

SB 21 Assessment Recommendations

The SB 21 Sub-committee recommends that Aging and People with Disabilities re-construct its service priority level framework to a model that better supports prevention and the maintenance and/or improving of function.

While the group suggested keeping a numerical system due to its broad familiarity, the group recommends that the current scale has room for improvement and revision. Specifically the current tool does not adequately measure differences across its 18 (13 for Medicaid) defined levels, tending to lump individuals into assessment levels 10, 7, 3, and 1. The group believes there should ideally be better stratification in any level system to more clearly distinguish needs and develop more person-centered service plans. On one side of the scale, the group found the current assessment tool does not adequately identify high need plans (too many exceptions) and on the other end, low needs plans, which may be one time interventions or preventative services are not included.

To address SB 21 goals of improving and strengthening Oregon's publicly funded long term care system, the group strongly supports DHS work within its current "level system" to redefine levels in a manner that promotes early intervention and prevention services consistent with the model framework developed by the sub-committee. See attached graphic.

The subgroup also reviewed broad recommendations for developing a new assessment tool from a previous internal workgroup. While supporting the many recommendations developed by the earlier group, the sub-committee wished to either emphasize or add the following:

- Consumer driven, person-centered, supports consumer empowerment and responsibility for consumer's own health. The model should incorporate consumer activation and education as part of the assessment process.
- Includes predictive modeling capacity supports the identification of risk and service plan focus on prevention
- Allows for testing program changes in test environment

- Allows for robust data collection, analysis and reporting at the state and local levels while providing the highest level of privacy protections
- Has internal quality checks that help avoid the entry of conflicting data and provide alerts/suggestions to workers
- Is easily modifiable and adaptable to meet changing needs over time
- Uses latest technology (features such as auto-fill, alerts, prompts and web-based, mobile devices) to minimize workload and maximize efficiency

See attached chart.

Assessment Tool Recommendation with SB 21 Assessment Sub-committee updates

1/2/14

| General Style/Approach: | Automation/Technology: | Components/Content: |
|--|---|--|
| <ul style="list-style-type: none"> • Doesn't re-ask things that don't change over time • Prompts for right questions and diagnosis at right time, good conversational flow • Intuitive to use • Prompts conversation with consumer • Simple for consumer to use and engages consumer • Easy to use and navigate • Role based access • Works to support consumer empowerment and responsibility • Consider using only 4 ADLs for consumers in facilities or make a streamlined assessment for those in facilities • Maintain highest level of security and consumer privacy protections • Always allows for exceptions • Focus on identifying risks and opportunities for preventative services | <ul style="list-style-type: none"> • Web based with Internet capability in the field, tablet with touch screen with ability to capture signatures in the field, send material to consumers • Oracle platform (<i>reconsider based on Cover OR?</i>) • Master file of information accessible to all programs that need that information (such as financial data) with modules serving individual program data needs • Connects, imports and exports to other systems, data resources (providers, medical systems, etc.) • Alerts, auto navigation to direct to other data fields as appropriate, pop-ups with relevant info • System auto sends or connects to consumers, providers, other programs and resources for referrals • System is more automated with auto-fill/auto-generation of forms related to both assessments, payments, rights, hearings, etc. as well as auto-generate and send requests when management approval is needed. Should also auto-generate from fields to narration • Auto translation • Voice recognition | <ul style="list-style-type: none"> • Includes person-centered, consumer friendly approach and be strengths based • Captures more information relevant to service planning including capturing support information when assessing each need, equipment used or needed • Reduction in data entry through eliminate of redundancies- pre-populate as many fields as possible, choose/require comments, drop downs, synopsis or narration (or check boxes if adopt them) but not all of these • Simplified navigation between elements (service planning, client details, assessment) • Simplified in-home plans / hrs. assignment, records # of hours assigned per worker, more automation of multiple caregiver plans • Best practice for cognition, dementia, traumatic brain injury, mental health, assessments- use externally validated tools and scales, train staff for use • Consider inclusion of a self-assessment component • For categorically eligible –requires only functional assessment & planning |

| | | |
|--|---|---|
| | <ul style="list-style-type: none"> • Video/picture capacity • Excellent search functionality across narratives, comments and other data fields • Has robust reporting capacity to meet program planning, development, integrity/quality assurance, transparency and predictive modeling needs at state and local levels • Has internal consistency and quality assurance checks built in so staff is unable to enter inconsistent information, or they get alerts to check • Auto generated, short summary of past service plans available at all times • Has ability to make small changes without having to re-work entire assessment or create a new one | <p>once eligibility is determined</p> <ul style="list-style-type: none"> • Exceptions continue if condition doesn't change <ul style="list-style-type: none"> ○ Look at existing data first and prompt or auto approval ○ Build in auto exceptions • Risk alerts <ul style="list-style-type: none"> ○ "Percolator" model- if an event occurs in other data systems (such as a hospital claim, an alert is generated • Provides on the spot training, guidance to workers, better help screens/tools and links to supplemental tools for example, sample questions workers can use in conversation with consumers • Provides on the spot educational tools for consumers at the time of assessment (ex. 3 minute video) • Quality Assurance functions- checks for conflicting, unusual data (ex. multiple workers with extensive hours) • Includes all necessary information to meet rule, waiver, state plan and other required elements |
|--|---|---|

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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

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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
- Sandra 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

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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

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- 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

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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

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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

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- 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

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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?

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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

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rolled out over 6 years statewide. Model contained standards for training; background checks. Needs the infrastructure to implement and support.

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- 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

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Appendix I

Aging and People with Disabilities SB 21 Paid/Unpaid Caregiver Analyses March 2014

Highlights:

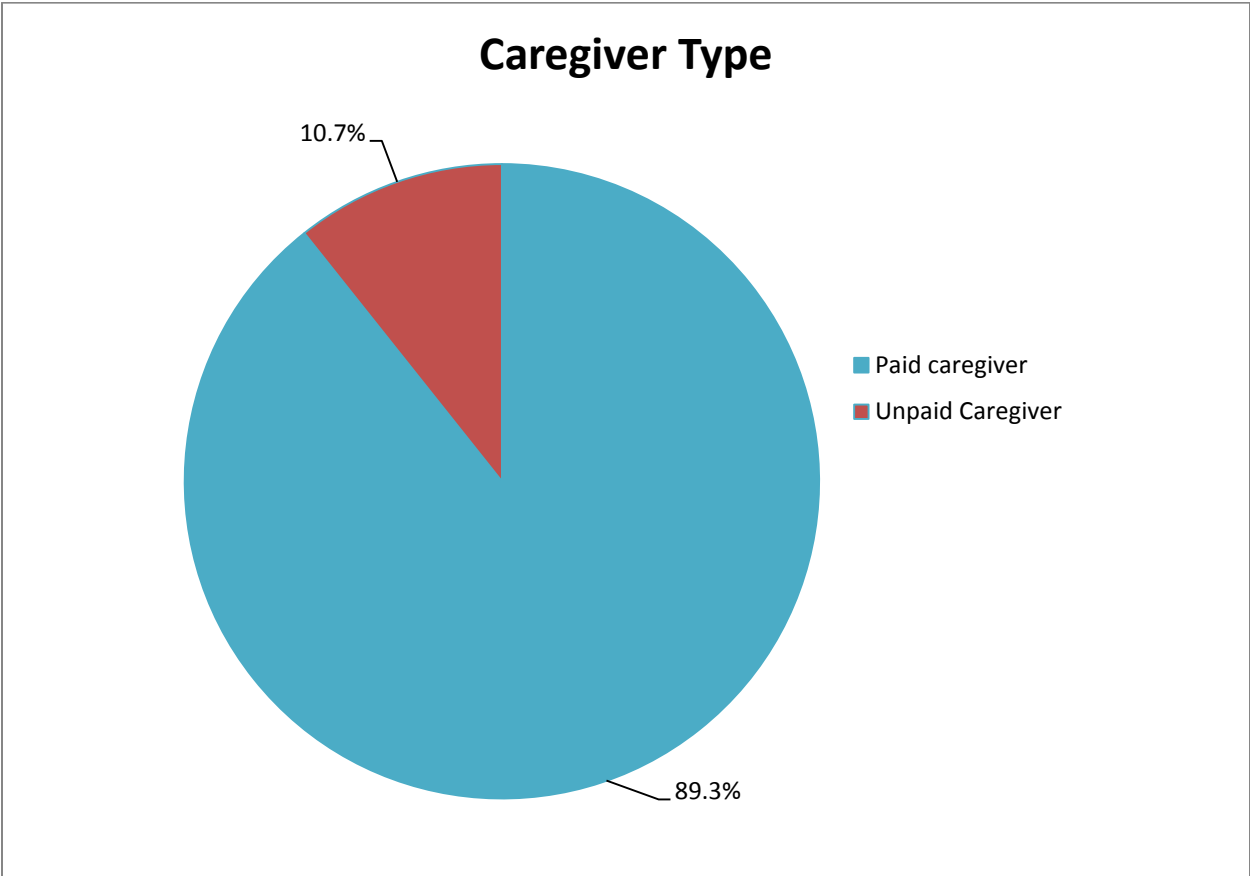
- The data was pulled from the Oregon ACCESS database, which has a variety of case management support tools. The data for this analysis includes only clients with a current benefit that is in approved status in February 2014.
- The majority of the caregivers are paid (89.3%). About 10.7% of the caregivers 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).

