PREFACE

Specific examination of the caregiving facet of long term services and supports (LTSS) was deemed critical in responding to the mandate of SB 21, which contains the following objectives:

1) To serve seniors and persons with disabilities in their own homes and community settings of their choosing
2) To support independence and delay the entry of individuals into publicly funded long term care
3) To serve individuals equitably, in a culturally and linguistically responsive manner

PROCESS

The Caregiver (CG) Subcommittee initially convened on January 7, 2014 and held 6 subsequent meetings (for a total of 7) through June 2014. Subsequent edits to this document occurred during July 2014. Members of the CG Subcommittee and represented stakeholder organizations were comprised of:

- Anne Bellegia, Chair – Long term services and supports advocate from Southern Oregon
- Meghan Moyer and Marilyn McManus – SEIU Local 503
- Jon Bartholomew, Public Policy Director, Alzheimer’s Association, Oregon Chapter
- Dave Toler, Senior & Disability Services Director, Rogue Valley Council of Governments
- Cheryl Miller, Executive Director, Oregon Home Care Commission
- Jan Karlen, Long Term Care Policy Analyst, Oregon Department of Human Services, Aging and People with Disabilities
- Mike Volpe, Consumer Advocate, Corvallis Oregon DHS
- Tina Treasure, Executive Director, State Independent Living Council
- Roxanne McAnally, Traditional Health Worker Coordinator, Oregon Home Care Commission

In addition to the subcommittee membership listed above, Anne Bellegia and Dave Toler were able to convene a small focus group to help the CG
Subcommittee obtain a more in-depth knowledge of the practical aspects of managing the caregiver resource and to assure the subcommittee was getting broader regional representation in formulating recommendations. Membership of the focus group was comprised of:

- Don Bruland, former Director, RVCOG Senior & Disability Services
- Sarah Laughlin, OHSU nursing student conducting a needs assessment of respite for elderly and disabled people
- Rose Menge, former Administrator, Hearthstone Nursing Home and RVCOG SAC member
- Berta Varble, RVCOG Senior & Disability Services Operations Manager
- Saundra Theis, former Dean, School of Nursing, OHSU and RVCOG SAC member (consulted separately)
- Ellen Waldman, Geriatric Care Manager (consulted separately)

The majority of the CG Subcommittee meetings were spent reviewing and discussing available data from national and state sources on caregivers – paid and unpaid; workforce issues including recruitment and retention; training opportunities and capacity; technology; volunteerism; and policy. Some of the data and literature review in the form of a bibliography can be found in Appendices of this document. The following focus statement defined early in the process to help guide the CG Subcommittee’s efforts:

*Human and technological caregiver resources need to be adequate to meet current and future needs in the delivery of LTSS in Oregon with the goals of a) serving seniors and people with disabilities in the home setting they choose; b) supporting independence and delaying the entry of individuals into publicly funded LTSS; and c) serving individuals in a culturally and linguistically responsive manner.*

Recommendations were developed keeping this focus in mind and comprise a mix of options that support a prevention based approach and honor Oregon’s foundational values in long term services and supports to maintain independence, choice and dignity. OAR 410.010(1) states, “older citizens of the 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”.

The CG Subcommittee was also able to review and discuss the final draft form of the “Oregon Caregiver Training Work Group Report”, a collaborative project of the Governor’s Commission on Senior Services and the Oregon Disabilities Commission, June 2014.

The CG Subcommittee recommends the SB21 Steering Committee adopt and support the key recommendations made in the Oregon Caregiver Training Work Group Report to include:

- Develop trainings to address unmet needs
- Increase access to Oregon Home Care Commission trainings
- More aggressive promotion of existing trainings
- Expand access to trainings statewide
- Ensure unpaid caregivers are informed about caregiving and how to choose a useful training

RECOMMENDATIONS

The CG Subcommittee recommends to the SB 21 Steering Committee the following strategies supporting the key objectives of SB21:

Caregiver Support and Training

Universal (Paid and Unpaid)

