LISTENING AND VISIONING PROJECT ON LONG-TERM CARE PHASE I & PHASE II OCTOBER 2011 - SEPTEMBER 2012



THE OREGON ASSOCIATION OF AREA AGENCIES ON AGING AND DISABILITIES THE MEYER MEMORIAL TRUST THE OREGON COMMUNITY FOUNDATION LISTENING AND VISIONING PROJECT ON LONG-TERM CARE PHASE I & PHASE II OCTOBER 2011 - SEPTEMBER 2012



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## ACKNOWLEDGEMENTS

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## INTRODUCTION

THE LISTENING AND VISIONING PROJECT FOR LONG TERM CARE (LVLTC Project) was initiated in September 2011, based on a proposal developed by the Oregon Association of Area Agencies on Aging and Disabilities (O4AD) and funded by the Meyer Memorial Trust and the Oregon Community Foundation. The ultimate purpose of this project is to develop a usable and meaningful vision and related recommendations that could help lead to a revitalized and workable long-term care system for Oregon--based on the often missing or unknown consumer voice.

It is worth emphasizing that gathering and using the consumer voice as the foundation of planning sets the LVLTC Project apart from many of the numerous and well-intentioned efforts to adapt Oregon's long-term care system to the dramatic and ongoing changes in resources, demographics, and needs. It is hoped that this information will eventually be useful to relevant private and public audiences and help refine Oregon's system to provide the best possible support to seniors, people with disabilities and their communities.

## **PROCESS**

KNOWING THAT STAKEHOLDER leadership (on a number of levels) was vital to the success in developing a vision, a group of key providers, advocates and stakeholders working in long-term care were brought together to serve as a Planning Team. It was determined that the Planning Team could be of greatest value by helping to refine the process, act as resources in the field, liaison with consumers and help develop the vision and recommendations.

Forming and organizing a Planning Team was essential to this project to help ensure that those committed to improving long-term care were well represented. At the same time, it was also clear that a wider circle was essential to generating a broad vision for the future. Because of this, it was understood that the consumer voice would guide the LVLTC Project and that other stakeholders, like providers and consumer advocates, would have the opportunity to give feedback as the vision and recommendations developed.

At the Planning Team's first meeting, participants quickly confirmed that the highest priority involved collecting the views of consumers. Perspective of providers on the front lines of service and care was also viewed as a priority. Planning Team members also knew that they would have limited time to meet and develop the vision of the future of long-term care until the 2012 Oregon Legislative Session was over. With this in mind, the Planning Team projected that their work would continue in some form past the time of the Legislative Session.

As a result, this first phase of the project has been primarily focused on developing the Planning Team and its goals and process and gathering information from consumers of long-term care.

This report is organized into two phases, including:

- Phase I Synthesis of Responses from Long-Term Care Consumers and Possible Next Steps
- Phase I Highlights of Feedback from Long-Term Care Providers & Advocates
- Phase II Guiding Principles and Recommendations

It is important to mention that the ideas presented here are qualitative and do not claim to be a statistically valid sampling. Instead this information is intended to serve as a beginning of what may be a wider sweep of consumers and providers that is attentive to geography, demographics and other often overlooked segments of the population.

## **SECTION 1**

## Phase I - Synthesis of Responses from Long-Term Care Consumers

THE LVLTC PROJECT visited five communities in different parts of Oregon (including Grants Pass, La Grande, Medford, Portland and Springfield) to hear what consumers most impacted by longterm care needs had to say about the system intended to provide support. Through facilitated focus groups (which took place between January 24 and February 3, 2012) over 40 seniors and people with disabilities (PWD) as well as some providers of long-term care offered their thoughts. Focus group participants were asked a set of questions by facilitators but were also encouraged to offer thoughts beyond the questions being posed. Please also see the visual representation created from one of the focus group meetings (page 12-14).

What follows is a synthesis of responses that have been organized into three related themes:

- Challenges to the Long-Term Care System
- Proven and Promising Practices
- A Vision of Long-Term Care

#### I. CHALLENGES TO THE LONG-TERM CARE SYSTEM

#### 1. Navigating long-term care is difficult

Participants noted that the process of navigating the long-term care system is difficult and can inhibit their ability to access appropriate care. A lack of coordination among care providers and difficulties accessing information where repeatedly mentioned as concerns. To address these challenges, the following suggestions were offered:

To address a lack of coordination:

- · Encouraging greater connection between care facilities and the local communities
- Increasing coordination between physical and mental health care is needed
- Creating umbrella community organizations staffed with people who can share information about options for care

#### To address difficulties in accessing information:

- Ensuring that information is clear and timely
- Enhancing the role of senior centers and libraries in providing information
- Information delivered in-person, through the media or in writing is better than by phone or electronically

#### **DIRECT QUOTES:**

"I never asked for help before and didn't know how. I thought that was for other people."