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Table 1. Provider Type

| Provider Type | Frequency | Percent |
|------------------|-----------|---------|
| Paid caregiver | 35,037 | 89.3% |
| Unpaid Caregiver | 4,219 | 10.7% |

Figure 1. Caregiver Type



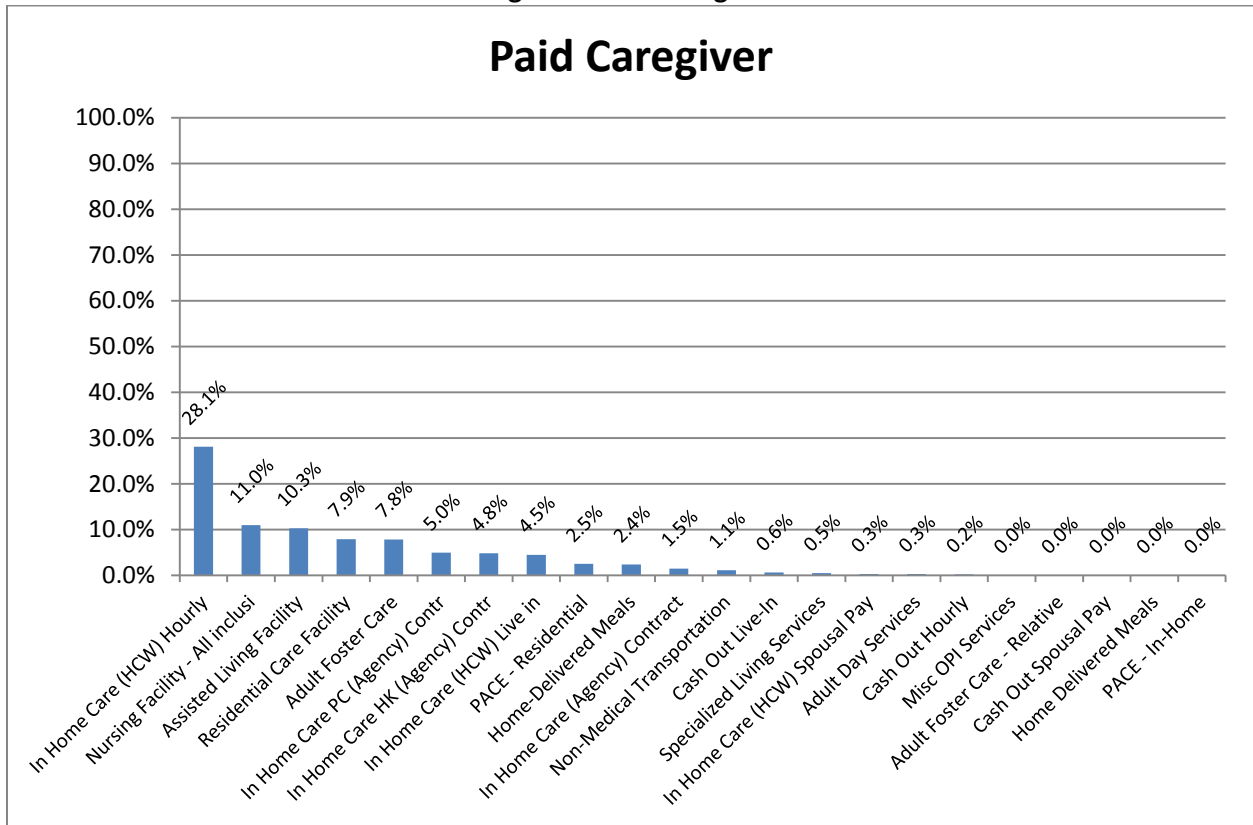
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Table 2. Support Type

| Support Type | Frequency | Percent |
|--------------------------------|-----------|---------|
| Paid Caregiver | | |
| In Home Care (HCW) Hourly | 11,030 | 28.1% |
| Nursing Facility - All inclusi | 4,330 | 11.0% |
| Assisted Living Facility | 4,062 | 10.3% |
| Residential Care Facility | 3,083 | 7.9% |
| Adult Foster Care | 3,044 | 7.8% |
| In Home Care PC (Agency) Contr | 1,945 | 5.0% |
| In Home Care HK (Agency) Contr | 1,897 | 4.8% |
| In Home Care (HCW) Live in | 1,766 | 4.5% |
| PACE - Residential | 978 | 2.5% |
| Home-Delivered Meals | 961 | 2.4% |
| In Home Care (Agency) Contract | 607 | 1.5% |
| Non-Medical Transportation | 428 | 1.1% |
| Cash Out Live-In | 224 | .6% |
| Specialized Living Services | 181 | .5% |
| In Home Care (HCW) Spousal Pay | 121 | .3% |
| Adult Day Services | 114 | .3% |
| Cash Out Hourly | 86 | .2% |
| Misc OPI Services | 11 | .0% |
| Adult Foster Care - Relative | 7 | .0% |
| Cash Out Spousal Pay | 7 | .0% |
| Home Delivered Meals | 5 | .0% |
| PACE - In-Home | 4 | .0% |
| Unpaid Caregiver | | |
| Natural Support | 1,625 | 4.1% |
| Natural Support - Live in | 1,399 | 3.6% |
| Natural Support - Hourly | 1,336 | 3.4% |
| Natural Support - Spousal Pay | 5 | .0% |