- Strengthen caregiver training
  - Utilize promotion and marketing to inform and educate all types of caregivers about the ongoing development of professionalization of caregiver careers in Oregon (see Career Lattice in Appendix IV)
  - Develop Caregiver training that is culturally and linguistically appropriate being mindful of delivery method and route
  - Support stress management training for direct service workers and unpaid caregivers
SB 21 LTC 3.0 Caregiver Subcommittee
Summary and Recommendations

- Develop caregiver training and support that is accessible to all and is available at a time, place, and manner that ensures all can take advantage
- Increase awareness through aggressive promotion of caregiver training and support opportunities, including working with employers
- Continue to develop and make available caregiver training that is tailored to the individual consumer’s needs (ex: Alzheimer’s; Dementia; Mental Health and Addictions; Veterans; Post-Traumatic Stress Disorder; Traumatic Brain Injury, Intellectual/Developmental Disabilities, etc.)

- Increase access to training and supports in rural and underserved areas of Oregon
- Develop communication, promotion, and marketing needed to inform and educate all segments of LTSS caregivers in Oregon, including long distance caregivers
- With the consent of the consumer, ensure that the designated caregiver(s), both paid and unpaid, receive the necessary knowledge, training and care team involvement to address changing consumer needs during all phases of services and supports, including prior to, during and post discharge
- Create an ongoing, supported, and multi-disciplinary stakeholder group to research needs for Oregon Caregivers, both paid and unpaid. Innovative approaches should be tested and evaluated for potential improvements. Best practices for supporting caregivers should be adopted.

Unpaid Caregivers

- Expand and support unpaid caregiver training opportunities – this is inextricably linked to providing respite care so caregivers fully participate in training
- Expand, develop and implement comprehensive consumer education about the available resources that support caregiving and utilize evidence based practices
- Encourage adoption of supports earlier in the caregiving process to insure that caregivers can maintain their physical and mental health
Paid Caregivers

- Remove policy barriers to provide cross-training of caregivers when transitions (departing and hiring of new ones) occur
- Expand the Oregon Home Care Commission centralized caregiver registry/resource to maximize options for consumers
- Promote the Homecare Choice Program and other mechanisms for private pay consumers to better assure quality and affordability of and access to services and supports
- Recognize that adult day services help reduce strains on the supply of paid caregivers
- Develop caregiver assessment tools that lead to development of a support plan

Respite

- Develop a coordinated approach to meeting caregiver respite care needs across a consumer’s lifespan, including adult day services options
- Develop respite care options to be person-centered, flexible, individualized, specific and culturally appropriate
- Fund and reestablish the Oregon Lifespan Respite Program

Technology

- Identify and support use of assistive technology that can extend the caregiver capabilities and/or provide support to individuals directly that allows them to stay in their homes independently, either with or without caregiver support
- Ascertain how costs for new durable medical equipment and other technological may support prevention services and approaches
- Employ technology in extending access to caregiving training and in developing support networks for caregivers
- Develop appropriate ongoing workgroup that is charged with staying current with technology changes and make recommendations to the
State for both public and private partnerships that would foster the development and application of technology

**Volunteerism and Community Service**

- Identify and prioritize critical volunteer and community based services and activities that relieve the burden of caregivers through assistance with such tasks as shopping, gardening, pet care, meal delivery and social contact
- Identify and collaborate with local community organizations (including faith based) that can provide the needed services with their volunteers and community service providers
- Develop an organized approach to the utilization of vetted volunteers
- Review established model programs such as Long Term Care Ombudsman, Retired and Senior Volunteer Program (RSVP) and Senior Companion Program (SCP) as well as intergenerational programs to learn from and build programs that can be replicated statewide

**Policy**

- Implement policy change to conform with recent Centers for Medicare and Medicaid Services (CMS) findings that allow the ability of continued payment of caregiver services while individual is hospitalized
- Provide continued support of BRFSS to capture caregiver trend data for incidence and impact
- Develop policies that support continued development and expansion of role of traditional health workers (AKA community health workers, personal health navigators, peer support specialists, or doula’s)
- Continue to fund the Innovation Fund (IF) and ensure there is general awareness of when and how to apply. The IF is designed to fund innovative activities that improve quality and cost savings for long term services and supports, including support of caregivers and consumers
Remove policy barriers to provide cross-training of caregivers when transitions occur (departing and hiring of new ones) and between care settings