"Even the language is intimidating. I had to look up the word 'respite'- I didn't know what they were talking about."

#### 2. Getting good care requires supporters and advocates

Participants reported that they receive better care when they have someone who can advocate and support them as they navigate the system. For some, advocates might be members of their family and, for others, they may be caregivers. In each focus group, consumers shared the need for decision makers to become more aware about the needs of seniors and people with disabilities, especially through more direct contact. Specific suggestions on this topic included:

- Having an ombudsman in specific geographic areas that would assess needs and talk to individual consumers
- Encouraging greater effort by governmental agencies to talk with people where they live

#### **DIRECT QUOTES:**

"Many people don't know how to ask for services, they don't know the right language... they have never had to ask for help before and now find it hard."

"The health care system has too many middle men and is too heavily influenced by the pharmaceutical industry and private insurance."

#### 3. Care is getting harder to afford

The cost of care is increasingly difficult for consumers. For some this required "spending down" to become eligible for Medicaid or relying only on emergency room services. Specific suggestions to address the high cost of care included:

- Prioritizing home-based care
- Prioritizing preventative care
- Finding ways to lower costs for consumers

#### **DIRECT QUOTES:**

"I shouldn't have to spend down my assets to get coverage."

"The working poor are falling through the cracks. Those who don't qualify for services, yet can't afford to pay often use the ER for primary care."

#### 4. Access to care is a challenge

Access to care, particularly in rural areas, is increasingly difficult. Safe and reliable transportation was repeatedly mentioned as a great challenge. For PWD, finding appropriately trained caregivers was also raised as a significant challenge. Specific suggestions to address accessibility included:

- Supporting and enhancing public transportation
- Ensuring that appropriately trained professionals are available particularly in rural areas

#### **DIRECT QUOTES:**

*"It is difficult to access physicians—ones that take our health insurance are often not conveniently located."* 

*"Finding caregivers for PWD is difficult and the state's list is usually exhausted and many on the list are busy or out of the area. I use Craig's List now."* 

#### **II. PROVEN AND PROMISING PRACTICES**

While consumers of long-term care face many challenges, many participants in this listening process had experience with what works as well as ideas about what could create improvements.

#### 1. Receiving support at home

Having health care support at home makes a big difference. Support at home can come in many different forms including:

- Getting equipment needed for home care
- Participating in Meals on Wheels
- Home hospice
- The Program of All-Inclusive Care for the Elderly (PACE) has been successful

#### 2. Building community

Participants reported that reducing isolation and being connected to a community is essential to good health. While there is no substitute for having supportive family and friends, simply being with other people can help. Other ideas for encouraging community included:

- · Enhancing the role senior centers and libraries play
- Creating accessible gatherings that are both social and informative
- Creating stable housing,
- Creating neighborhood level connections in a community

#### 3. Volunteers and direct service providers

Volunteers and direct service providers are a big source of support. Participants noted the importance of a wide range of service providers (e.g., hospice care workers, hospital social workers, case-workers and law enforcement) and the important role and under-reported role of volunteers. Suggestions in this area included:

- · Enhancing both training and compensation for caregivers
- Supporting the coordination of volunteers
- Making it easier for people to find out how to volunteer and how to access volunteer support

#### **III. A VISION OF LONG-TERM CARE**

Many participants described a vision of long-term care and a type of "quality of life" that would allow them to be both self reliant and engaged and connected to others. They also spoke about system of care that was responsive to their needs and would allow them to be heard. Some specific ideas included the following:

Ideas about being self reliant and connected included:

- Living without fear
- Being of service to others
- Being loved
- Being mobile
- Being able to afford care
- Not being a burden to others
- Not being isolated or lonely
- Living with dignity and respect

Ideas about being part of a responsive system included:

- Having choices
- Being heard by decision makers
- Feeling valued by decision makers
- Having faith that the system of care is sustainable
- Focusing more on preventative care
- Receiving more support at home
- Knowing that caregivers are valued and appropriately trained
- Having greater access to appropriate care

## **SECTION 2**

## Phase I - Highlights of Feedback from Long-Term Care Providers and Advocates

THIS SECTION OF the report is intended as a brief addition to the Synthesis of Responses from of Long-Term Care Consumers. Ideas here were drawn from discussions among Planning Team members as well as individual interviews with key stakeholders. It is important to note that these ideas do not reflect the development of shared analysis or prioritization but instead represents a sampling of key thoughts that have emerged to date.

