Riding the Wave: A call to action

A Report on the Future of Long-Term Care in Oregon and Long-Range Planning for Oregon's Communities

> November 2006 Governor's Commission on Senior Services



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When we look out at the future of Oregon's population, the numbers are startling: In less than 20 years, nearly one out of every five Oregonians will be over the age of 65.

A few months ago, the members of the Governor's Commission on Senior Services went out across the state to talk with people about the aging of Oregon's population. In our conversations with people, one thing became clear: We are not prepared. While some communities have begun a dialogue on this topic and are thinking ahead, the vast majority of Oregonians and Oregon communities have not begun to plan for what is coming.

Oregon's long-term care system does not have the funding or the infrastructure to deal with the "demographic tidal wave" of boomers and seniors; our communities and local organizations do not have the capacity to meet the projected needs of the aging population; and our citizens have not done the planning they need to do for their own future.

At the same time, this crisis presents an enormous opportunity. And we can seize this opportunity to create a continuing dialogue to plan for the future, enhance our infrastructure through using our untapped human resources, make needed changes in our service array, and make smart funding choices based on what Oregon will look like in the future.

What is "the state" but a composite of its communities and citizens? The real question is not "what can 'the state' do for us," but what can we all do for us? This report presents both stark realities that must be faced, as well as opportunities and recommendations for the future, based on our conversations with Oregonians in twenty cities.

As Governor Kulongoski said when he charged the Commission on Senior Services with conducting these meetings around the state: "The time to prepare for this situation is now."

This dialogue must be a continuing dialogue. The landscape of Oregon is changing. And there are potentially challenging times ahead if we do not prepare now. But if we face the task together, and apply ourselves as Oregonians historically have done time after time, we will have a future that is even brighter than our past.

JA KA

John C. Helm, Chair Governor's Commission on Senior Services

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Executive Summary Community Forums on Long-Term Care and Long-Range Planning

Overview

In 2005, about one in every eight Oregonians was 65 years old or older. By 2030 the statistic is expected to be about one in every five, or more than 850,000 of 4.6 million Oregonians. The rising number of older adults potentially means great changes for Oregon.

In August 2005, DHS convened the Future of Long-Term Care workgroup to help identify and address the challenges for the future. The workgroup met in smaller committees that developed ideas and proposals around seven key questions on how to address the future needs of an aging Oregon.

In May and June 2006, the Governor's Commission on Senior Services held a series of community forums in partnership with DHS' Seniors and People with Disabilities and local AAAs to get feedback on the questions with the public about the aging of Oregon and what it may mean for Oregon communities. Over 500 Oregonians attended these forums through nine in-person and two video forums.

Finding

A. Responses to the SEVEN Questions:

◆ *Data* — The participants were universally impressed with data that was compiled on their communities.

♦ *Healthy Aging* — Participants overwhelmingly endorsed a focus on preventing more chronic conditions through awareness and encouragement of healthy lifestyle choices. Many proposed collecting revenues from new "sin taxes" on soda pop, video games, and candy as a way to pay for the cost of these preventive programs.

The Future of Long-Term Care workgroup ... developed ideas and proposals around SEVEN KEY QUESTIONS on how to address the future needs of an aging Oregon.

◆ *Planning for Retirement* — Participants largely agreed that individuals are not doing enough to prepare for financial and health care needs during retirement years. Long-Term Care Insurance was mentioned as a possible tool by many.

◆ *Livable Communities* — Participants engaged in rich and varied discussions about the critical needs of a healthy community that supports seniors and people with disabilities and how best to help communities plan for the future. Support was expressed for the idea of "seed money" going to support a total community effort that included major partners in designing a community's service delivery system for the future.

◆ *Preventive Services That Avoid More Costly Care* — Participants agreed that the state should bring resources to help Oregonians avoid more expensive services. Some questioned whether the money is there to invest; however, they and others argued "we can't afford not to." Oregon Project Independence was named most frequently as an existing program people saw as able to keep people from needing more expensive services.



