiver services in-home has decreased over 31%.<sup>27</sup> However, even with reductions of this magnitude, Oregon is spending 54.9% of its Medicaid LTC dollars on HCBS, it is still ranked first in the country,<sup>28</sup> and it is serving 80.8% of its nursing home level-of-care population with home and community-based waiver services.<sup>29</sup>

This paper explores the details of the 2003 cuts, the past and current impact on clients, providers, and the system as a whole, and what this may mean for the future. States continue to face the challenges of expanding populations needing long-term services and supports. The author hopes this paper will provide guidance to states with well-developed home and community-based services systems.

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<sup>25</sup> Burwell (2004)

<sup>26</sup> SPD data (2003a)

<sup>27</sup> SPD data (2007b)

<sup>28</sup> Burwell (2007)

<sup>29</sup> SPD data (2007b)

## **Background**

The State of Oregon is well known and highly regarded for its work developing home and community-based services for individuals with disabilities of all ages. For over thirty years Oregon has supported policies that enable older adults to receive long-term services at home and avoid the need for institutionalization, and for over twenty-five years it has done the same for other individuals with disabilities. Throughout this time, it has actively developed home and community-based services to give people a range of alternatives to institutional care.

There have been challenges to the expansion of home and community-based services over the years, but none more dramatic than the budget cuts of 2003, which removed over 4000 people from the Medicaid LTC system. This paper tracks the major impacts of these cuts and draws conclusions about financing challenges for well-developed state long-term care systems.

### **Developing a Home and Community-Based Care System**

#### **Early History**

In 1981, Oregon became the first state in the country to apply for a Section 1915(c) Home and Community-Based Services (HCBS) Medicaid Waiver which allows resources to be spent on community services as an alternative to nursing facility services. This is where researchers normally begin when they chronicle Oregon's long-term care (LTC) history.

Oregon's current program took shape in the 1970s. In 1975, the Oregon Legislature established and funded a program called Oregon Project Independence, which used state funds to provide services to people in their homes so they would not have to go to a nursing facility to receive needed services. Although the state-funded program has changed over the years, it still serves thousands of people who need care, are not eligible for Medicaid, and who are at risk of institutionalization.<sup>30</sup>

In 1979, Oregon received approval from the U.S. Administration on Aging and the Health Care Financing Administration (now the Centers for Medicare & Medicaid Services) to conduct a demonstration program to test the outcomes of using Medicaid funds to provide community-based services as an alternative to nursing facility services.<sup>31</sup> Both of these programs gave the state the confidence that it could provide cost-effective, community-based services to individuals to avoid their institutionalization.

During this same time period, from 1975 to 1980, senior citizen advocates were trying to create a state-level agency for senior programs. They wanted to elevate the Office of Elderly Affairs, within the Oregon Department of Human Resources (DHR), to a division status. Policy makers considered the Office and its programs too small to

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<sup>30</sup> DHS OPI Paper (2004)

<sup>31</sup> Justice (2003)

become a division and these efforts failed.<sup>32</sup> Finally in 1980, DHR did recommend a new division with the Office of Elderly Affairs, Medicaid, Title XX long-term care programs, and Title V Senior Employment programs. However, senior advocates did not like the plan and they visited Governor Victor Atiyeh, who told them they should develop their own proposal if they did not like the one produced by DHR. They accepted the challenge and drafted a paper that would become the basis for both a state policy on aging and a new Senior Services Division.<sup>33</sup>

### **Senior Services Division and the HCBS Waiver**

In 1981, economic problems were confronting Oregon and its state budget. One of the budgetary issues raised was the rapidly increasing cost of nursing facility care. The need to control spiraling costs, combined with the goals of having a higher-level state entity focused on a broader range of senior services, resulted in a new Senior Services Division. This entity dedicated to providing services to enable people to “live independently at home or with others as long as the citizen desires without requiring inappropriate or premature institutionalization” (Oregon Revised Statutes 410.020 (3)(a)). Another major part of the law stated that “it is appropriate that savings in nursing home services allocations...be reallocated to alternative care services“ (ORS 410.050 (2)).<sup>34</sup> This authority gave the new division the opportunity to create and pay for new community-based services within a total budget allocation for long-term care.

The new Senior Services Division was given the authority to administer Medicaid long-term care (LTC) funds, Title XX (Social Services) funds, Older Americans Act, and Oregon Project Independence funds.<sup>35</sup> This was the first time in any state that a single administrative unit was assigned all these responsibilities. Area Agencies on Aging located in densely populated areas of the state became the designated local entities to coordinate and administer these same programs at the local level and provide case management, and they became a “single point of entry” for federal, state and local programs.