Support policy that ensures that hospitals and nursing facilities provide caregivers, at the direction of the consumer, with the necessary training to provide care prior to, during and post discharge

Future considerations

“Business as usual” seems unlikely to provide for the needs of aging and disabled Oregonian adults at an affordable cost over the next 15 years. It is therefore suggested that Oregon adopt a comprehensive and sustained initiative to consider, pilot test and evaluate creative approaches in LTSS. This should include an evaluation of key aspects of the LTSS system with a direct bearing on the caregiver resource that were not addressed as separate subcommittees in the SB 21 process, specifically:

- Existing home and community based settings; do they facilitate effective caregiving and avoid caregiver injury; how might they be improved?
- Preventative care/education: can consumers be encouraged to achieve healthy aging and avoid the development of chronic conditions through better management in order to reduce or delay the need for caregiving?
- Case management: do present case loads and case manager training contribute to the development of optimal care plans that benefit both the consumer and the caregiver?
- Healthcare providers: are they providing the consumer and his/her natural supports with realistic assessments of their health status and prognosis so that caregiving needs can be anticipated and planned for?
- Caregiver ratios: is there a way to relate the needs or status of the specific population served to the numbers/type of caregivers that can adequately address those needs?
- “Professional” navigation of the LTSS system on a sliding fee basis: would an enhanced version of options counseling for those not yet in the publicly funded LTSS system via case managers from the public LTSS system or by providing funding for utilization of private geriatric
care managers lead to better care plans that would prevent or delay entry into publicly funded care?

- Measurement of all costs: does fragmentation of how costs are measured lead to sub-optimal policy decisions from an overall state budget standpoint? For example, including:
  - Public cost for healthcare, food and other supports in assessing compensation paid to direct care workers in the publicly funded LTSS system
  - Healthcare costs of caregivers when evaluating LTSS costs
- Utilization of “big data”: would capturing key variables in the care delivered and synthesizing these with outcomes lead to better decisions and savings both for individuals and the LTSS system?
- Best practices: would a workgroup focused on mining the extensive resources that are available and on tracking/evaluating already piloted programs from around the nation and the world, streamline Oregon’s programs for caregivers?
BIBLIOGRAPHY


AARP PPI, Scan Foundation & Commonwealth Fund June 2014 LTSS Scorecard Report: [http://www.longtermscorecard.org/AARP](http://www.longtermscorecard.org/AARP)


DHS Staff informational interview on Oregon Lifespan Respite Program summary:

- Oregon Lifespan Program was developed from a model created for a pilot respite project in Klamath County in 1996.
- Stakeholders were invited to view the model and adopted it as the statewide Lifespan Respite model.
- One-point access model: A central point of contact with access to all budgets to cover respite needs for all programs at state level; recruit and train providers to meet all respite needs; to be funded GF and
rolled out over 6 years statewide. Model contained standards for training; background checks. Needs the infrastructure to implement and support.

- Dobbertin K. The health of caregivers. *Oregon Health and Science University (PPT presentation)*. April 22, 2014.
- Legislature adopted model but approved no funding. Two rounds of Federal funding opportunities since that time and Oregon chose not to apply both times.
- Oregon Lifespan Model adopted by Nebraska and then Montana – now 36 of 50 states have adopted the Lifespan Respite model so it’s national and is expanding internationally


Jeon YH, Chenoweth L, McIntosh H. Factors influencing the use and provision of respite care services for older families of people with a severe mental illness. *International Journal of Mental Health Nursing.* 2007; 16:96-107.


Lavelle B, Mancuso D, Huber A, Felver B. Expanding eligibility for the family caregiver support program in SFY 2012: updated findings. DSHS|RDA No 8.31; April 2014.


Oregon Behavior Risk Factor Surveillance System (BRFSS) data. 2012.


- Pavel M, Jimison H, Hayes T, Kaye J. Technology in support of successful aging.
- Meyer J. Designing in-vehicle technologies for older drivers.
- Marottoli R. Safe mobility for older persons.
- Czaja SJ, Sharit J. The aging of the population: Opportunities and challenges for human factors engineering.