These highlights have been organized into two areas including:

- The Emerging Future: What do we need to address?
- A Vision for the Future: What could long-term care look like?

#### I. THE EMERGING FUTURE: WHAT DO WE NEED TO ADDRESS?

Participants were asked to reflect on what they know now or sense will be emerging needs related to the system of long-term care and identify specific topics that require attention. Please also see the visual representation developed at one of the Planning Team discussions (attached).

#### 1. Recognize and name our current condition

As needs grow and both government funding (e.g., entitlements) and personal saving diminish, more people are falling between the cracks or being left behind. Reduced funding and a lack of options are creating an environment where survival of the "fittest" rather than "the collective" is becoming the norm.

#### 2. Real change will be tough and requires bold thinking

It is unclear how much will exists to transform the long-term care system and whether or not people can see beyond their specific interests and habits. While change will not be easy, it will be aided by creating opportunities to truly think creatively and boldly about a redesign in a way that is exciting and compelling. Strong advocacy will also be required.

#### 3. Demographic changes require changes in our approach

Demographic and cultural shifts as well as inadequate savings for self-care are moving more people into the system. Some specific issues that are requiring more attention include:

- For baby-boomers, the importance of choice and autonomy are paramount
- There are a growing number of people with insufficient resources that will need care
- There are real gaps in consumer's ability to use technology which requires an ongoing need for "high touch" as well as "high tech"

#### II. A VISION OF THE FUTURE: WHAT COULD LONG-TERM CARE LOOK LIKE?

#### 1. Paradigm Shifts Must Occur

Fundamental change is needed. For this to happen, thinking about long-term care will need to happen in fundamentally different ways. This might include:

- Shifting from a prescriptive to person-centered accountability model
- Shifting from the notion of a "case manager to "case coach"
- Emphasizing thriving over surviving
- Exploring the potentially pivotal role of community health workers can play
- Learning from "collective cultures" from other parts of the world
- Shifting our thinking from long-term care to long-term living

- Being clear about the true cost of using federal funds that are not focused on preventative care
- Being clear about what best practices already exist, and are working
- Defining more clearly what responsibility our society and government has for consumers of long-term care
- · Being honest about the extent to which we are an age and disability-friendly society

#### 2. Encourage Personal and Community Empowerment

Families and communities must become more empowered to take care of themselves and explore what they can do on their own. This may require overcoming some cultural expectations of what families can and cannot manage. Some specific ways this can be encouraged include:

- Reframing notions of long-term care
- Providing education and training that supports home and preventative care
- Encouraging intergenerational conversations and increasing the participation of younger people in the discussion
- · Encouraging communities where people increasing look out for each other
- Advocating for preventative programs and support

#### 3. Strengthen Coordination and Connection

Connections between the long-term care community and others, starting with medical providers, needs to be strengthened for the sake of enhancing person-centered care. Ways this can be encouraged include:

- Rethinking roles and sharing resources
- Building stronger connections with the Department of Human Services
- Placing greater importance on coordination
- Building or augmenting what currently works