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Figure 2. Paid Caregiver



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Figure 3. Unpaid Caregiver

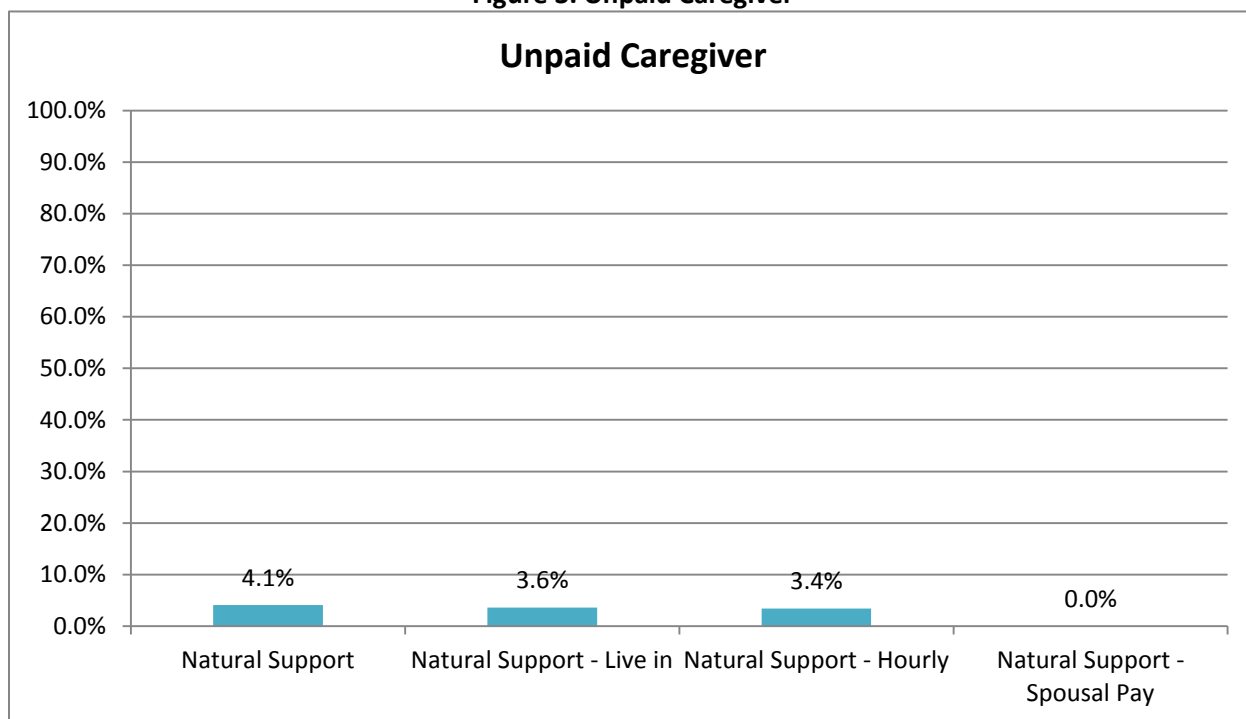
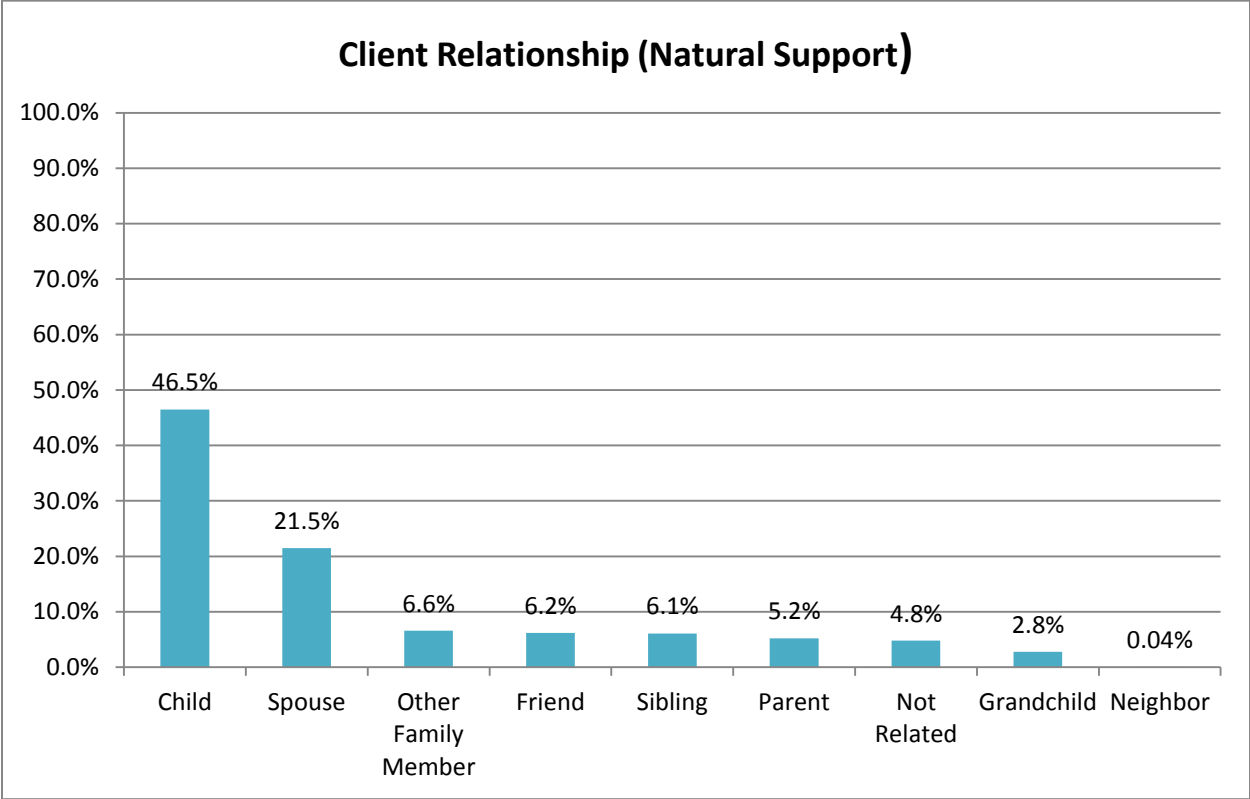


Table 3. Client Relationship (Natural Support)

| Relationship | Frequency | Percent |
|---------------------|--------------|---------------|
| Child | 1,916 | 46.5% |
| Spouse | 885 | 21.5% |
| Other Family Member | 273 | 6.6% |
| Friend | 256 | 6.2% |
| Sibling | 250 | 6.1% |
| Parent | 213 | 5.2% |
| Not Related | 198 | 4.8% |
| Grandchild | 114 | 2.8% |
| Neighbor | 18 | .4% |
| Total | 4,123 | 100.0% |

Figure 4. Client Relationship

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Table 4. Caregiver by County

| County | Paid Caregiver | | Unpaid Caregiver | | 65 and over * | | Disability * | |
|-------------------|----------------|-------|------------------|-------|---------------|-------|--------------|-------|
| | # | % | # | % | # | % | # | % |
| BAKER | 123 | .4% | 33 | .8% | 3,590 | 22.3% | 3,000 | 19.1% |
| BENTON | 282 | .8% | 13 | .3% | 10,411 | 12.2% | 8,606 | 10% |
| CLACKAMAS | 2,539 | 7.6% | 91 | 2.2% | 52,187 | 13.8% | 42,579 | 11.3% |
| CLATSOP | 379 | 1.1% | 55 | 1.3% | 6,368 | 17.2% | 6,447 | 17.7% |
| COLUMBIA | 329 | 1.0% | 70 | 1.7% | 6,926 | 14.0% | 6,968 | 14.2% |
| COOS | 992 | 3.0% | 114 | 2.8% | 13,674 | 21.7% | 14,000 | 22.6% |
| CROOK | 196 | .6% | 79 | 1.9% | 4,303 | 20.4% | 3,825 | 18.3% |
| CURRY | 277 | .8% | 17 | .4% | 6,240 | 27.9% | 5,547 | 25.0% |
| DESCHUTES | 1,040 | 3.1% | 44 | 1.1% | 23,985 | 15.1% | 19,066 | 12.1% |
| DOUGLAS | 1,161 | 3.5% | 120 | 2.9% | 22,733 | 21.2% | 22,852 | 21.4% |
| GILLIAM | 14 | .0% | 0 | 0% | 406 | 21.3% | 425 | 22.4% |
| GRANT | 61 | .2% | 4 | .1% | 1,746 | 23.7% | 1,538 | 21.1% |
| HARNEY | 92 | .3% | 27 | .7% | 1,404 | 19.1% | 1,532 | 21.1% |
| HOOD RIVER | 95 | .3% | 15 | .4% | 2,799 | 12.6% | 2,217 | 10.0% |
| JACKSON | 2,011 | 6.0% | 137 | 3.4% | 36,177 | 17.8% | 32,259 | 15.9% |
| JEFFERSON | 161 | .5% | 9 | .2% | 3,333 | 15.3% | 3,540 | 16.9% |
| JOSEPHINE | 996 | 3.0% | 62 | 1.5% | 18,404 | 22.3% | 13,816 | 16.9% |
| KLAMATH | 536 | 1.6% | 120 | 2.9% | 11,480 | 17.3% | 11,574 | 17.6% |
| LAKE | 48 | .1% | 6 | .1% | 1,593 | 20.2% | 1,501 | 20.1% |
| LANE | 3,984 | 11.9% | 332 | 8.1% | 53,449 | 15.2% | 51,391 | 14.7% |
| LINCOLN | 493 | 1.5% | 23 | .6% | 10,090 | 21.9% | 8,746 | 19.2% |
| LINN | 1,345 | 4.0% | 119 | 2.9% | 18,142 | 15.5% | 18,982 | 16.4% |
| MALHEUR | 393 | 1.2% | 116 | 2.8% | 4,681 | 15.1% | 4,459 | 15.8% |
| MARION | 2,589 | 7.7% | 768 | 18.8% | 41,047 | 13.0% | 43,319 | 14.0% |
| MORROW | 55 | .2% | 6 | .1% | 1,368 | 12.3% | 1,748 | 15.7% |
| MULTNOMAH | 7,871 | 23.4% | 472 | 11.6% | 78,778 | 10.7% | 85,534 | 11.7% |
| POLK | 656 | 2.0% | 117 | 2.9% | 11,447 | 15.2% | 10,428 | 13.9% |
| SHERMAN | 14 | .0% | 3 | .1% | 401 | 21.5% | 339 | 18.2% |
| TILLAMOOK | 191 | .6% | 92 | 2.3% | 5,276 | 20.9% | 3,607 | 14.7% |
| UMATILLA | 646 | 1.9% | 45 | 1.1% | 9,685 | 12.8% | 9,710 | 13.5% |
| UNION | 242 | .7% | 15 | .4% | 4,319 | 16.8% | 4,211 | 16.6% |
| WALLOWA | 68 | .2% | 5 | .1% | 1,618 | 23.3% | 1,375 | 20.0% |