Highlights:

- The data was pulled from the Oregon ACCESS database, which has a variety of case management support tools. The data for this analysis includes only clients with a current benefit that is in approved status in February 2014.
- The majority of the caregivers are paid (89.3%). About 10.7% of the caregivers are unpaid (Table 1 & Figure 1). [Editor’s Note: Conversely, unpaid caregivers are the dominant source of caregiving in Oregon overall. Based on estimates from 2009 (Feinberg et al), as many as 463,000 Oregonians assist with some activities of daily living at any given point in time].
- The types of support provided by caregivers can be found in Table 2. For paid caregivers, about 28.1% are In Home Care (HCW) Hourly, 11% in nursing facility, and 10.3% in assisted living facility (Figure 2). For unpaid caregiver, about 4.1% are Natural Support (unspecified), 3.6% is Natural Support –Live in, and 3.4% is Natural Support – Hourly (Figure 3).
- Among the unpaid caregivers, child (46.5%) and spouse (21.5%) provide the most support (Table 3 & Figure 4).
- Most paid caregivers can be found in Multnomah and Lane counties (Figure 5). Most unpaid caregivers can be found in Marion, Washington, and Multnomah counties (Figure 6).
Table 1. Provider Type

<table>
<thead>
<tr>
<th>Provider Type</th>
<th>Frequency</th>
<th>Percent</th>
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<td>Paid caregiver</td>
<td>35,037</td>
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<tr>
<td>Unpaid Caregiver</td>
<td>4,219</td>
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Figure 1. Caregiver Type

- **Paid caregiver:** 89.3%
- **Unpaid Caregiver:** 10.7%
Table 2. Support Type

<table>
<thead>
<tr>
<th>Support Type</th>
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<td>In Home Care (HCW) Hourly</td>
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Figure 2. Paid Caregiver

Paid Caregiver
Figure 3. Unpaid Caregiver

Table 3. Client Relationship (Natural Support)

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<th>Relationship</th>
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<tr>
<td>Child</td>
<td>1,916</td>
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<td>Spouse</td>
<td>885</td>
<td>21.5%</td>
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<td>Other Family Member</td>
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<td>Friend</td>
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<tr>
<td>Parent</td>
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<tr>
<td>Not Related</td>
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<tr>
<td>Grandchild</td>
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<tr>
<td>Neighbor</td>
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<tr>
<td>Total</td>
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Figure 4. Client Relationship
Client Relationship (Natural Support)

- Child: 46.5%
- Spouse: 21.5%
- Other Family Member: 6.6%
- Friend: 6.2%
- Sibling: 6.1%
- Parent: 5.2%
- Not Related: 4.8%
- Grandchild: 2.8%
- Neighbor: 0.04%
# Table 4. Caregiver by County

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</tbody>
</table>
WASCO  336  1.0%  10   .2%  4,489  17.9%  3,635  14.7%
WASHINGTON  2,438  7.3%  687  16.9%  54,056  10.2%  49,307  9.3%
WHEELER  8   .0%  1   .0%  406  31.5%  272  21.2%
YAMHILL  932  2.8%  250  6.1%  13,536  13.7%  12,942  13.4%

*American Community Survey 2012, 5-years estimates

Figure 5. Paid Caregiver by County

Figure 6. Unpaid Caregiver by County
Oregon: Size of Direct-Care Workforce, 2012

Total: 43,860

- Personal care aides: 15,380
- Home health aides: 4,690
- Nursing assistants: 12,570
- Independent providers*: 11,220

* Oregon Home Care Commission

Source: PHI National.org

Oregon: Occupational Growth Projections, 2010-2020

- Personal care aides: 29%
- Home health aides: 43%
- Nursing aides, orderlies, & attendants: 30%
- All Direct-care workers: 33%
- All occupations: 18%

Source: PHI National.org
Oregon: Median Hourly Wages for Direct-Care Workers, 2002 - 2012
Adjusted for Inflation (2012 dollars)