♦ *Changes in the Array of Services* — Participants disagreed about whether transitioning to a "pyramid model" of tiered service would be of benefit to individuals. People were curious about the details of such a proposal. Many saw a new array as an important strategy for preserving some portion of Oregon's nationally touted long-term care system.

♦ *Acute and Long-Term Care* — Participants had questions about the details of pilot efforts to combine responsibility for providing acute and long-term care services in the hands of a single entity. Some said the proposal seemed logical, while others expressed caution about a for-profit company putting profit over people in the implementation.

B. Other Topics Brought Forward:

• *Planning* — Participants were generally upbeat that the state is beginning a planning process for addressing the future; they would like to see it continue and for them to have the opportunity to be involved. Many expressed concern about the timing of the process.

• *Funding* — Participants expressed concern about current funding levels for existing services and urged that existing programs remain funded. Several people expressed the need for overall tax reform within Oregon to provide stable funding for not only existing programs, but also for services that had been eliminated or reduced during the previous five years.

◆ *Partnerships* — The community forums illustrated the power of partnership in communities, and highlighted a general willingness among service providers to partner with one another. However, community demand in nearly every community has exceeded capacity.

• *Transportation* — Transportation emerged as a theme in both rural and urban communities. There appears to be a lack of adequate transportation for seniors and people with disabilities.

• *Volunteerism* — Participants at the forums urged a new focus on promoting volunteerism among boomers and seniors as a way to both maximize dollars, wisdom and experience, and to keep people engaged and vital throughout their lives. A sub-theme emerged in many communities regarding the importance of looking at the aging trend and the increasing number of seniors as an opportunity — not a problem.

• *Physical Disabilities* — Disability advocates asserted that they did not see a clear focus on people with physical disabilities in either the charge to the Future of Long-Term Care workgroup, or the demographic data put together, or the draft recommendations.

Recommendation;

Planning

 DHS should continue the long-range planning effort, reaching out more broadly.

 DHS and partners should develop and distribute a toolkit for communities to use in planning for the aging demographic.

Infrastructure

• DHS and funding partners should implement a "Livable Community Initiative."

• Community organizations should use untapped resource of boomers and seniors as volunteers.

• The governor, legislature, and DHS must ensure adequate support for family caregivers.

Category	Item	To Whom							Term		
		Gov	Leg	DHS	Cities	County	Orgs	Business	Near	Med	Long
Planning				·				·		·	
	Continue planning, reach out more broadly			x	x	x	x	x	x	x	x
	Develop and distribute toolkit for communities to use for planning			x			x		x	x	x
Infrastructure				·							
	Use untapped resource of boomers and senior volunteers						x		x	x	x
	Ensure adequate support for family caregivers			x			x		x	x	
	Implement "Livable Community" initiative			x	x	x	x	x	x	x	x
	Enhance education and outreach to help people find appropriate services			x			x		x	x	
Service Array											
	Develop and implement "new model" of investment strategy along with tiered Medicaid	x	x	x					x	x	x
	Cautiously pursue question #7	x	x	x					x	?	?
Funding											
	Identify and prepare for long-term costs of long-term care	x	x	x					x	x	x
	Fund existing services and restore services cut since 2001	x	x	x					x		

• The governor, legislature, DHS, and community partners need to enhance education and outreach services to help people find appropriate services.

"RECOMMENDATIONS" continues next page...

"RECOMMENDATIONS" continued...

Service Array

• The governor, legislature and DHS should develop and implement a "new model" investment strategy, that includes preventive strategies to keep people from needing more expensive care, and a tiered approach to Medicaid-funded acute and long-term care.