Also in 1981, Oregon became the first state to apply for a Medicaid Home and Community-Based Services (HCBS) Waiver, as it began to focus on expanding HCBS choices for older adults. The state already had experience delivering in-home services, but there were few options available for people to live and receive care in residential housing arrangements.

### **Developing Residential Alternatives**

At least two housing with services models existed in 1981: adult foster homes and residential care facilities. The adult foster home program was very small in 1981. The homes cared for five (5) or fewer persons needing LTC services. Providers received training, were registered with the state, but received low state reimbursement.

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<sup>32</sup> Ladd (1996)

<sup>33</sup> Ladd (1996)

<sup>34</sup> Ibid

<sup>35</sup> Ibid

Residential care facilities, comparable to what other states call “board and care” homes, cared for six (6) or more individuals and were not licensed until the early 1990s.<sup>36</sup>

Senior Services Division decided that the adult foster home model was one that could be developed more quickly and it chose to promote its expansion. It assigned roughly fifteen (15) staff statewide as adult foster home developers, whose job it was to actively recruit providers, raised reimbursement levels and successfully expanded this option.<sup>37</sup> One of the reasons rapid development was important was that in 1982, the Senior Services Division began a nursing home relocation program. Soon after the program started, the Division realized that the people it was re-locating often no longer had a home or were unable to live alone. Thus, the adult foster home became an essential option.

## **Continued Development of Nursing Home Alternatives**

### **Assisted Living**

In 1987, the state began developing a nursing facility replacement model called assisted living. An assisted living facility was to be a licensed facility requiring private apartments with accessible bathrooms and kitchenettes. The emphasis was on privacy and independence for the individual while having the opportunity for social interaction with residents living there and unskilled care when needed. Assisted living was added to the Medicaid HCBS Waiver in 1990 and grew steadily throughout the next decade.

### **Residential Models**

Although adult foster homes and assisted living facilities became popular residential options for older adults, there were options developed for both older adults and adults with physical disabilities. It should be noted that the Senior Services Division became the Senior and Disabled Services Division in 1989, getting administrative authority for long-term support programs for adults with physical disabilities.

### **Specialized Living**

Facilities were developed to serve specific populations of individuals with disabilities, such as individuals with head injuries, spinal cord injuries and HIV/AIDS. These facilities are generally congregate housing arrangements with more targeted services and the opportunity for shared attendant services. Specialized living services were added to Oregon’s HCBS Waiver in 1991.<sup>38</sup>

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<sup>36</sup> Ibid

<sup>37</sup> Ladd (1996)

<sup>38</sup> Justice (2003)

## **Relative Adult Foster Homes**

This model was designed to allow relatives of a Medicaid client to become an adult foster home provider and care for that client. These services were included in the HCBS Waiver in the 1980s<sup>39</sup> and are still being utilized today.

## **Additional In-Home Models**

**The Spousal Pay Program** was designed and implemented in 1984 and used state funds to pay spouses as providers of in-home care services to prevent institutional placement. This small program provided help to persons whose were dependent in four or more activities of daily living.<sup>40</sup>

**The In-Home Live In Program** was developed for people who wanted to remain in their own homes, but needed personal care assistance on a 24-hour basis.

**The Independent Choices Program** is Oregon's consumer-directed program in which consumers receive an individualized budget based on a needs assessment and have control over hiring attendants, including spouses, and purchasing needed goods and services. This program was implemented in 2001 as a Medicaid Section 1115 Waiver demonstration.

## **LTC Trends before State Budget Cuts in 2003**

The number of people receiving long-term care (LTC) services under the Medicaid Home and Community-Based Services (HCBS) Waiver grew steadily during the late 1980s, following rapid growth in the immediate years after the Waiver's implementation. By 1990, almost 9,000 individuals were being served under the Waiver. In contrast, individuals receiving Medicaid nursing facility services declined at a slower, but steady pace.<sup>41</sup>

After the budget reduction of 1991-93, where services were eliminated for 270 Medicaid clients with the lowest impairment, individuals served by the HCBS Waiver increased dramatically during the 1990's to approximately 23,500 by the year 2000.<sup>42</sup> Medicaid enrollees served in nursing facilities continued to decline during the 1990's. An April 1998 Senior and Disabled Services Division presentation cited an almost 9 percent drop in Medicaid enrollees supported in nursing facilities since 1985 while the percentage growth in HCBS over the same period was 224 percent.<sup>43</sup>