### **SECTION 3**

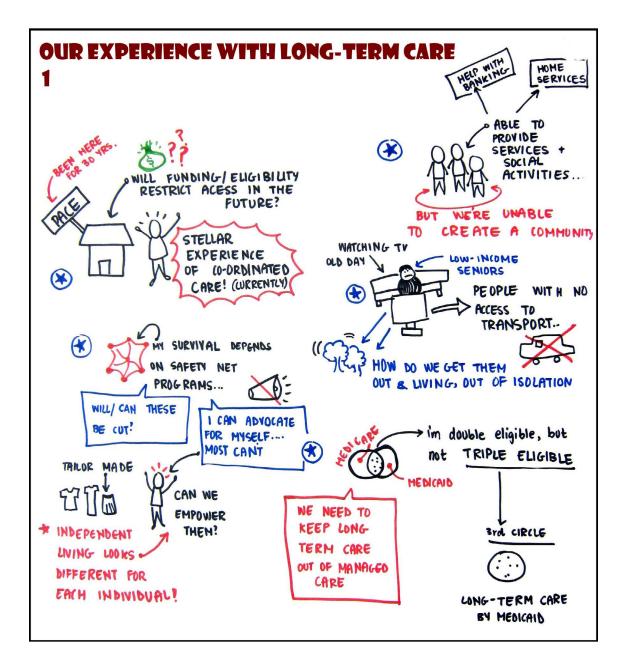
## **Phase I - Possible Next Steps**

THE ULTIMATE GOAL of the LVLTC Project is to create a usable and meaningful vision of longterm care in Oregon. To do this, the Planning Team will need to consider possible ongoing activities. Some that have been suggested in this process to date include the following:

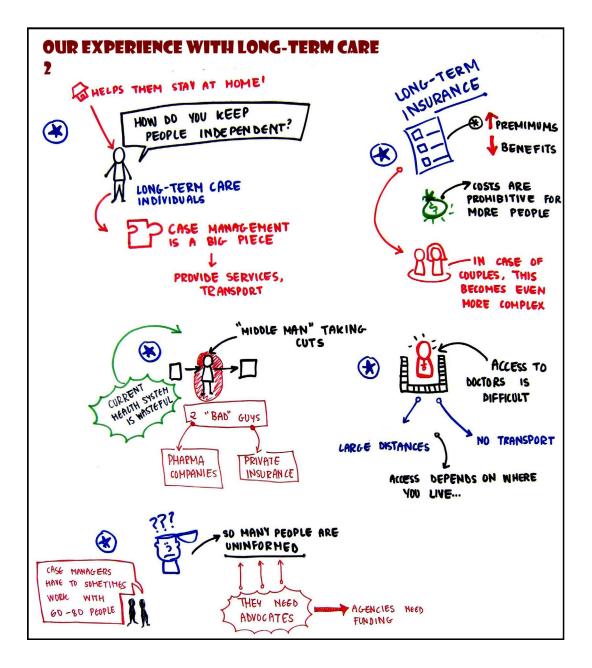
- Additional value-added activities to maximize legitimacy of the final plan
- Further refine and analyze the information collected through this process
- Explore ways to amplify consumer voice
- Engage in additional information collection from key consumers
- Review evidence based practices
- · Research and synthesize existing data that highlights consumer voice
- Conduct a survey of key providers and consumer advocates
- Develop a specific set of recommendations and next steps