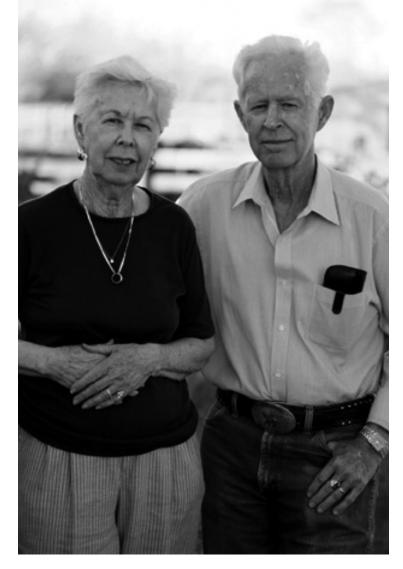
• DHS should, with the support of both the governor and the legislature, cautiously pursue the integration of acute and long-term care.



Funding

• The governor and legislature must identify and prepare for the long-term costs of long-term care.

• The governor and legislature should fund existing services and restore service cuts that have been implemented since 2001.



The Aging of Oregon A "Demographic Tidal Wave"

The number of Americans over the age of 65 is projected to nearly double within the next 25 years, growing to more than 71 million by 2030.¹ According to the best demographic projections available, Oregon is expected to closely follow this pattern.

In 2005, about one in every eight Oregonians was 65 years old or older. By 2030 the statistic is expected to be about one in every five, or more than 850,000 of an estimated 4.6 million Oregonians.²

The rising number of older adults will require Oregon and Oregon communities to take a closer look at the services available to older adults and people with physical disabilities and how those services are delivered.

For more than 25 years, Oregon has had a nationally recognized long-term care system in which older adults and people with

disabilities live primarily in community settings rather than in institutions. However, as the population ages, Oregon will face a major challenge in how it will continue to pay for this nationally recognized long-term care system. Even with a reasonable rate of growth in future revenues, the burgeoning number of seniors and people with disabilities needing long-term care could easily overwhelm Oregon's capacity to pay for needed services³ as currently structured.

The aging of Oregon will require communities and civic leaders to think about changes in zoning, housing, transportation, and economic development. Leaders must look at their community's infrastructure and ask themselves whether what they have now is sufficient for a strong quality of life in ten or twenty years if that infrastructure remains constant. If the answer is no, then they need to start thinking now about what it will take to have a high quality of life in their local area.

Workgroup on the Future of Long-Term Care Addressing the Forecast

he 2005-07 Governor's Recommended Budget directed the Department of Human Services (DHS) to begin a long-range planning process for long-term care.⁴

At the same time, the Legislative Fiscal Office noted that future legislators need to confront the challenge of sustaining Medicaid long-term care, warning that double-digit increases in General Fund spending on Seniors and People with Disabilities can be maintained "only at the expense of other state funding priorities."⁵

In August 2005, DHS created a workgroup on the future of long-term care that included experts in the field of geriatrics, health care and long-term care, leaders from state human service and consumer service agencies, and key advocates for services to seniors and people with disabilities.

The workgroup was charged with developing a plan for the future of Oregon's long-term care system that preserved "the key values of independence and choice and Oregon's noted paradigm of home and community supports."⁶

In addition, the workgroup was to address the "inevitable squeeze in future resources,"⁷ and to propose strategies for keeping Oregonians independent and healthy and to better align acute and long-term care services.

DHS asked the workgroup to answer seven key questions:

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 that will promote healthy aging and prevent or mitigate the chronic conditions or diseases that frequently trigger a person's need for long-term care?

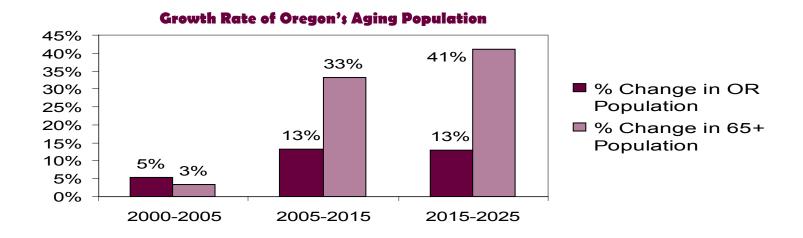
3. What broad and effective public and private sector strategies can be developed to encourage Oregonians to plan for their retirement and long-term care needs using appropriate financial and retirement tools? Examples should include LTC insurance, estate planning, reverse mortgages, living wills, choice counseling, etc. 4. What models of elder and disability-friendly communities could Oregon replicate that would help 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 people 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 care and long-term care could Oregon develop to serve certain individuals with chronic conditions and diseases?