## **The Budget Cuts of 2003**

Oregon state revenue shortfalls began again in 2001, and the Oregon Legislature began the first of its five Special Sessions of 2002 on February 8. At its final Special

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<sup>39</sup> Ibid

<sup>40</sup> Ibid

<sup>41</sup> SDSL Caseloads Chart (1997)

<sup>42</sup> Congressional Research Service (2003)

<sup>43</sup> Auerbach Presentation (1998)

Session of 2002, held September 1-18, it referred a temporary income tax rate increase ballot measure to the state's voters. The ballot measure was defeated in a January 28, 2003 Special Election.

In order for the state to balance its two-year budget for 2001-03, the Seniors and People with Disabilities (SPD) Division (renamed in 2001) was mandated to reduce its LTC spending by nearly 30%.<sup>44</sup> Three thousand, two hundred, thirty-one clients received notices that their funding for long-term care services had been cut off effective February 1, 2003.<sup>45</sup> All LTC clients receive assessments using a standardized tool, the Client Assessment/Planning System. People assessed in Service Priority Levels 15-17 (see Appendix A for definitions) were the ones who received the cut off notices. Another 1,643 received cut off notices effective April 1, 2003. These individuals were assessed in Service Priority Levels 12-14. For the next budget period, July 1, 2003-June 30, 2005, the Legislature restored services to Levels 12 and 13.

### **The Impact of the Budget Cuts**

Oregon developed a Survival Priority Level System (now called Service Priority Level) using a standardized statewide assessment instrument for individuals seeking LTC services well before the first cuts to its LTC system in 1991. The assessment data gave them the ability to compare individuals statewide across all program categories. Policy makers had decided that if cuts were required, they should be made based on need for services, not on income levels. Without this assessment data, reductions would more likely be made by reducing services, provider payments or the number of people served, without regard to delivering services to individuals who needed the most assistance. The 1991-93 budget had eliminated Survival Priority Level 18, but Levels 1-17 were funded until 2003.

#### **Impact on State and Local Government Agencies**

Seniors and People with Disabilities (SPD) staff had to develop operational protocols to cut an estimated 3,231 people from LTC services effective February 1, 2003. On January 10, it sent an Executive Letter to all Area Agency on Aging Directors, state staff, and local state staff to officially notify them that LTC services were being eliminated for clients in Survival Priority Levels 15-17 (definitions in Appendix A). It explained that certain individuals might be eligible for the limited State Plan Personal Care services for up to 20 hours a month, subject to "distinct" eligibility criteria, and that medical benefits would continue until February 28, 2003.<sup>46</sup>

Clients who had income above the financial eligibility standard had to have their financial eligibility re-determined to evaluate eligibility for different medical programs before their "case" was closed. Additionally, clients due for assessments, or those whose assessments did not reflect their current needs, had to be triaged by the local office staff, based on standards of frailty and vulnerability, to decide whether they needed to have a

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<sup>44</sup> Congressional Research Service (2003)

<sup>45</sup> SPD Report (2007a)

<sup>46</sup> SPD Executive Letter (2003c)

targeted assessment. Staffs were given guidelines to determine when to conduct such a targeted review, which included how a client would function “without a support system.”<sup>47</sup> Finally, staffs were informed about clients’ rights to a hearing and whether any services would be paid during the hearing process.

SPD distributed another Executive Letter on February 25, 2003 regarding the elimination of LTC services to individuals in Survival Priority Levels 10-14 (definitions in Appendix A) effective April 1, 2003. This change eliminated LTC services to an estimated 6,359 individuals.<sup>48</sup> The instructions to staff were similar to the earlier letter regarding functional reassessments and financial re-determinations. A total of 9,590 letters were sent to clients out of a total LTC service population of 33,393 in December 2002. This was a loss of LTC benefits for 29% of all people being served.

Two weeks later, on March 10, 2003, SPD issued another Executive Letter announcing a new transition service that was offered only to clients in Survival Priority Levels 12-14 who were losing LTC services on April 1.<sup>49</sup> These new services, called the Community Resource Development Project, were only available to clients losing services due to the budget cuts and included: teaching individual life skills, such as money management, medication management, nutrition, preventing falls, using assistive technology and public transportation; teaching and training unpaid care givers to provide personal care tasks; home modification; assistive technology; one-time set-up expenses for transition from residential care to home care; and one-time rent or security deposit. The maximum amounts authorized for rent or security deposits were \$800 and \$1200. The estimated number of clients impacted was 2,182.