## **IMAGES: Portland Consumer Focus Group**

## **OUR EXPERIENCE WITH LONG-TERM CARE 1**

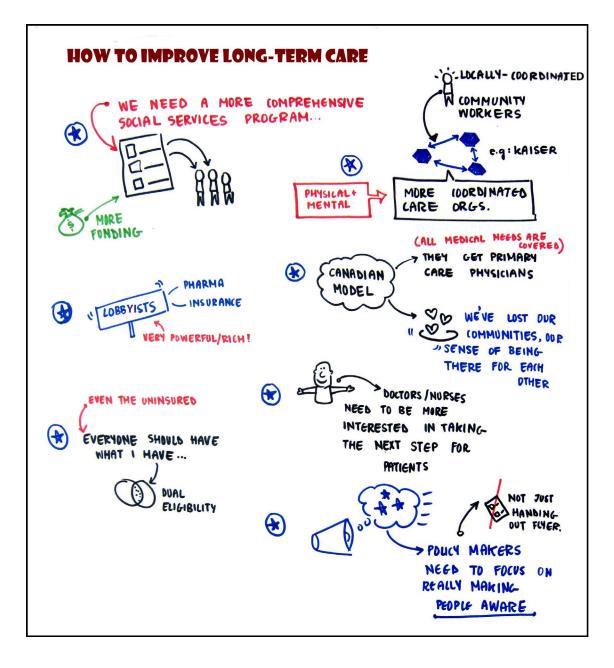


## **OUR EXPERIENCE WITH LONG-TERM CARE 2**



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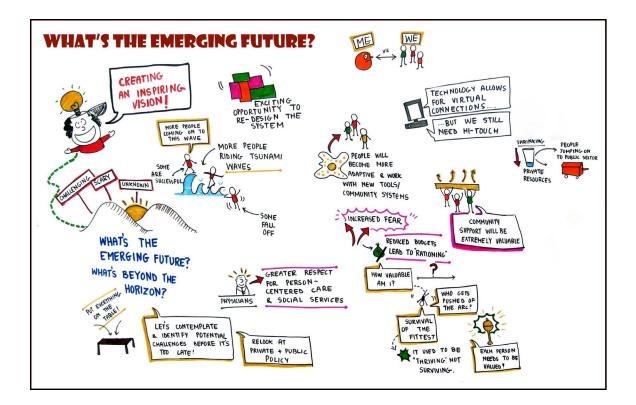
## HOW TO IMPROVE LONG-TERM CARE



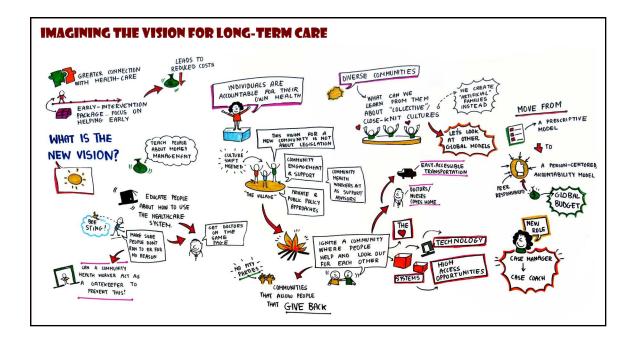
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## **IMAGES: LVLTC Project Planning Team's Visioning Session**

## WHAT'S THE EMERGING FUTURE



## **IMAGINING THE VISION FOR LONG-TERM CARE**



## **SECTION 1**

## **Phase II - Guiding Principles and Recommendations**

PHASE II OF THE LVLTC Project report, Guiding Principles and Recommendations, includes:

#### **SECTION 1**

- A. Executive Summary
- B. Project History
- C. Guiding Principles
- D. Policy Recommendations
- E. Conclusion

#### APPENDIX

• History and Impact of Oregon State Mandate 410.010

#### A. EXECUTIVE SUMMARY

This report builds upon Oregon Revised Statutes Chapter 410, enacted over 30 years ago. Chapter 410 declares the rights of seniors to live their lives with health, honor and dignity, affirms the entitlement of people with disabilities to lives of maximum freedom and independence, and establishes the right of "all persons regardless of age or any disability. . . to live their lives with dignity and to participate in society to the maximum extent possible."

It also builds upon the results of Phase I of this project: input from Oregonians who use or may need services. Their voices add a crucial and here-to-fore missing component to the on-going discussion and planning about long-term care.

This report recognizes the importance of continually measuring the services we provide against the vision of Chapter 410. We also acknowledge the rapidly changing healthcare environment and the increasing tension between available resources and the needs of our citizens. During the timeframe of this project, for example, economic changes and the forward momentum of the Affordable Care Act have significantly altered the landscape in which we are assessing how best to go forward. As we face these changes, we must not turn our backs on those among us most in need, who have no chance of thriving without support.

Below is a summary of principles and four policy recommendations related to the ultimate goal of living up to the Statute and responding to our citizen input from Phase I.

#### **Guiding Principles:**

- Do no harm.
- Preserve a person-centered and -directed approach.
- Affirm the responsibility of the state, organizations, and communities to maximize the number of citizens who have access to care, through a variety of methods.
- Maximize fairness.
- Increase the transparency and accountability of the long-term care system and its outcomes.

#### Legislative Policy Recommendations For 2013:

1. Establish a regular, explicit, mandated process to monitor areas in which Oregon is being true to the ideals of 410 and – most importantly – where the state is falling short.

2. Take advantage of the opportunities inherent in the development and mandate of the Oregon Insurance Exchange (OIE).

3. Expand and enhance family and community supports for care at home.

4. Invest in services, supports and all-age-friendly planning by communities and the private sector to lessen and prevent the need for crisis management and to promote better care and coordination between vulnerable families/caregivers and health providers.

All members of the Project Committee have endorsed these guiding principles and recommendations. More detail is provided on each in the relevant section below.