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| | | | | | | | | |
|-------------------|-------|------|-----|-------|--------|-------|--------|-------|
| 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

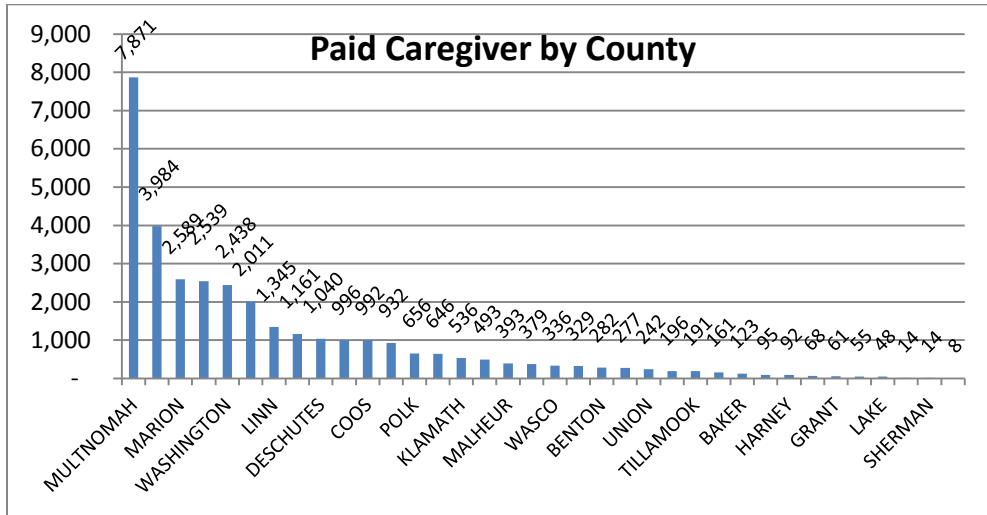
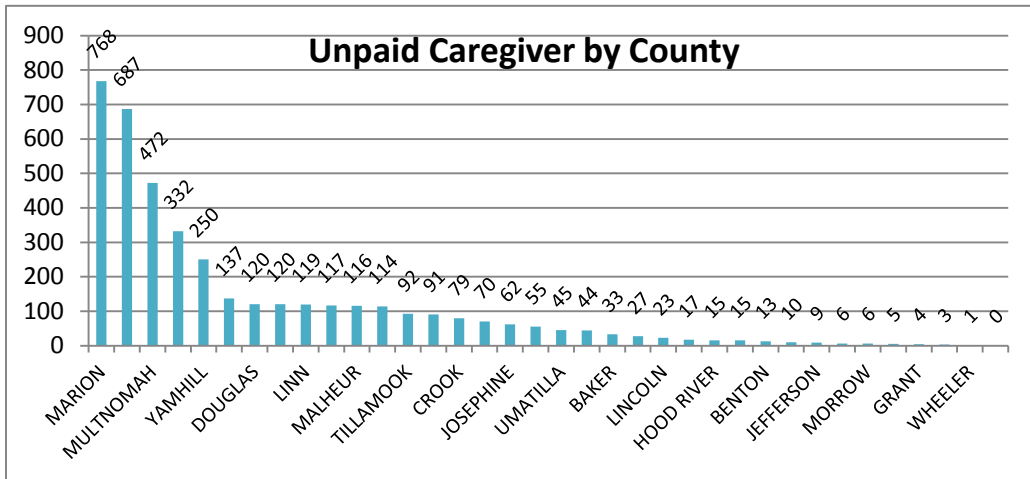
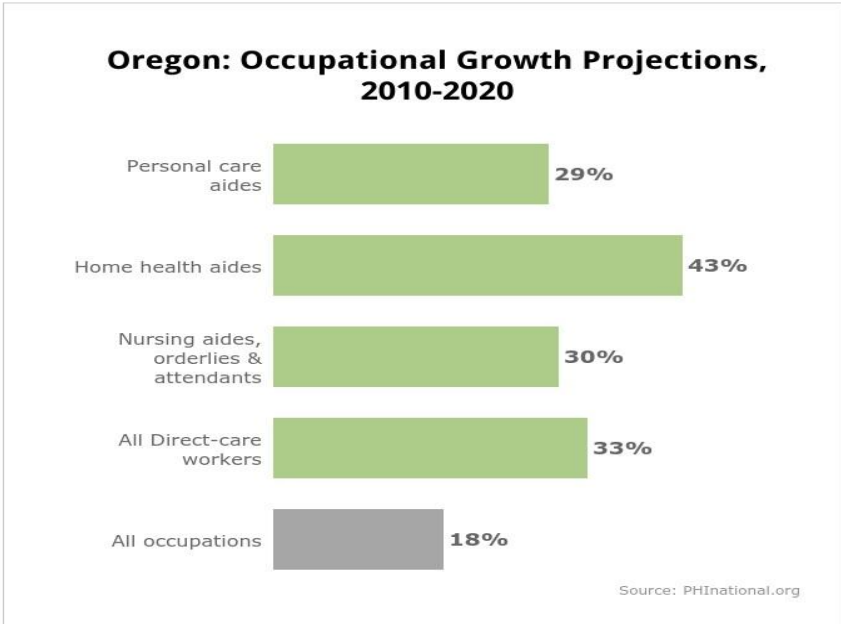
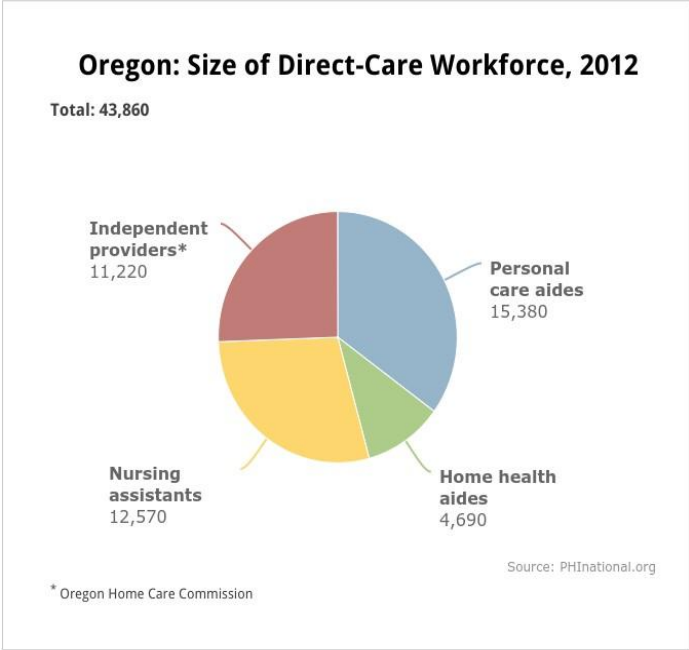