On the next day, SPD sent an Executive Letter announcing that the Legislature had restored services for clients with Survival Priority Levels 10-11 and that letters were being sent to inform them that their benefits were not being eliminated on April 1. An estimated 4,177 clients’ benefits had been restored.<sup>50</sup> The Legislature also restored funding for individuals who met the requirements of Survival Priority Levels 12-13 for the budget period 2003-2005.

### **Impact on Providers**

SPD sent letters dated January 13, 2003 to all licensed LTC facilities informing them of the cut in services for clients who were in Survival Priority Levels 10-17. These letters also stated that a list of their affected clients in Levels 15-17 (the cut of February 1) was to be sent in a separate mailing. Providers were also informed of the cutoff of services to Levels 10-14 as of April 1. They were told that letters would be mailed to clients by approximately February 15, and then letters would be sent to facilities with a list of clients who would no longer receive funding.<sup>51</sup>

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<sup>47</sup> Ibid

<sup>48</sup> SPD Executive Letter (2003d)

<sup>49</sup> SPD Executive Letter (2003e)

<sup>50</sup> SPD Executive Letter (2003f)

<sup>51</sup> SPD Executive Letter (2003g)

Providers were informed that Oregon Administrative Rules required certain actions for involuntary move-out, discharge, or transfer. First, the provider was obliged to bill the resident on a private pay basis. If, according to written facility policy, payment was not made on a timely basis, a 30 day written notice could be issued. However, Medicaid clients who requested a hearing on their eligibility could still receive benefits pending a final determination. In those cases, move-out notices, discharge, or transfer notices could not be sent since the facility would still be receiving Medicaid payment. Providers were responsible for ascertaining the hearing status of each affected Medicaid resident. They were also informed that once a move-out notice had been sent, the resident had a right to a hearing, and payment for services would not continue pending the hearing on an involuntary move-out notice.<sup>52</sup>

Hospitals, home health agencies, physicians, and health plan medical directors also received notices about the budget cuts in a letter from SPD dated January 17.<sup>53</sup> They were informed about upcoming service cuts for LTC clients, those clients' potential loss of primary and acute care benefits, and the loss of primary and acute care benefits for clients who had been eligible under Medicaid's Medically Needy program and the state's General Assistance program (not examined in this paper). Hospitals and health care providers were warned about potential increases in emergency room utilization, delays in hospital discharge, and problems in care coordination that could result from lost eligibility. Physicians were warned about potential clinical deterioration of clients who would lose assistance with medication management or activities of daily living.

### **Impact on Clients**

SPD sent letters to 9,590 clients during January-February 2003 informing them that they would be losing their Medicaid LTC benefits: 3,231 starting February 1; and, 6,359 starting April 1. In addition, clients who had income above the regular Medicaid financial eligibility limit and only received medical benefits because they needed LTC services (where income limits were up to 300% of the SSI standard) were also informed that they would lose their medical coverage. They were sent letters that informed them that they would lose Medicaid medical coverage, but would still have their Medicare premium paid or both Medicare premium, deductibles and co-insurance paid. Clients were also informed that they could request a hearing if they did not agree with their service (Survival Priority) level assessment.

There were 3,321 clients in Survival Priority Levels 15-17 removed from LTC services on February 1, 2003. Although 133 were not identified as to services being received, 87% (2,701) of those identified appear to have been living at home, 11% in residential care, and 2% in nursing facilities.<sup>54</sup>

There were 2,182 clients in Survival Priority Levels 12-14 were sent a notice that they would be removed from LTC services on April 1 (an additional 4,177 in Levels 10-11 were also sent notices, but funding was restored before they lost services). Although

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<sup>52</sup> SPD Executive Letter (2003g)

<sup>53</sup> SPD Executive Letter (2003h)

<sup>54</sup> SPD data (2003b)

91 clients were not identified as to where services were being received, 54% of those appear to have been living at home, 41% in residential care, and 5% in nursing facilities.<sup>55</sup> As stated above, the Legislature provided funding for Levels 12-13 for the 2003-05 budget, so if an individual's assessed level remained the same they would have only lost benefits for three months.