Source: PHInational.org

Oregon: Direct-Care Workers Without Health Insurance, 2009-2011
OR figures are for Pacific Division (AK, CA, HI, OR, WA)

Oregon Direct-Care Workers: 29%
U.S. Civilian Workers: 18%

Source: PHInational.org

Oregon: Direct-Care Workers Covered by Employer-Sponsored Health Insurance, 2009-2011
OR figures are for Pacific Division (AK, CA, HI, OR, WA)

Oregon Direct-Care Workers: 44%
U.S. Civilian Workers: 67%

Source: PHInational.org
Oregon: Direct-Care Worker Households Relying on Means-Tested Public Assistance, 2009-2011

- Any Public Assistance: 55%
- Medicaid: 45%
- Food and Nutrition: 33%

OR figures are for Pacific Division (AK, CA, HI, OR, WA)

Source: RHSnational.org
Appendix II

Unpaid Caregiver Supports/Volunteerism Examples

- **Store to Door**
  - Low cost grocery service
  - [http://www.storetodooroforegon.org/](http://www.storetodooroforegon.org/)

- **Meals on Wheels People**
  - Home delivered meals
  - [http://www.mealsonwheelspeople.org/](http://www.mealsonwheelspeople.org/)

- **Retired Senior Volunteer Program (RSVP)**
  - Senior volunteer activities

- **Senior Companions**
  - Seniors providing assistance and companionship for adults

- **OR Project Independence (OPI)**
  - Home care services sliding fee scale
  - [https://apps.state.or.us/Forms/Served/de1100.pdf](https://apps.state.or.us/Forms/Served/de1100.pdf)

- **Elder Helpers**
  - Free senior home assistance
  - [http://www.elderhelpers.org/index2.php](http://www.elderhelpers.org/index2.php)

- **Partnership for Prescription Assistance**
  - Prescription assistance for all age groups
  - [https://www.pparx.org/](https://www.pparx.org/)

- **Lifeline Program for low income consumers**
  - Free phone services
  - [http://www.fcc.gov/lifeline](http://www.fcc.gov/lifeline)

- **Home Energy Assistance Program ( HEAP)**
  - Help with energy costs

- **Village to Village Networks**
  - Managing aging through community volunteer organizations

- **Foster Grandparents**
  - Senior mentors serving children with exceptional needs
OREGON’S CAREGIVER RESOURCE
Southern Oregon Stakeholder Input

FUNDAMENTAL CONCEPTS

1. The relationship between the individual receiving care and the caregiver is an intimate one, and client satisfaction is largely driven by the quality of that relationship

What Strengthens the Relationship(s)
- Adequate time to address needs (caregiver ratio)
- Physical capacity of caregiver that will avoid stress and injury, maintain health
- Appropriate caregiving skills (including communication skills)
- Consistency in relationship (low turnover)
- Compensation fairness (as perceived by both parties)

2. The need for caregiving can be prevented, delayed or reduced

What Fosters Independence
- Preventive healthcare (including diet, nutrition, exercise)
- Education (e.g., fall prevention)
- Effective disease management
- Social connections
- Debility-friendly housing
- Financial stability
- Technology support (e.g., medication reminders, connectivity tools)

3. The care plan is the foundation of deploying appropriate caregiving support that avoids excess debility and increased healthcare costs and maximizes client satisfaction

What Contributes to a Good Plan
- An emphasis on an individualized, comprehensive and holistic approach
- Case manager time (sufficient number of case managers; appropriate case load)
- Case manager skills
IDEAS

1. Better Caregiving Relationships

- Increased pool of paid caregivers
  - Compensation synced to skills
  - Predictable schedule and number of hours needed to address financial needs
  - Career lattice
    - Those at bottom level must be aware of higher level jobs
    - They must perceive those jobs as desirable
    - Route to higher level jobs does not require significant out-of-pocket expense for caregiver or interruption of paid hours
- Reduction in family caregiver burnout
  - Respite care (perhaps pre-Medicaid)
  - Connection with others
- Better caregiver skills for paid caregivers
  - Relevant skill training
  - Delivered online or on-the-job with transferrable certification
  - Tied to increased compensation
- Family caregiver training
  - Must be free or affordable
  - Must be tied to respite
- Technology supports to reduce caregiver burden (lifts, medication reminders)
- Technology supports to transmit client data from caregiver to case manager
- Volunteer supports (beyond personal care)