Figure 6. Unpaid Caregiver by County

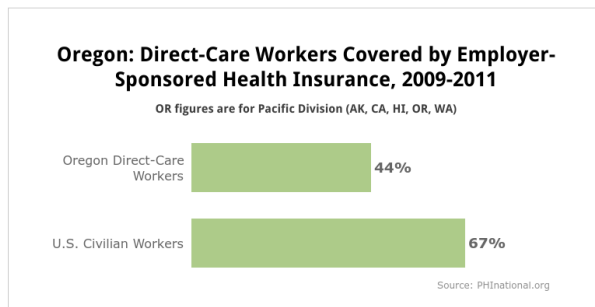
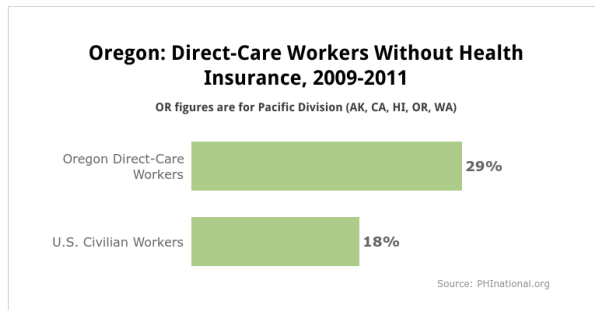
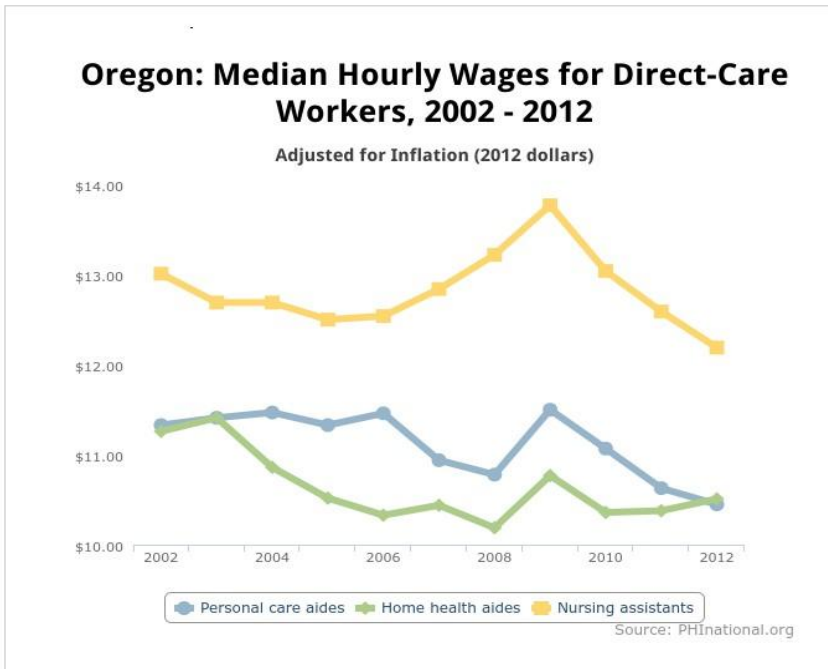


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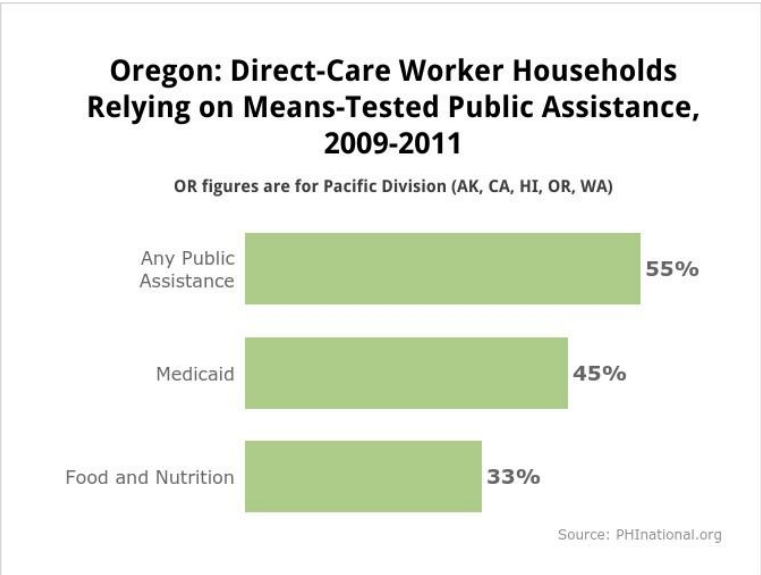
PHI Oregon Data



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Appendix II

Unpaid Caregiver Supports/Volunteerism Examples

- Store to Door
 - Low cost grocery service
 - <http://www.storetodooroforegon.org/>
- Meals on Wheels People
 - Home delivered meals
 - <http://www.mealsonwheelspeople.org/>
- Retired Senior Volunteer Program (RSVP)
 - Senior volunteer activities
 - <http://www.nationalservice.gov/programs/senior-corps/rsvp>
- Senior Companions
 - Seniors providing assistance and companionship for adults
 - <http://www.nationalservice.gov/programs/senior-corps/senior-companions>
- OR Project Independence (OPI)
 - Home care services sliding fee scale
 - <https://apps.state.or.us/Forms/Served/de1100.pdf>
- Elder Helpers
 - Free senior home assistance
 - <http://www.elderhelpers.org/index2.php>
- Partnership for Prescription Assistance
 - Prescription assistance for all age groups
 - <https://www.pparx.org/>
- Lifeline Program for low income consumers
 - Free phone services
 - <http://www.fcc.gov/lifeline>
- Home Energy Assistance Program (HEAP)
 - Help with energy costs
 - <http://www.acf.hhs.gov/programs/ocs/programs/liheap/about>
- Village to Village Networks
 - managing aging through community volunteer organizations
 - http://www.vtvnetwork.org/content.aspx?page_id=22&club_id=691012&module_id=65139
- Foster Grandparents
 - Senior mentors serving children with exceptional needs
 - <http://www.nationalservice.gov/programs/senior-corps/foster-grandparents>

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Appendix III

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

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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

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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 Montrúe'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)

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- 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

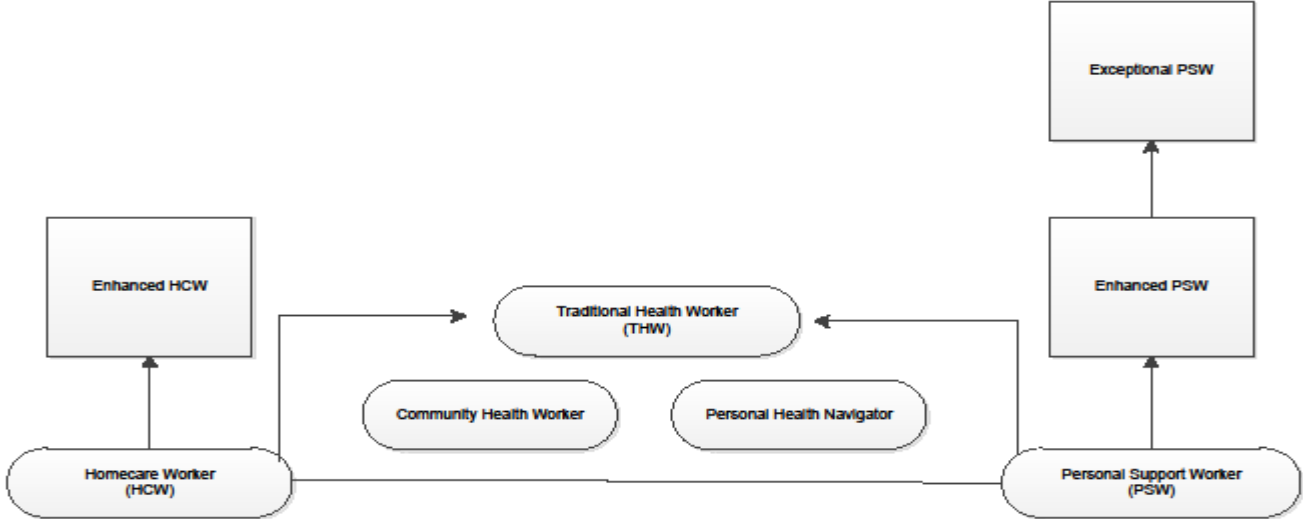
Items 2 and 3 – refer to Steering Committee with suggestion to assign subcommittee(s) or as part of continued LTC 3.0 beyond 2015 legislative session

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Appendix IV

Oregon Home Care Commission

Homecare and Personal Support Worker Career Lattice



Program and Policy Strategies

Senate Bill 21 Service Equity Subcommittee

The Senate Bill 21 Service Equity Subcommittee was charged with developing “strategies to serve individuals equitably in a culturally and linguistically responsive manner.” (Senate Bill 21, April 17, 2013).