### **Analysis of Clients who Lost LTC Services**

SPD was asked to produce a report on what happened to people who lost LTC services in Levels 15-17 and Levels 12-14, even though funding for Levels 12-13 was restored three months after the benefit cut. Below are highlights of its data:<sup>56</sup>

#### **Level 15-17 Clients**

Three thousand, two hundred and thirty one clients in Levels 15-17 lost their LTC services effective February 1, 2003. As of February 2003:

- 33% (1,071) not only lost their LTC benefits, but also their medical coverage because they could not qualify for "regular" Medicaid, likely because of too much income (LTC income eligibility is three times higher than standard eligibility);
- 53% (1,713) lost their LTC benefits, but were eligible for medical coverage;
- 13% were reassessed into Levels 1-13 and received both HCBS and medical coverage; and
- Less than 1% were reassessed into Levels 1-13 and received both nursing facility services and medical coverage.

By November 2004, almost two years later:

- An additional 6% (192) of the total lost both LTC and medical coverage;
- 19% (603) fewer individuals of the total were receiving medical coverage only;
- An additional 12% (390) of the total individuals were reassessed into Levels 1-13 and were receiving both HCBS and medical coverage; and
- Less than 1% of the total were reassessed into Levels 1-13 and received nursing facility services.

By November 2006, almost 4 years later:

- An additional 3% (111) of the total had lost both LTC and medical coverage, for a grand total of 43% for the period;
- 3% fewer of the total were receiving medical coverage only, for a grand total of 31% for the period;
- Less than 1% fewer were reassessed into Levels 1-13 and were receiving both HCBS and medical coverage, for a grand total of 25% for the period; and

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<sup>55</sup> Ibid

<sup>56</sup> SPD Report (2007a)

- Approximately 1% additional individuals were reassessed into Level 1-13 and received nursing facility services, for a grand total of approximately 2.5% for the period

### **Impact Analysis of Level 15-17 Clients**

Over the period reported, the number of people receiving no services increased. Since such a large percentage (87%) were identified as living at home, individuals may have continued to live at home and received LTC supports from unpaid sources such as family, friends, community organizations, and from privately paid caregivers. The large majority received medical coverage from Medicare and could have used that source for their sole medical coverage. In addition, prescription drug coverage was added to the Medicare benefit during this period.

People reassessed and eligible for LTC services increased during the first two years after the initial cut, but remained about the same over the next two years. Additionally, there was a small percentage increase in the number who received services in nursing homes as compared to HCBS.

People who received medical coverage only decreased significantly (603) over the first two years and only slightly over the next two years. Analyzing this high-level data, it appears that these people were either reassessed and began receiving LTC services again or dropped medical coverage, possibly due to the enhanced Medicare benefit.

### **Level 12-14 Clients**

One thousand, six hundred and forty three clients in Levels 12-14 lost LTC services effective April 1, 2003.

As of April 2003:

- 25% (408) not only lost their LTC benefits, but also their medical coverage because they could not qualify for “regular” Medicaid, likely because of too much income (LTC income eligibility is 3 times higher than standard eligibility);
- 30% (498) lost their LTC benefits, but were eligible for medical coverage;
- 36% were reassessed into Levels 1-13 and received both HCBS and medical coverage; and
- 9% were reassessed into Levels 1-13 and received both nursing facility services and medical coverage

By November 2004, almost two years later:

- An additional 14% (232) of the total lost both LTC and medical coverage;
- 13% (222) fewer individuals of the total were receiving medical coverage only;
- An additional 1% (20) of the individuals were reassessed into Levels 1-13 and were receiving both HCBS and medical coverage; and

- 2% fewer (30) were reassessed into Levels 1-13 and received nursing facility services;

By November 2006, almost 4 years later:

- An additional 7% (114) of the total had lost both LTC and Medical coverage, for a grand total of 46% for the period;
- Less than 1% fewer were receiving medical coverage only, for a grand total of 16% for the period;
- 4% fewer were reassessed into Levels 1-13 and were receiving both HCBS and medical coverage, for a grand total of 33% for the period; and
- 2% fewer individuals were reassessed into Level 1-13 and received nursing facility services, for a grand total of 5% for the period

### **Impact Analysis of Level 12-14 Clients**

During this period, the number of people receiving no services almost doubled in number from 408 to 754. The 54% of the total that lost LTC services were identified as living at home before the cut. Those individuals may have continued to live at home and received LTC supports from unpaid sources such as family, friends, community organizations, and from privately paid caregivers. The large majority received medical coverage from Medicare and could have used that source for their sole medical coverage. In addition, prescription drug coverage was added to the Medicare benefit during this period.