In May 2006, the preliminary work of each group was put into a draft report – *Recommendations on the Future of Long-Term Care in Oregon* – that outlined the key discussion points and thoughts of each group. That draft, though not formally adopted by the workgroup, served as the basis for more discussion and community feedback.



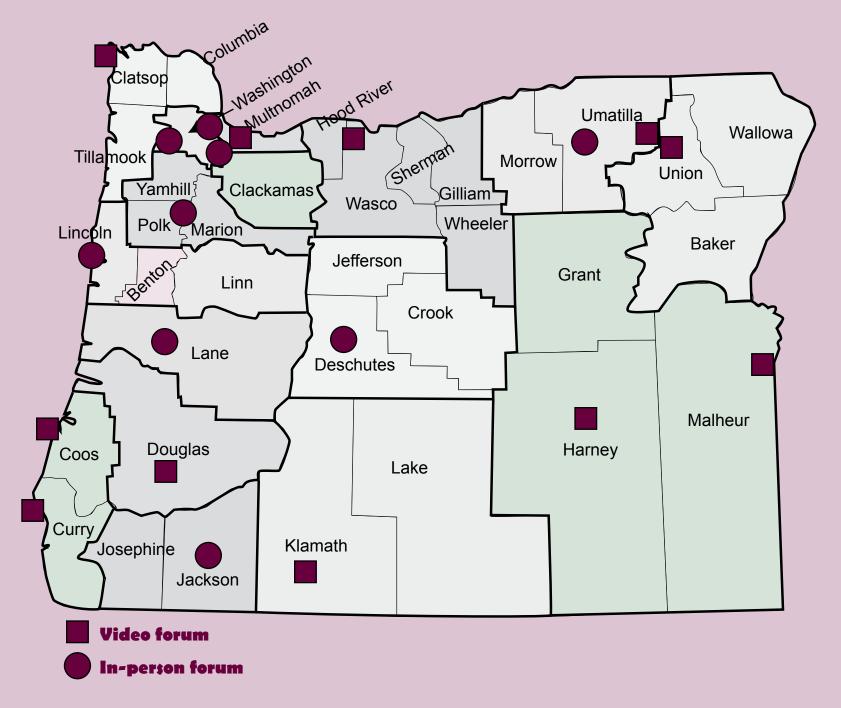
Community Forums on Long-Range Planning: **Preparing Oregonians for the Wave**

n early 2006, the Governor's Commission on Seniors Services (GCSS) held in-person and video conference meetings around the state to talk with seniors, people with disabilities, advocates, service providers, community leaders and other members of the public about the aging of Oregon's population.

Each meeting included demographics specific to each county and an overview of the efforts to date of workgroups from the Future of Long-Term Care Committee in each of seven areas. Staff compiled the questions and comments from each session to assist in the development of this report.

In all, more than 500 people participated in the community and video forums.

Community and Video Forum Locations



I. Participants' Responses to the SEVEN Questions

Question 1—Research and Data

Most participants who commented directly on this topic were impressed with the demographic data that had been compiled on Oregon and their community. However, it generated a certain amount of concern about the future in Oregon and its communities.

"Looks grim," commented one individual from Salem. Similarly, a participant in the Bend forum said, "I have a question about the numbers — I think they're even more grim."

Others found the demographic data a source of excitement: One attendee of the Portland forum found "forecasting and demographics very helpful."

Question 2—Healthy Aging

This topic received more attention and discussion than any other single question except for the general category of Elder and Disability-Friendly Communities. A Washington County Commissioner asked, "What can we do to provide more walking facilities to promote healthy aging?" Another participant in Oregon City asked, "What if we developed a matrix of assets for healthy, active aging to apply to our communities?" An attendee in Pendleton said, "We ought to re-establish a presidential [or state] fitness program."