Comprised of a diverse group of advocates, consumers, providers, and other stakeholders, the Senate Bill 21 Service Equity Subcommittee worked from February to July of 2014 to develop a comprehensive set of policy and program recommendations that address issues and concerns related to long term services and supports in regards to culturally underserved older adults and people with disabilities. The Subcommittee identified seven overarching principles from which its recommendations are based:

- 1. Engagement, Collaboration and Trust**
- 2. Service Provision for Diverse Populations**
- 3. Workforce Development**
- 4. Collaboration with Other Agencies**
- 5. Accessibility**
- 6. Data Collection and Reporting**
- 7. Strengthening the Aging and Disability Resources Connection (ADRC) Network**

Paramount to the Subcommittee’s focus were two concepts: *community engagement* and *cultural competence*. (Please see Attachment A for a definition of terms used in this document.) Both of these concepts highlight the importance of government agencies and staff working with and empowering communities, rather than taking a paternalistic role and attempting to solve problems in isolation. To this end, the Subcommittee’s recommendations revolve around engaging with diverse communities, building long-term relationships, creating partnerships with diverse stakeholders, and respecting all cultures represented in a community, while still treating each person as a unique individual.

It was also important to members of the Subcommittee to provide recommendations that represented a future long term services and supports system that was truly

inclusive and equitable, rather than simply deliberate on changes that could be made immediately under the current system's parameters and limitations.

The Subcommittee quickly agreed on the need to expand the scope of work to include equity issues surrounding sexual orientation and gender identification, in addition to culture and language. Much of the group's discussion revolved around the need for ongoing engagement and relationship-building with members of diverse communities throughout the state, more training and education for both paid and unpaid caregivers, improved accessibility to information and services, increased granularity and transparency in the data collected from consumers, and more culturally specific outreach efforts.

An examination of data related to utilization patterns of long term services and supports among communities of color reveals that consumers of color utilize home and community based services at a higher rate and nursing facilities at a lower rate than their White counterparts. (Please see Attachment B.) Based on preliminary analysis, these patterns of usage of among communities of color equate to over \$34 million dollars per biennium, compared to the case if communities of color utilized services at the rate of white consumers.

In order to correct the inequalities within the LTSS system, Aging and People with Disabilities and partner agencies need to dedicate more time, effort, and resources to building long-term relationships with diverse communities, to empowering these communities to work alongside agencies to design programs and policies that are flexible and accessible, and to providing information and outreach to these communities where they are and in formats that are accessible and understandable.

Providing a person-centered approach is central to the goals of ORS 410, and such an approach is crucial in providing culturally competent services and supports. Only by consistently engaging and empowering diverse groups at both the local and state levels, can a system be created that meets consumers' needs in a truly equitable way.

Finally, the Subcommittee wishes to emphasize that these strategies are to be taken as a whole, not in part. Each strategy plays an important role in ensuring that the LTSS system functions equitably for the benefit of all Oregonians.

1. Engagement, Collaboration and Trust

Local and state staff have developed long-term relationships with members of each diverse community based on mutual respect and trust, and together, they plan and develop policies and programs that ensure flexible, accessible, and culturally and linguistically responsive long term services and supports.

STRATEGIES:

- Recognize and identify inequities and make financial investments that build on the strengths of different cultural groups to implement innovative and flexible systems that meet the varying needs of Oregon’s diverse population of seniors and people with disabilities.
- Commit to reaching out and communicating with underserved populations and to listening and responding to their needs.
- Ensure that the voices of diverse ethnic and cultural communities are being heard within strategic planning processes to ensure that programs and services meet the needs of culturally diverse populations of seniors and people with disabilities.
- Understand that consumers from traditionally underserved populations may be reluctant to share personal demographic information. Take time to build trust by explaining that information shared will be kept confidential and used to help ensure equitable services in each community and statewide.
- Support local and state partnerships and other collaborative efforts around cultural diversity and equity issues that engage diverse stakeholders, including consumers, advocates and providers.
- Conduct ongoing local strategic planning processes that emphasize equitable involvement of consumers, advocates, care providers and policy-makers in order to ensure that the needs of diverse communities are being met.
- Ensure that all Area Agencies on Aging (AAA) and Aging and People with Disabilities (APD) offices employ a designated staff person who is specifically tasked with engaging diverse communities to ensure that service needs are being addressed equitably.

2. Service Provision for Diverse Populations :

Culturally and linguistically responsive services and supports are available in every community throughout Oregon, regardless of how rural or remote, and consumers are able to receive needed services in the place of their choosing.

STRATEGIES:

- Create evidence-informed long term services and supports that are specifically focused on the needs of underserved populations, taking into consideration:
 - literacy
 - geographic diversity
 - disability
 - diversity in sexual orientation and gender identification
 - cultural/ethnic diversity
 - age

- Create working partnerships that break down silos within and between the different service systems (Department of Human Services (DHS)/Aging and People with Disabilities (APD), Oregon Health Authority (OHA)/Addictions and Mental Health (AMH)) to ensure the provision of mental health and addiction services and supports that:
 - focus on the needs of diverse populations
 - emphasize preventative approaches
 - offer effective treatment options including individual and group counseling, peer counseling, community education, and other supportive services.

- Establish increased standards for case managers and screening staff related to cultural awareness and competency in areas such as:
 - avoiding assumptions and stereotypes
 - understanding and honoring consumer preferences and choices
 - recognizing loneliness and isolation among consumers and offering culturally sensitive supports and services in response
 - accessing technology that can aid in providing individualized services and supports
 - informing consumers about the services and supports they are eligible to receive and how to apply for those benefits

3. Workforce Development

Oregon's long term services and supports delivery system has a knowledgeable and well-trained workforce that reflects the inherent diversity of each community, and long term services and supports are provided by this workforce in a culturally-competent, person-centered manner.

STRATEGIES:

- Integrate a required, basic cultural responsiveness and confidentiality component into all training for current and incoming service providers including
 - DHS/APD office and field staff
 - OHA/AMH office and field staff
 - home care workers
 - community health workers
 - home and community based services (HCBS) providers
- Create strong training and support systems for home care workers from the Home Care Registry to ensure they are prepared to meet the needs of diverse consumers and to provide culturally responsive services and care.
- Utilize traditional/community health workers as liaisons between diverse communities and the long term services and supports system to engage consumers and to maintain and strengthen consumers' natural support systems.
- Promote opportunities and remove barriers to encourage members of diverse communities to become entrepreneurs in providing culturally specific long term services and supports, while also creating economic development in their communities and financially supporting themselves and their families.
- Invest time, effort, and resources in developing, piloting, and implementing state and local programs that support volunteers, family members and other unpaid caregivers of diverse elders and people with disabilities.

4. Collaboration with Other Agencies

APD and other service partners (including OHA, Coordinated Care Organizations (CCOs), Centers for Independent Living (CILs), AMH, AAAs, and State Medicaid Offices) actively collaborate to create a seamless long term service and support delivery system

that is culturally and linguistically responsive. Agencies continuously work in partnership to raise awareness of and to develop and disseminate best practices in serving diverse populations.

STRATEGIES

- Engage in thoughtful planning and collaboration across agencies to develop and implement evidence-informed programs, services and supports that meet the specific service needs of diverse populations.
- Encourage CCOs and other partners to adopt National Culturally and Linguistically Appropriate Services (CLAS) Standards in Health and Health Care.¹ (Please see Attachment C.)
- Ensure that CCOs have strategies for addressing the needs of traditionally underserved elders and people with disabilities, especially those with dual diagnoses including mental illness, cognitive impairment, HIV/AIDS, and chronic conditions such as Parkinson's disease or diabetes.

5. Accessibility

Information about long term services and supports is available in a variety of formats to meet individuals' diverse linguistic, literacy, and communication needs, and agencies make this information available in locations visited and formats used by traditionally underserved populations.

- Invest in technology and resources that allow Aging and People with Disabilities to provide effective communication to all individuals, regardless of language, literacy, or disability.
- Partner with diverse communities to increase access to programs designed to increase safety and security. Involve important people in the lives of consumers, including: neighbors, postal workers, grocery and drug store clerks, bank employees, auto repair persons, and other service providers within a community.

¹ Office of Minority Health: U.S Department of Health and Human Services (2013). The National CLAS Standards. Retrieved February 4, 2014 from <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15>

6. Data Collection, Reporting and Investment

APD adheres to a measurement and public reporting standard that allows for effective monitoring and meaningful evaluation of the quality and capacity of long term services and supports provided to diverse older adults and people with disabilities.