The number of people reassessed and eligible for LTC services stayed about the same during the first two years after the initial cut, but decreased over the next two years. Additionally, the number of individuals reassessed and receiving nursing facility services was initially much larger than the numbers in Levels 15-17, but then decreased over the four-year period. The increase in nursing facility services could be explained by the higher assessed need levels in this group.

People who received medical coverage only decreased significantly, from 498 to 276 over the first two years and only slightly over the next two years. Analyzing this high-level data, it appears that these people dropped medical coverage, possibly due to the enhanced Medicare benefit.

### **Impact on the LTC System**

Researchers and policy makers look at different data to measure how states are doing in developing HCBS for individuals with disabilities. Two commonly accepted measures are the percentage of Medicaid expenditures spent on HCBS compared to total LTC expenditures, and the percentage of individuals served with HCBS compared with those served in institutions.

Medicaid expenditure data is available through sources that publish data that states report to the federal Centers for Medicare & Medicaid Services (CMS). Even though there are limitations to the data and variables to consider, these data are frequently used. Since this paper analyzes the cuts to services for older adults and adults with physical disabilities, we report that expenditure data. In federal fiscal year 2002, the last fully reported year before the 2003 cuts, Oregon spent 59.2% of its Medicaid LTC dollars on HCBS for its “aged and disabled” (Medicaid waiver terminology) population. In federal fiscal year 2004, the first fully reported year after the cuts, that number goes down to 53.1% of Medicaid LTC dollars spent on HCBS. For the last reported year, federal fiscal year 2006, the number goes back up to 54.9%, which resulted in Oregon being ranked first in the country in proportionate spending on its aged and disabled populations.<sup>57</sup>

Perhaps the more important measure is the number of Medicaid LTC enrollees who are served with HCBS compared with institutional services. These data are not generally available for comparative purposes, as states do not always track and report the number of people who receive Medicaid personal care at home with no waiver services. However, even without comparators this is an important measure for states and has been an especially important measure in Oregon Medicaid’s LTC history. Before the cuts, in December 2002, Oregon was serving 83.4% of its LTC older adults and adults with disabilities populations outside of institutions. In July 2004, about 18 months after the first cuts, that percentage had decreased to 80.5%. In the latest available data, December 2007, that number was 80.8%.<sup>58</sup>

From December 2002 through December 2007, Oregon Medicaid LTC is serving:

- 5,027 (31.3%) fewer individuals receiving in-home waiver services;
- 1,260 (10.7%) fewer individuals receiving residential waiver services;
- 433 (7.8%) fewer individuals receiving nursing facility care; and
- 6,720 (20.1%) fewer total individuals receiving waiver/nursing facility services.

### **Continued Impact and Future Considerations**

Oregon has made major reductions in the number of people it serves in its Medicaid LTC system. It made those cuts based on assessed functional need for services rather than by changes in financial eligibility, but it retained the needed infrastructure to continue serving almost 81% of its enrollees in HCBS. Even though there has been reduced funding due to reduced numbers being served and workloads have increased,<sup>59</sup> the Area Agencies on Aging (AAAs) and the SPD offices continue to perform the same necessary work as they did before the reductions.

Inadequate staffing at the local and state levels could cause major issues for Oregon’s LTC system. Slower eligibility decisions could result in unnecessary institutionalizations. Higher case management workloads could result in slower detection of problems, which could also result in more hospitalizations and institutionalizations.

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<sup>57</sup> Burwell (2004, 2007)

<sup>58</sup> SPD data (2003a, 2004, 2007)

<sup>59</sup> Toews Interview (2008)

Fewer licensing and monitoring staff could lead to quality of care issues. In addition, smaller staffs likely result in less outreach to other community partners and the public.

### **Provider Concerns**

Budget problems not only affected the number of people who could be served in Oregon's LTC system, but also affected adequate payment for community-based care providers. Provider payment is a constant issue for Medicaid programs across the country and Oregon is no different in this regard. Issues of reasonable reimbursement and payments based on assessed service need were issues before the 2003 cuts and became even bigger issues after the cuts. According to SPD, adult foster homes and residential care facility rates had increased 5.7% from January 2002 to January 2008, and there was an 11.6% rate increase for assisted living facilities during that time. Nursing facility rates, with the help of a provider tax, had increased over 73%.<sup>60</sup>