#### **B. PROJECT HISTORY**

The Listening and Visioning Project for Long Term Care (LVLTC Project) was initiated in September 2011, based on a proposal developed by the Oregon Association of Area Agencies on Aging and Disabilities (O4AD) and funded by the Meyer Memorial Trust. The goal of this project is a practical, meaningful vision for a revitalized long-term care system in Oregon – a vision based on the input of voices often missing or unknown in these discussions: our citizens currently using long term care services or those anticipating needing them in the relative near term. Collecting this information from consumers formed the heart of what became Phase I of this project. This was completed in March 2012.

The second Phase of this project focused on using the research from Phase 1 to develop guiding principles and policy recommendations. The Project Committee hopes that these principles will serve as a guide for the legislature when they are faced with the difficult choice of determining which services are most important to preserve. We also hope that the principles can be useful criteria for any group seeking to focus their decisions and resources, and help strengthen alignment among all sectors working for our citizens on the issue of long-term care. We hope these principles serve both near-term decisions and as a "guiding light" in the midst of the challenges and opportunities of health care reform and significant economic changes.

#### **C. GUIDING PRINCIPLES**

ORS Chapter 410's landmark values and principles must continue to serve as the primary standard against which we all measure our successes and shortcomings in addressing the issues of long-term care. This commitment must drive our innovation, resource allocation and decision-making. (Please see Appendix A for more on the history of 410 and on Oregon's leadership and successes in staying true to the principles of this landmark document.)

The following principles are consistent with 410 and have been developed to reflect and incorporate the feedback collected in Phase 1.

• Do no harm. Ensure that services and supports continue to provide the essentials for minimum livability that Oregonians most value.

• Preserve a person-centered and -directed approach. Provide services specific to the individual, based on his or her goals, abilities, needs, and preferences. Foster approaches guided by the values of independence, dignity, choice, and financial security for our aging citizens and people with disabilities. Recognize and value the importance of consumer direction in achieving these goals.

• Affirm the responsibility of the state, organizations, and communities to maximize the number of citizens who have access to care, through a variety of methods. Oregon and Oregonians have a shared responsibility toward all our older adults and individuals with disabilities. It is time to develop a system of care/support that encompasses more of the population than those eligible for means-tested programs; such a system will benefit our state's economic viability in this area and fulfill our obligation to more of our citizens.

• Maximize fairness. Ensure that Oregonians have the equitable, timely and culturally responsive services they need, and that they do not experience discrimination or disparity when accessing the system.

• Increase the transparency and accountability of the long-term care system and its outcomes. Accountability criteria should be evidence-based and ensure quality of care and supportive services. This will help to ensure adequate safeguards and protection for vulnerable Oregonians who utilize long-term services and supports.

#### D. LEGISLATIVE POLICY RECOMMENDATIONS FOR 2013

These recommendations are guided by the principles outlined above and offer specific policy options for the coming year, as well as for the longer-term.

## 1. Establish a regular, explicit, mandated process to monitor areas in which Oregon is being true to the ideals of 410 and – most importantly – where the state is falling short.

Accomplishing this goal could be achieved by assigning this charge to a pre-existing advocacy commission (or commissions) or an independent body, perhaps on a bi-annual basis. This recommendation does not encompass adding additional assignments or workload to the Department of Human Services.

Input from consumer advocacy groups and citizens should be an important component of the proposed

monitoring process (See Phase I Report). Existing data from outside our state may also provide affordable and valuable comparisons.

Rationale: ORS Chapter 410 is the guiding document for Oregon's comprehensive approach to long-term care. However, no regular, systematic review process exists to assess progress in adhering to the goals and values of 410 and to identify needed course corrections. A review process like the one we recommend is especially important during these times when economic and human resource pressures tempt us to act too quickly and reactively, influencing us to lose sight of what should be the highest priorities for our available resources.

#### 2. Take advantage of the opportunities inherent in the development and mandate of the Oregon Insurance Exchange (OIE).

Hawaii has used the creation of its insurance exchange to develop its approach to long-term care for elders and people with disabilities. Can Oregon follow suit?

Develop the Oregon Insurance Exchange as a medium through which buyers (individuals and small businesses) and long-term care insurance programs can find each other. The Exchange would serve as an expert go-between and connector, helping to meet the needs of different populations, and serve as a clearing-house for information and resources on long-term care insurance. A cooperative structure like this would serve as an incentive to businesses and encourage their participation. Other roles may emerge for the Exchange as this new vehicle and its potential is investigated. The exchange should develop an expertise in grouping consumers seeking like services and matching them to insurers who will be offered a new opportunity to provide services, especially with the incentive of enhanced (bundled) customer volume.