STRATEGIES:

- Increase the granularity of data collected to allow for better, more equitable distribution of services, including demographic questions related to:
 - Race/ethnicity
 - Gender
 - Sexual orientation
- Ensure that any personal demographic information a consumer chooses to share remains confidential and anonymous and that consumers understand that data is collected in order to determine the need for future services within a community or statewide.
- Collaborate with diverse communities and with other agencies, including the Oregon Health Authority Office of Equity and Inclusion and the Department of Human Services Office of Equity and Multicultural Services, to identify metrics that offer meaningful information about APD's progress in serving diverse populations of older adults and people with disabilities.
- Create access to updated technology for both workers and consumers to enable greater effectiveness in the data collection, as well as delivery of care and services to members of traditionally underserved populations.
- Use data as means of determining the financial investment needed to achieve culturally and linguistically responsive services in underserved communities.

7. Strengthening the Aging and Disability Resources Connection (ADRC) Network

The Aging and Disability Resource Connection (ADRC) has the capacity to equitably serve consumers from all diverse communities within Oregon and is known as the first and primary contact for anyone in need of information and resources.

STRATEGIES:

- Create a streamlined referral process that works across systems to serve the multiple needs of Oregon’s consumers with cultural and linguistic responsiveness.
 - Ensure that any government-based service system that touches any older adult or person with a disability is engaged in and understands the “no wrong door” system and referral process.
- Require that all government-affiliated information and referral and screening staff meet established ADRC standards, with the eventual goal that these standards will also apply to private information and referral providers.
- Establish formal guidelines for ADRCs to work with other information and referral sources, such as *211*.
- Ensure that local ADRCs employ staff who speak the language(s) of consumers in their respective areas, and continue to invest in and improve resources, such as the Language Line, that provide language assistance when needed.
- Ensure local ADRC staff work with area businesses and other organizations to guarantee that information and materials are available in locations visited and in formats used by diverse members of the local community.
- Continue to develop more comprehensive referral networks so that ADRCs can effectively connect diverse older adults and people with disabilities, as well as their families and other care partners, with culturally and linguistically responsive long term services and supports.

Attachment A: Definition of Terms:

Community: A group of people united by at least one common characteristic. Such characteristics could include geography, shared interests, values, experiences, or traditions.²

Community Engagement: The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.³ Community engagement is not a one-time event but rather an evolutionary process. At each successive level of engagement, community members move closer to being change agents themselves rather than targets for change, and collaboration increases, as does community empowerment.⁴

Culture: The dynamic and multidimensional context of many aspects of the life of an individual. It includes gender, faith, sexual orientation, profession, tastes, age, socioeconomic status, disability, ethnicity, and race.⁵

Cultural Competence: A stance of recognition and respect taken toward culture, rather than a discrete status or simple mastery of particular knowledge and skills. Cultural competence involves engaging with diverse segments of communities to include cultural and contextual dimensions important to the policy or program being considered.⁶ Cultural competence is a willingness to continually learn about other cultures and act as an ally in conjunction with various cultural groups.

² Centers for Disease Control (CDC). *Community Engagement: Definitions and Organizing Concepts from the Literature*. Retrieved June 29, 2014 from http://www.alz.org/alzheimers_disease_facts_and_figures.asp

³ Centers for Disease Control (CDC). *Community Engagement: Definitions and Organizing Concepts from the Literature*. Retrieved June 29, 2014 from http://www.alz.org/alzheimers_disease_facts_and_figures.asp

⁴ State of Oregon. (2014). Office of Equity and Multicultural Services (OEMS).

⁵ Wells M.I. (2001). Beyond cultural competence: A model for individual and institutional cultural development. *J Community Health Nursing*, 17:189-99.

⁶ Adapted from: American Evaluation Association. (2011). *American Evaluation Association statement on cultural competence in evaluation*. Retrieved June 18, 2014 from <http://www.eval.org/p/cm/ld/fid=92>.

Cultural Sensitivity: The awareness and acceptance of the morals, standards, and principles of a specific culture, society, ethnic group or race, joined by a motivation to adapt to one's own actions with these.⁷

Diversity: Seeking, recognizing, and honoring each individual's uniqueness and differences from others. Differences can relate to the dimensions of race, ethnicity, gender, sexual orientation, socioeconomic status, age, physical abilities, religious beliefs, political beliefs, or other ideologies.

Dual-Eligible: Medicare beneficiaries who receive Medicaid assistance, including those who receive the full range of Medicaid benefits, as well as those who receive assistance only with Medicare premiums or cost-sharing.

Engagement: The Centers for Disease Control and Prevention describe engagement as "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people. True community engagement involves investing in long-term relationships and lasting partnerships that are built on collaboration and trust."⁸

Equity: Fairness and justice in *outcomes* for all people. Equity is a measure of *results*, not effort. Due to historic, economic, and other social factors, some populations require greater resources in order to create parity in outcomes. Equity creates opportunities for people to have equal results, even if the effort to achieve those results differs.

Evidence-Informed: Practices that use the best available research and practice knowledge to guide program design and implementation. This informed practice allows for innovation while incorporating the lessons learned from the existing research literature. Ideally, evidence-informed programs and practices should be responsive to families' cultural backgrounds, community values, and individual preferences.⁹

⁷ Fleming, M. & Towey, K. (2001). *Delivering culturally effective health care to adolescents*. Chicago (IL): American Medical Association. Retrieved June 23, 2014 from <http://www.AmericanMedicalAssociation.org/ama1/pub/upload/mm/39/culturallyeffective.pdf>.

⁸ Centers for Disease Control and Prevention (1997). *Principles of community engagement* (1st ed) Atlanta (GA): CDC/ATSDR Committee on Community Engagement. Retrieved June 24, 2014 from http://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_Chapter_1_SHEF.pdf.

⁹ Children's Bureau (HHS), Child Welfare Information Gateway, FRIENDS National Resource Center for Community-Based Child Abuse Prevention, & Center for the Study of Social Policy-Strengthening

Service Equity: Providing the highest quality services for all Oregonians while helping them attain the best possible health and well-being.¹⁰ Achieving service equity involves engaging diverse cultural groups and working in partnership with these groups to develop programs and policies that meet their needs.

Underserved Populations: Populations that have been documented to show lower comparative levels of access and use of services due to area of residence, (rural versus urban versus frontier), disability, age, race, socioeconomic status, gender, or sexual orientation. Underserved populations may also be overlooked or misunderstood in the policy-making process.

Acronyms Used in this Document:

- (AAA)** – Area Agency on Aging and Disabilities
- (ADRC)** – Aging and Disability Resource Connection
- (AMH)** – Addictions and Mental Health
- (APD)** – Aging and People with Disabilities
- (CBC)** – Community Based Services
- (CCO)** – Coordinated Care Organization
- (CIL)** – Center for Independent Living
- (DHS)** – Department of Human Services
- (HCBS)** – Home and Community Based Services
- (LTSS)** – Long Term Services and Supports
- (OHA)** – Oregon Health Authority

Families. (2011). *Strengthening Families and Communities: 2011 Resource Guide*. Retrieved February 11, 2011 from www.childwelfare.gov/pubs/guide2011/guide.pdf#page=17.

¹⁰ Oregon Health Authority (2011). State of Equity Report: Summary of Findings, June 2011. Retrieved on June 22, 2014 from http://www.oregon.gov/oha/OHPR/RSCH/docs/hospital_report/state-of-equity-report.pdf.

Attachment B: Equity Utilization Gap: Medicaid Consumers

The attached data indicates that Medicaid consumers of color utilize home and community based services at a higher rate than their white counterparts, thereby costing the Medicaid system over 34 million dollars *less* per biennium than if they followed the utilization patterns of White consumers. Although this data is preliminary, it suggests an emerging pattern of disparity in the utilization of certain Medicaid Services. Past policies of segregation and discrimination in access to medical services among the African-America, Latino, and LGBT populations, for example, likely provide direction as to what is occurring within the long term services and supports (LTSS) system.

Studies conducted by the National Survey of Children's Health in 2003 and 2007 show continued disparities among African American children and their access to annual exams, specialists, and a personal physician or nurse. This lack of access results in a higher incidence of obesity, cognitive disabilities and asthma than Caucasian children. These medical issues also persist into adulthood (Flores and Lin, 2013)¹¹.