Caveat: Move to aggregate caregiver hours across clients may make the State the co-employer, with PERS implications; consider supplanting CEP model with agency model after calculating real cost of the former (with administrative costs and PERS included)

2. Preventing/reducing need for caregivers

Areas for emphasis

- Home safety assessment that identifies needed modifications or suggests relocation
- Fall prevention education and physical training
- Nutritional support
- Chronic disease self-management
- Anticipation/planning for future
Resources

- Home safety assessment tool (one such exists in paper form and is being developed as an iPad app by Age-Friendly Innovators, an Oregon company)
- Collaboration with healthcare providers (doctors, nurses, discharge planners) to identify those at risk of losing independence to allow earlier intervention
- Volunteers (Food & Friends volunteers and others) that can be deployed for assessment and education – but only if trained and supervised by a paid volunteer coordinator
- Oregon Project Independence
- Living Well
- Food & Friends
- Technology support (state-of-the-art medication reminders, status indicators, mobility devices, connectivity tools)
- Collaborations with organizations such as AARP, YMCAs around education
- Modification of the Oregon Advance Directive to foster debility planning, i.e., provision to appoint a caregiver or care supervisor, with that person acknowledging acceptance of the role, similar to the healthcare representative

3. Better Care Plans

- Standardized assessment and reporting
  - Assessment of current needs
    - Type of needs (ADLs requiring assistance)
    - Extent of needs (hours in the day)
    - Caregiver identification (natural supports and/or paid in-home caregivers)
    - Caregiver skills required for the specific individual and his/her condition(s) (physical vs. cognitive)
    - Caregiver capacity (physical strength, health – respite as integral part of plan)
    - Appropriateness of setting preferred by the client (does it facilitate or detract from delivering the needed care)
  - Anticipation of future needs and timetable for re-assessment of status
- Reduced case manager client load
  - Utilize extenders, e.g., case associates
  - Consider using private geriatric care managers on a contract basis, perhaps for certain types of cases
  - Provide tools to increase case management efficiency – tablets with app that functions to record patient status, actions taken, etc. (envisioned like Montrue’s Sparrow emergency department app with pull down menus, voice recognition and connection to larger database, ideally allowing integration with electronic medical records and providing way to aggregate for predicting resource needs)
SB 21 LTC 3.0 Caregiver Subcommittee
Summary and Recommendations

- Development of standardized training/certification for the LTSS case manager role (grandfather existing managers) and the case aide (could be part of the career lattice)

**ACTION ITEMS**

**1. Caregiver Resource Expansion**

*Near-term recommendations*

- OFMLA – review and recommend updates to language to reflect support of caregivers
- Recommend review of ORS 410 to request adding in Oregon Lifespan Respite
- Recommend continued support of BFRSS to capture caregiver trend data for incidence and impact
- Review funding made available through SPA related to caregiver training and access and make recommendations regarding future funds
- Evaluation of support for AARP CARE Act

**Next Steps**

- Further staff exploration of demonstrated successes in other states for possible implementation in Oregon
- Demonstration projects with tracking of costs and outcomes
  - Assessment of respite alternatives – paid caregivers, stays in congregate living and/or facility settings, volunteer “sitters”, day care
  - Use of respite pre-Medicaid to evaluate delayed entry into publicly funded care
  - Deployment of volunteers (with training and supervision) to assist caregivers in providing non-personal care
  - Teaching caregivers or volunteers “comfort touch” techniques

*Items 2 and 3 – refer to Steering Committee with suggestion to assign subcommittee(s) or as part of continued LTC 3.0 beyond 2015 legislative session*
Appendix IV

Oregon Home Care Commission

Homecare and Personal Support Worker Career Lattice

Exceptional PSW

Enhanced HCW

Traditional Health Worker (THW)

Community Health Worker

Personal Health Navigator

Personal Support Worker (PSW)

Enhanced PSW

Homecare Worker (HCW)