Several communities' participants — including Portland, Pendleton and Salem – expressed support taxing soda pop to pay for programs that promote healthy living, while others wanted to go further and tax other items, including "junk food," candy and video games to help fund efforts to encourage healthy lifestyles. A speaker at the Portland forum wanted to look even more broadly than physical health into "what does it take to have people be passionate and motivated" in life.

Question 3—Planning for Retirement

Much of the discussion on this topic centered on long-term care insurance. Many agreed with the report's findings that it was vastly underused as a tool to reduce the stress on people's personal finances. Most agreed that individuals are not doing enough to plan for the future. A Pendleton participant commented that more could be done to help Oregonians plan for this stage of life. "We're asking eighth graders to plan for careers. Why not ask people to do formal thinking about what their plans are for later life?"

However, not all were convinced that long-term care insurance is a "cure-all" for people's financial and long-term care planning, noting that plans can change: "People need to be sure that their long-term care insurance is really taking care of them," said a Medford participant. Several others echoed a need for strong regulatory oversight of long-term care

insurance providers to make certain people receive the benefits they expect when they purchase it. It was also noted in several sites that many people, including people with disabilities, are unable to purchase long-term care insurance.

Question 4—Livable Communities

This issue generated more discussion than any other of the "key questions." The wide-ranging and varied comments included housing options that called for pilot projects around planned communities, *(Hillsboro)* organizing seniors into "pods" for shared housing, *(Coos Bay)* using housing codes that allow people to remain in their home as long as possible and to enable adults with physical disabilities to visit friends and family, *(Oregon City)* and even turning "McMansions" into shared housing. *(Medford)*

Transportation was also a major theme of community livability as was economic development. A Newport participant noted, "It takes a village to assist a 91-year-old mother!"

Question 5—Preventive Lower-Cost Services



Many people addressed the general idea of preventing more expensive long-term care costs. Typically, many hailed prevention and providing lower-cost supports for people as they age as wise investments: "Possibly, finally, perhaps a shift in dollars toward preventive ends. ..." *(Eugene)* "I'm excited (about) "looking to low-cost alternatives to long-term care." *(Oregon City)*

"SEVEN Questions" continues next page...

"SEVEN Questions" continued...

Oregon Project Independence (OPI) was the program most frequently seen by participants as a way to keep people out of more expensive Medicaid services: "The OPI program may be able to provide that kind of lower-cost...service for customers," a Eugene participant said. Attendees in Portland and Hillsboro expressed concerned about a lack of support for OPI. Others saw the question not as a way to lower the cost of services, but to move some current services away from public funding: "To develop partnerships with providers instead of the government trying to do everything makes a lot of sense. ..."(*Medford*)

Question 6—Changes in the Array of Services

Changes discussed for the Medicaid system generated a lot of attention — both positive as well as cautionary: "I do think the tiered approach to Medicaid is a key element..."; *(Bend)* "Are we prepared in Oregon to invest in this? We need tremendous resources to catch some people and implement this program fully. Can we afford it?" *(Hillsboro)*

Others were curious about how a "tiered Medicaid" model would be constructed, where the lines would be drawn, who would be included at what level of service, and of those who receive services now, who would be left out.

Other comments dealt with less fundamental changes, such as who would receive services, and addressed adjustments to the current methods of paying the costs of Medicaid: Is there an ability for families to supplement payment on the Medicaid side? Other states allow this — what about Oregon? *(Medford)*

Question 7—Acute and Long-Term Care

This topic was addressed by fewer individuals than any other key question, and most of the comments were negative. Concern was expressed about a single organization having influence over both long-term and acute care. Some raised questions about for-profit companies playing a role of provider or broker: "I have a concern about the corporate structure — there may be a built-in conflict of interest (between maximizing profit and helping people be well." *(Eugene)* Many others expressed concern that there be ample government oversight if such a plan were to be implemented.