In addition to disparities in access to medical services as mentioned above, Latinos have also faced discriminatory legislation that would have denied them emergency medical services as well as caused increased scrutiny of their resident status when accessing medical services. Arizona's Senate Bill 1070 and California's Proposition 187 required that hospitals and other public institutions verify the resident status of those suspected to be in the US without documentation. These laws were overturned in the court system; however, the fear of racial profiling resulting from the laws kept some Latinos from utilizing medical services nonetheless (Murphy, 2012)¹².

Lesbian, gay, bisexual, and transgender (LGBT) individuals have also been denied access to medical services and medications. When certain providers learn of their LGBT status,

¹¹ Flores, G. and Lin, H. (2013). Trends in racial/ethnic disparities in medical and oral health, access to care, and use of services in US children: has anything changed over the years? *Journal for Equity in Health*. 12(10). Retrieved from: <http://www.biomedcentral.com/content/pdf/1475-9276-12-10.pdf>

¹² Murphy, R. (2012). *Arizona's Senate Bill 1070: A Case-Study on State-Sponsored Immigration Policy*. Retrieved from: <http://repository.usfca.edu/cgi/viewcontent.cgi?article=1055&context=thes>

these individuals face increased scrutiny and questions regarding their sexual orientation. This has caused some LGBT individuals to withhold reporting their sexual orientation or prevented them from seeking medical services altogether (Mayer et al, 2008)¹³. Currently, Oregon's LTSS system does not attempt to identify LGBT consumers, let alone offer specific programs or services geared toward meeting their specific needs.

It is reasonable to assume that these past policies of segregation and discrimination may be perpetuated in the LTSS system; however, in order to rectify inequities such as these within Oregon's LTSS system, it is necessary to collect data that will allow for a better understanding of how the current system has created barriers for underserved communities and what may be done to remove these barriers and create greater accessibility. Investing funds to collect and analyze data, as shown in section 6 of the Senate Bill 21 Service Equity Subcommittee strategies, is crucial to understanding the barriers to access and where improvements in the LTSS system can be made.

With advice and direction from diverse communities, data can be gathered and analyzed, and state and local staff working with seniors and people with disabilities can work with each population to implement policies and programs that meet consumers' needs. This is described in more detail in the outreach and engagement section (section 1) of the SB 21 Service Equity Subcommittee strategies.

The subcommittee recommends that a portion of the funds that have failed to reach underserved communities be invested in efforts to remove the barriers these communities have faced to accessing services. This investment can help to answer critical questions about why services are underutilized, what barriers exist and in which communities. Using these funds for engagement efforts is a much needed step toward correcting past injustices and creating an equitable LTSS system in the state of Oregon.

¹³ Mayer, K.H et al. (2008). Sexual and Gender Minority Health: What We Know and What Needs to Be Done. *American Journal of Public Health*. 2008 June; 98(6): 989–995 Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2377288/>

Attachment B (continued)
Data: Equity Utilization Gap

| White (\$2,502.60) | # of Consumers | Cost/Month |
|--|-----------------------|----------------------|
| NF | 4,328 | 28,132,000 |
| CBC | 10,426 | 22,937,200 |
| In-home | 10,085 | 11,093,500 |
| Total # LTSS consumers | 24,839 | \$62,162,700 |
| Allotment of total | 87.6% | \$60,659,058 |
| Over/under utilization per month | | + \$1,503,642 |
| Over/under utilization per person per month | | + \$61 |

| African American (\$2097.10) | # of Consumers | Cost/Month |
|--|-----------------------|--------------------|
| NF | 140 | 910,000 |
| CBC | 163 | 358,600 |
| In-home | 635 | 698,500 |
| Total # LTSS consumers | 938 | 1,967,100 |
| Allotment of total | 3.3% | 2,285,102 |
| Over/under utilization per month | | - \$318,000 |
| Over/under utilization per person per month | | - \$339 |

| Asian American (\$1,815.60) | # of Consumers | Cost/Month |
|--|-----------------------|--------------------|
| NF | 103 | 669,500 |
| CBC | 195 | 429,000 |
| In-home | 779 | 856,900 |
| Total # LTSS consumers | 1,077 | 1,955,400 |
| Allotment of total | 3.8% | 2,631,329 |
| Over/under utilization per month | | - \$675,929 |
| Over/under utilization per person per month | | - \$628 |

| Hispanic (\$2,041.00) | # of Consumers | Cost/Month |
|--|-----------------------|--------------------|
| NF | 126 | 819,000 |
| CBC | 263 | 578,600 |
| In-home | 635 | 698,500 |
| Total # LTSS consumers | 1,027 | 2,096,100 |
| Allotment of total | 3.6% | 2,492,836 |
| Over/under utilization per month | | - \$396,738 |
| Over/under utilization per person per month | | -\$386 |

| Native American (\$2,299.00) | # of Consumers | Cost/Month |
|--|-----------------------|-------------------|
| NF | 64 | 416,000 |
| CBC | 124 | 272,800 |
| In-home | 214 | 235,400 |
| Total # LTSS consumers | 402 | 924,200 |
| Allotment of total | 1.4% | 969,437 |
| Over/under utilization per month | | - 45,237 |
| Over/under utilization per person per month | | -\$113 |

| Pacific Islander (\$2,058.80) | # of Consumers | Cost/Month |
|--|-----------------------|-------------------|
| NF | 8 | 52,000 |
| CBC | 20 | 44,000 |
| In-home | 40 | 44,000 |
| Total # LTSS consumers | 68 | \$140,000 |
| Allotment of total | .2% | 138,491 |
| Over/under utilization per month | | + 1,509 |
| Over/under utilization per person per month | | +\$22 |

(Please see the following page for a summary of data.)

Summary of Underutilization

Per Month:

| | <u>By Group:</u> |
|------------------|--------------------------|
| African American | \$318,000 |
| Asian American | \$675,929 |
| Hispanic | \$396,738 |
| Native American | <u>\$ 45,237</u> |
| TOTAL | \$1,435,904/month |

x 12 months \$17,248,968/year

x 24 months \$34,497,936/biennium

NOTES:

- *All figures based on a total of 28,351 Medicaid LTSS consumers, at a total cost of \$69,245,500/month.*
- *Estimated monthly costs: NF = \$6500; CBC = \$2,200; In-home = \$1,100*

Attachment C:

National Culturally and Linguistically Appropriate Services (CLAS) Standards in Health and Health Care¹⁴

Principal Standard

1. Provide effective, equitable, understandable and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy and other communication needs.

Governance, Leadership and Workforce

2. Advance and sustain organizational governance and leadership that promotes CLAS and health equity through policy, practices and allocated resources.
3. Recruit, promote and support a culturally and linguistically diverse workforce that are responsive to the population in the service area.
4. Educate and train governance, leadership and workforce in culturally and linguistically appropriate policies and practices on an ongoing basis.

Communication and Language Assistance

5. Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to all health care and services.
6. Inform all individuals of the availability of language assistance services clearly and in their preferred language, verbally and in writing.
7. Ensure the competence of individuals providing language assistance, recognizing that the use of untrained individuals and/or minors as interpreters should be avoided.
8. Provide easy-to-understand print and multi-media materials and signage in the languages commonly used by the populations in the service area.

Engagement, Continuous Improvement and Accountability

9. Establish culturally and linguistically appropriate goals, policies and management accountability, and infuse them throughout the organization's planning and operations.

¹⁴ Office of Minority Health: U.S Department of Health and Human Services (2013). The National CLAS Standards. Retrieved February 4, 2014 from <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15>

10. Conduct ongoing assessments of the organization's CLAS-related activities and integrate CLAS-related measures into assessment measurement and continuous quality improvement activities.
11. Collect and maintain accurate and reliable demographic data to monitor and evaluate the impact of CLAS on health equity and outcomes to inform service delivery.
12. Conduct regular assessments of community health assets and needs and use the results to plan and implement services that respond to the cultural and linguistic diversity of populations in the service area.
13. Partner with the community to design, implement and evaluate policies, practices and services to ensure cultural and linguistic appropriateness.
14. Create conflict and grievance resolution processes that are culturally and linguistically appropriate to identify, prevent, and resolve conflicts or complaints.
15. Communicate the organization's progress in implementing and sustaining CLAS to all stakeholders, constituents and the general public.