Once the initial and critical mandate for the OIE is accomplished —to meet the time-line for implementing the new medical insurance model, according to the guidelines of health care reform—it is hoped that the Exchange will be able to function in this vital, connecting role. Still to be determined is the question of how such an Exchange might be utilized in a long-term strategy for continuous improvement. Because the federal mandates of the Exchange must be fulfilled first, this recommendation is likely a longer-term strategy. Nevertheless, the possibilities are worth exploring as these early phases of developing the Exchange unfold.

Other longer-term ideas for similar innovative partnerships include: Involve the Oregon Department of Consumer and Business Services and the State Treasurer's Office, as well as appropriate business, labor, and consumer advocacy groups, in developing coordinated policies to improve resources and access to education, and incentives related to financial management and savings for retirement. (See Early Intervention and Preventative Services: Number Four, below.)

Rationale: The development of the OIE provides opportunities to increase the resources available to help citizens develop tools to plan for, and ultimately address, the availability, costs, and quality of long-term care services.

#### 3. Expand and enhance family and community supports for care at home.

Our focus groups in Phase I, along with other research data, consistently identify the ability to live at home as a crucial high level priority. Both to promote well-being and as a cost-saving measure, help people stay in whatever place they call home more effectively whenever possible, meeting their physical and emotional needs there. It is important to use our resources to foster naturally occurring retirement communities and to establish services where elders and people with disabilities already live.

Specific priorities of our Consumer Focus Groups included:

- The need for and accessibility to home care equipment
- · Improving affordability of home-based care
- Home health supports
- Meals on wheels access

The Project Committee identified the following as additional examples of support for family and volunteer caregivers. These supports would enable them to sustain themselves and their services over time, as well as maintain home care toward the end of life.

- Respite care for family caregivers
- Palliative care and hospice care

The importance of community, and the link between family and community, cannot be overstated in any discussion about keeping Oregonians longer and healthier in their preferred homes. We must provide well-rounded supports to caregivers and take steps to establish structures to reduce isolation among elders and people with disabilities.

Recognizing that an individual's "family" can include community members, and that not all biological families are available or sufficient, it is crucial to include community supports, both as compliments to family care and, where necessary, as its replacement

Our Consumer Focus Groups identified reduced isolation and community connection as essential factors for good health and for their on-going ability to live independently. Their suggestions included any public or private tools that would assist:

- Creating accessible gatherings that are both social and informative
- Using a Peer Support model
- Creating stable housing

- Creating neighborhood-level connections in a community
- Enhancing the involvement of community/adult (senior) centers and libraries

Rationale: Oregon already reaps savings from the slower growth of LTSS/HCBS (public funding) versus health care and other highly inflationary costs. Those savings are best re-invested in programs that allow the elderly and people with disabilities to stay in their homes or in home-like settings of their choice. Meeting this goal is not only more satisfying for our citizens, but the potential for cost savings is significant: if people are at "home" just six months longer, the need for public funds can be significantly reduced.

# 4. Invest in services, supports and all-age-friendly planning by communities and the private sector to lessen and prevent the need for crisis management and to promote better care and coordination be-tween vulnerable families/caregivers and health providers.

Public policy changes, including those related to employee assistance and labor policies, could support programs such as those outlined below. Further study will undoubtedly establish other effective approaches that could creatively address the intentions of this recommendation.

- Family caregiver assessments following significant problematic events, followed by options counseling, providing unbiased information through a trusted and well-trained source.
- Easy-to-access information and assistance for individuals/families with needs and questions about services for seniors and people with disabilities. When people are provided with information they need early in the process, they will be able to use their financial resources more effectively, thus postponing or eliminating the need for public assistance.

• Money management training and services that prevent financial loss due to diminished capacity, death of the knowledgeable spouse, or fraud. This could include expanding services such as those provided through the AARP Money Management Program model administered in several communities by Easter Seals of Oregon.

• Develop incentives or mandates for health care providers to coordinate prescription management in order to prevent unnecessary hospitalizations.

• Provide supports to make it easier for seniors and people with disabilities to make or attain modest home improvements that make substantial differences in their ability to stay safe and in good health and remain as independent as possible.