Still, several people seemed to believe that the integration of acute and long-term care was a common-sense proposal, and that there was ample research and experience to start a large-scale project in Oregon: "It seems to make sense. Why is it controversial?" *(Newport)* "There's a lot we can learn from the PACE program (Programs of All-Inclusive Care for the Elderly)." *(Portland)*

II. Other Topics of Interest

Following is a list of other topics discussed most frequently by attendees:

◆ *Planning* — Participants were upbeat that the state is beginning a planning process for addressing the future. They would like it to continue and to be involved. There was concern that individuals and communities are not doing all they need to.

◆ *Funding* — Participants were concerned about current funding levels for existing services and programs. Many urged that existing programs remain funded even as new answers are being sought and tested. Several expressed the need for overall tax reform within Oregon to provide stable funding for not only existing programs, but also for services that had been eliminated or reduced during the previous five years.

◆ *Partnerships* — The community forums illustrated the power of partnership in many local communities and highlighted a general willingness among service providers to form partnerships for greater effectiveness.

• *Physical Disabilities* — At many forums, disability advocates said they did not see a clear focus on people with disabilities in the charge to the Future

of Long-Term Care workgroup, the demographic data put together, or the draft recommendations. DHS has since put together "Workgroup 8," whose charge is to gather sources of demographic data and projections about people with physical disabilities within the general population, and to review the other questions from a disability perspective.

• *Volunteerism* — Many urged a focus on promoting volunteerism among baby boomers and seniors as a way of making better use of money, wisdom and experience, and in keeping people vital throughout their lives. A sub-theme emerged regarding the importance of looking at the increasing number of seniors as an opportunity, not a problem.

• *Transportation* — This emerged as a theme in rural and urban communities. Many decried a lack of adequate transportation for seniors and people with disabilities.

• *Nursing Home Safety* — Unions representing nursing home workers and the owners and administrators of nursing homes attended several of the forums to address the issue of nursing home staffing ratios.



Recommendations

Carving out a New Landscape for Oregon Ten Recommendations for Ensuring a Quality Future for All Oregonians as Our Populations Ages

PLANNING

Recommendation #1 Continue the Long-Range Planning effort with broader outreach.

• DHS should hold additional discussions with those who attended the first round of in-person and video meetings, to share the findings of the first round, and to discuss subsequent planning efforts, including expanding the focus of these conversations to include mental health and elder abuse.

• DHS should engage in further, targeted conversations with local officials and business leaders.

Recommendation #2 Develop and distribute a toolkit for communities to use in planning for the aging demographic.

• DHS and experts from the Future of Long-Term Care workgroup should create a "toolkit" to assist local groups to work collectively in response to the broad need cited at the forums for such a resource.

• DHS should work with local service providers and local officials to distribute the toolkit to communities everywhere.

INFRASTRUCTURE

Recommendation #1

Implement a "Livable Community Initiative" in a small number of pilot communities to grow the infrastructure needed for an aging population.



• DHS should work with local elected officials, local businesses and foundations in a coalition to assist a small number of communities to use the toolkit to develop a sustainable infrastructure for an aging population.

• The coalition should pilot the initiative in at least one urban, one suburban, and one rural site.

- Areas of focus for community livability should include:
 - \Diamond Adequate transportation and access to transit services
 - \Diamond Appropriate low-income and affordable housing
 - \Diamond Caregiver supports
 - \Diamond Information and referral
 - \diamond Access to adequate health- and mental health-related services
 - Access to information and services regarding nutrition and exercise programs

Recommendation #2 Use untapped resource of boomers and seniors as volunteers.

• Community organizations should engage the tremendous experience, knowledge and skill of the boomer and senior populations.

• DHS should help communities use the resources of boomers and seniors through an effort similar in nature to the former DHS Community Partnership Team.

• Communities should develop a position of community volunteer coordinator to assist with the coordination of volunteer resources.

Recommendation #3 Ensure adequate support for family caregivers.

• Stakeholders should create a Family Caregiver Support Coalition to heighten awareness of and advocate for caregiver needs.

• Stakeholders and state leaders should advocate for more federal funding in the upcoming reauthorization of the Older Americans Act.