In October 2006, SPD saw an increase in the number of HCBS providers who notified the state that they wanted to gradually withdraw from Medicaid by not taking any new Medicaid enrollees.<sup>61</sup> By January 2008, 45 facilities were on gradual withdrawal contracts, of which 31 were assisted living facilities and 14 were residential care facilities serving clients with an Alzheimer's diagnosis. SPD projected a Medicaid HCBS two-year decrease of 15.1% in assisted living facilities and an additional decrease in adult foster home utilization due to low reimbursement. Altogether, SPD projected losing access to 700 Medicaid beds in community-based care facilities over the 2007-09 budget period. SPD warned that this lack of access meant restricted choice for consumers and increased more expensive utilization of nursing facilities.<sup>62</sup>

SPD proposed an increase of \$260 a month for adult foster homes, residential care facilities, and assisted living facilities to a 2008 Special Session. These increases would narrow the gap between what providers received from Medicaid and what they receive from the private pay market, and would make more community-based residential capacity available for Medicaid enrollees.<sup>63</sup> The Legislature approved the proposed HCBS provider increases beginning July 2008.

### **Planning for the Future**

Addressing the needs of a system with fewer resources was an immediate focus, but in August 2005, the Oregon Department of Human Services (DHS) convened a Workgroup on the Future of Long-Term Care in Oregon. This Workgroup was comprised of representatives of state and local government, senior and disability advocacy organizations, and provider organizations, many of whom had spent decades developing the existing LTC system. The DHS asked the Workgroup to answer seven questions:<sup>64</sup>

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<sup>60</sup> SPD Paper (2008a)

<sup>61</sup> SPD Paper (2008a)

<sup>62</sup> Ibid

<sup>63</sup> Ibid

<sup>64</sup> OR DHS Workgroup Report (2006)

1. What specific research or data about senior and disability population trends are needed to guide the development of the long-range plan?
2. What evidence-based practices can be taken to scale, which will promote healthy aging and prevent or mitigate the chronic conditions or diseases that frequently trigger a person's need for long-term care?
3. What broad and effective public and private sector strategies can be developed to encourage Oregonians to plan for their retirement and long-term care needs using appropriate financial and retirement tools? Examples should include LTC insurance, estate planning, reverse mortgages, living wills, choice counseling, etc.
4. What models of elder and disability-friendly communities could Oregon replicate that would keep seniors and people with disabilities healthy and safe in their home neighborhoods and communities?
5. What non-entitlement-based set of safety net services might be offered to seniors and persons with disabilities for whom a little help would delay their need for comprehensive long-term care supports?
6. With a concern that future revenues may not stretch to pay for a vastly expanded population using the current mix of service choices, what changes in the array of services should be considered? How might the concept of "bounded choice" (from the previous Governor's task force) be incorporated?
7. What cost-effective and quality-based combinations of acute and long-term care could Oregon develop to serve certain individuals with chronic conditions and diseases?

This Workgroup was not the first to address these issues. Governor Kitzhaber created a Governor's Task Force on the Future of Services to Seniors and People with Disabilities. Most of same interest groups were represented on that Task Force, except it included legislators. While many of the same ideas that were discussed in that Task Force continue to be considered today, the initial process was driven by immediate budget pressures, while the current policy focus appears to be on the results of the more recent DHS Workgroup process.

### **Preliminary Report and the Long Range Plan**

The Workgroup issued a preliminary report in May 2006, which contained many recommendations to: promote healthy aging and implement evidence-based programs; counsel broad and diverse groups on planning for long-term care and utilizing sound financial tools to pay for expected care; develop accessible and affordable housing and transportation and disability-friendly communities; strengthen care by friends and family, information and referral, systems navigation and a variety of additional local resources; develop a "tiered" approach to LTC focusing on earlier delivery of limited supports to

people who need them and delaying or avoiding full Medicaid services; and develop a pilot program of integrated care for people who are dually eligible for Medicare and Medicaid.

These recommendations and those presented by the Governor's Commission on Senior Services in November 2006, after 17 public forums across the state, continue to be discussed within the Executive and Legislative branches. The most recent iteration distributed by SPD includes an outline for the next draft of a Long Range Plan.<sup>65</sup> It includes interesting recommendations grouped in three areas:

1. Community Demographic Readiness: Developing strategies that will keep seniors and people with disabilities independent, healthy, and safe in their own homes and home communities;
2. Realignment of Medicaid-Reimbursed LTC Services: Stabilizing Oregon's publicly-financed LTC system and preparing for the huge influx of new clients
3. Protection of Vulnerable Adults: Increasing quality of care in long-term services

Recommendations in the Community Demographic Readiness area include:

- information and assistance networks to help people select services options which avoid premature spend-down of personal resources;
- access to training and back-up relief for caregivers;
- tools for post-retirement financial planning to preserve financial independence; and
- healthy living programs that focus on chronic disease management, falls prevention, diet and exercise programs.