• Promote proactive land use and community planning, including universal home design, mobility options, and features that make communities all-age friendly.

• Promote Village models of community care based upon the Beacon Hill model of community supports.

Rationale: ORS Chapter 410 asserts the state's obligation to provide attention to the "most frail and vulnerable older citizens." Prevention and early intervention services can reduce the number of our valuable citizens that ever reach the distressing need for crisis management, the isolation it causes and the costly care associated with it.

#### E. CLOSING

The LVPLTC Team sees the work of this grant project as a foundational framework for future state planning. The principles and recommendations articulated here are based on the input of stakeholders: consumer focus groups, subject matter advocates and experts on long-term care. Any plans submitted for administrative or legislative review should be evaluated by assessing how well they conform to these principals and guidelines.

The LVPLTC Team believes that adhering to the principles and guidelines outlined in this report will result in the greatest potential for broad public and stakeholder support for additional and refined policies.

Based on this foundation, the LVPLTC Team believes that future state initiatives regarding Oregon's longterm care services and supports will enhance the State's reputation as a national leader in serving aging individuals and people with disabilities.

#### **APPENDIX A**

# History and Impact of Oregon State Mandate 410.010

OREGON IS HOME to a system of long-term care that has been held up as the model for the country. Advocates and policy makers cooperatively created this system in the 1970s and 80s. Most remarkably, the Legislature codified the shared values of Oregon's system when it adopted ORS 410.010 – 410.030 more than three decades ago.

Today, ORS 410.010 still reads like the unsurpassed foundational document for informing long-term care policy decisions. "The Legislative Assembly finds and declares that, in keeping with the traditional concept of the inherent dignity of the individual in our democratic society, the older citizens of this state are entitled to enjoy their later years in health, honor and dignity, and citizens with disabilities are entitled to live lives of maximum freedom and independence."

In achieving this noble purpose, the Legislature declared that the state shall, "Assure that health and social services be available that: (a) Allow the older citizen and citizen with a disability to live independently at home or with others as long as the citizen desires without requiring inappropriate or premature institutionalization. (b) Encourage, by expansion of existing programs for older citizens and citizens with disabilities, by school programs, by meals-on-wheels, by counseling or by other means, public and private development of nutrition programs for older citizens and citizens with disabilities that prevent or minimize illness or social isolation. (c) Assure that if institutionalization is necessary, the institution should be of the highest quality where the older citizen and citizen with a disability may live in dignity. (d) Protect the older citizen and citizen with a disability may live in dignity. (d) Protect the older citizen and citizen with a disability may live in fraudulent practices."

With ORS 410.010 as its foundation, Oregon has long been a leader in funding home and community based care as an alternative to institutional care. In the 1990s, Oregon was recognized as one of three states (the others being Washington and Wisconsin) that had already shifted care from nursing homes to the community, reducing the ratio of nursing home beds per 1,000 persons 65 years of age and older from 47 in 1982 to 36 in 1992.

This shift has continued, with Oregon having only 24 beds per 1,000 persons 65 years of age and older in 2010 compared to the national average of 42.

Oregon was recently ranked third among the 50 states and Washington, D.C., across four dimensions of long-term system and supports (LTSS) system performance:

- 1. Affordability and access
- 2. Choice of setting and provider
- 3. Quality of life and quality of care
- 4. Support for family caregivers

Oregon's other outstanding rankings include:

3<sup>rd</sup> - Percentage of Medicaid long-term care spending on home and community-based services (HCBS3) for the aged and disabled (2009)

- 2<sup>nd</sup> Number of assisted living and residential care units per 1,000 population age 65+ (2010)
- 3<sup>rd</sup> Number of adult consumers self-directing their services (2009)
- 5<sup>th</sup> Percent of adults w/ disabilities reporting they usually or always get needed supports (2009)
- $\mathbf{1}^{st}$  Access to caregiver supports
- 1<sup>st</sup> Degree to which health maintenance tasks can be delegated

When considering all that has been achieved in Oregon since the adoption of 410.010, it is important to note that these gains have been realized through the sustained hard work and vigilance of Legislators, advocates, providers, and government officials at the state and local levels. Oregon has accomplished the most elusive objective: to increase choice and enhance quality while controlling long-term costs and remaining sustainable. This report seeks to present a short status report on long-term care in Oregon and present new proposals and initiatives that will augment the already strong foundation that was built here more than three decades ago.



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