• DHS should continue to aggressively pursue grant opportunities to bring additional support for family caregivers.

Recommendation #4 Enhance education and outreach services to help people find appropriate services.

- DHS and state leaders should continue to invest in and encourage the use of the Network of Care.
- DHS and the AAAs should develop statewide standards for information and referral around the state.

• The governor, legislature, and DHS should provide additional support to smaller AAAs to ensure that all citizens have access to adequate information and referral resources.

SERVICE ARRAY

Recommendation #1 Develop and implement "new model" investment strategy, along with a tiered Medicaid approach.

• DHS, the governor, and legislature should re-think the traditional model of long-term care supports that forces people into poverty before services can be accessed. Preventive programs such as Oregon Project Independence that can delay the need for more costly institutional care should play a greater role in this new strategy. (See Appendix A)

• DHS should prepare a comprehensive proposal to the Centers for Medicare and Medicaid Services to move to a "tiered approach" to Medicaid, in which a graduated set of services becomes available to more Oregonians, based on income and severity of disability.

Recommendation #2

Cautiously pursue the integration of acute and long-term care.



Recommendation #2 Fund existing services and restore services cut since 2001.

• The governor should acknowledge in his 2007-09 Recommended Budget the real cuts that have been made within the past three biennia to Oregon's system of long-term care and supports, and restore as many of these services as possible, in addition to funding all existing long-term care services and supports.

• The legislature should include funding for current services as well as those services cut since 2001 in the Legislatively Adopted 2007-09 Budget, as a base from which to build back a sustainable system for the future.

♦ DHS should continue planning for a pilot program that demonstrates how acute and long-term care can be integrated for highquality, lower cost heath care. Adequate attention must be given to consumer protection in the development of the model.

• DHS should get stakeholders' review and comment before proceeding with implementation of a pilot in this area.

FUNDING

Recommendation #1 Identify and prepare for long-term costs for long-term care.

♦ State leaders must be made aware of the actual and projected costs of long-term care through at least 2011, and it should be assumed that these costs will only increase without changes to how services are made available, delivered and funded.

• The governor and legislature should work with DHS and its service providers in the next biennium to identify projected adjusted costs for the system based on implementation of the new investment model.

Acknowledgment

hank you to the many stakeholders of Oregon's long-term care system for their contributions toward meeting the challenges of the future, for their help in organizing community and video forums around the state and also for their input into what we must think about and do to ensure a healthy future for Oregon.

Also, thanks to community-based individuals and organizations who helped sponsor and promote the community forums, provided refreshments, and helped us feel welcome in every community we visited!

The Governor's Commission on Senior Services would also like to acknowledge the contribution of the leadership and staff of the Department of Human Services and the local Area Agencies on Aging for providing publicly funded services to tens of thousands of older adults each day in Oregon.

Additionally, nonprofit and for-profit service providers, senior centers, adult foster homes, hospitals, nursing facilities and assisted living facilities provide essential services on a daily basis to Oregon's older adults.



Contacts

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- Also, visit the *Future of Long-Term Care Web page* at: http://www.oregon.gov/DHS/spwpd/ltc/fltc/index.shtml

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- Also, visit the *Governor's Commission on Senior Services Web page* at: http://www.oregon.gov/DHS/spd/adv/gcss/home.shtml

2006 GCSS Report on the Future of Long-Term Care in Oregon and Long-Range Planning for Oregon's Communities

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Endnotes

¹ Your Community in Focus, May 23, 2006. DHS Seniors and People with Disabilities.

² ibid.

³ Future of Long-Term Care Web site. Oregon Department of Human Services.

⁴ Recommendations on the Future of Long-Term Care in Oregon, May 2006. DHS Seniors and People with Disabilities.

⁵ 2005-07 Budget Highlights, October 2005. Legislative Fiscal Office.

⁶ Recommendations on the Future of Long-Term Care in Oregon, May 2006. DHS Seniors and People with Disabilities.
⁷ ibid.

Governor's Commission on Senior Services