Recommendations in the Realignment of Medicaid-Reimbursed LTC services area include:

- instituting a new rate structure which addresses acuity levels, closes the gap with private pay and rewards Medicaid participation;
- controlling institutional costs by relocating nursing home residents and re-establishing nursing facility diversion efforts;
- converting all nursing facility payments to be time-limited with periodic re-evaluation for HCBS opportunities;
- implementing a cash and counseling state plan amendment;
- redesigning the state-funded Oregon Project Independence as a pre-Medicaid program designed to avoid full Medicaid services;

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<sup>65</sup> SPD Paper (2008b)

- exploring state plan option 1915(i) for HCBS for individuals with mental illness;
- initiating new model waivers for several high-need groups such as ventilator dependent, bariatric, traumatic brain injury; and
- developing enhanced case coordination models for people with high needs for both medical and LTC needs.

Recommendations in the Protection of Vulnerable Adults area include:

- increased licensing and regulatory staff to ensure adequate, timely inspections of all facility types, as well as the capacity to monitor poor performers;
- creation of a sufficiently large and sustainable quality assurance fund to assure workforce development, training, and technical assistance for providers that chronically under-perform;
- implement legislation to create an abuse registry; and
- streamline the trusteeship statute to assure quicker intervention and external temporary management of facilities that pose an imminent risk to their residents.

The next draft of the Long Range Plan is scheduled for completion on July 1, 2008 and many pieces will likely be part of a legislative package for Oregon's 2009 legislative session.

## **Conclusion**

Oregon has arguably built the most successful home and community-based long-term care system in the United States. It built the needed infrastructure to support individuals outside of institutions, developing both strong community-based administrative support and strong community-based providers. It also built a standardized statewide needs assessment instrument which allowed it to better manage services across different programs and settings. That assessment system, supported by increasingly sophisticated computer software and hardware, allowed Oregon to make decisions to serve fewer in its Medicaid HCBS program based on individuals' need for services rather than their income. It also allowed all program services to continue, although serving fewer people, and its basic infrastructure to remain intact.

Oregon's HCBS system grew steadily until 2003 when state revenue shortfalls led to the first major cutbacks in the system. Because such a firm foundation had been built and people were receiving services according to assessed need, Oregon was able to make decisions to serve fewer people in its Medicaid HCBS program, but retain its services and its administrative infrastructure. Today it still serves over 80% of its older adults and adults with physical disabilities in home and community-based settings. Even as the state works to reinforce its administrative and provider infrastructures, it is planning additional initiatives to prepare for the long-term services and supports needs of the coming generations.

## Appendix A

### Survival (Service) Priority Levels

Priority levels include groups of impairments and levels of impairments. Individuals with the most impairments are assessed at a higher priority level. As an example, individuals at Level 1 have a much higher level of need than does a level 15 to 17.

**Level 1:** Clients need full assistance in all major activities of daily living. They need another person to provide hands-on care throughout the entire day.

**Level 2:** Clients require full assistance in mobility, eating, and cognition. The major difference with clients in Level 1 is with these individuals do not need help with elimination.

**Level 3:** Clients need full assistance in at least one of the following activities of daily living: mobility, cognition or eating.

**Level 4:** Clients need full assistance in elimination.

**Level 5:** Clients are only slightly less impaired than individuals assessed at the higher levels. At this level clients need substantial assistance with mobility and eating and require assistance with elimination.

**Level 6:** Clients require substantial assistance with mobility and eating.

**Level 7:** Clients need substantial assistance with mobility and assistance with elimination.

**Level 8:** Clients need assistance with mobility and eating and elimination.

**Level 9:** Clients need assistance with eating and elimination.

**Level 10:** Clients need substantial assistance with mobility.

**Level 11:** Clients need assistance with elimination and minimal assistance with ambulation.

**Level 12:** Individuals need assistance with eating and minimal assistance with ambulation.

**Level 13:** Individuals need assistance with elimination.

**Level 14:** Individuals need assistance with eating.

**Level 15:** Individuals need minimal assistance with ambulation.

**Level 16:** Individuals need full assistance with bathing or dressing

**Level 17:** Individuals need assistance with bathing or dressing.

This list was accessed at [www.oregon.gov/DHS/spwpd/ltc/adl.shtml](http://www.oregon.gov/DHS/spwpd/ltc/adl.shtml)

As of April 2008, LTC services are available for individuals at Level 13 and above.

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