

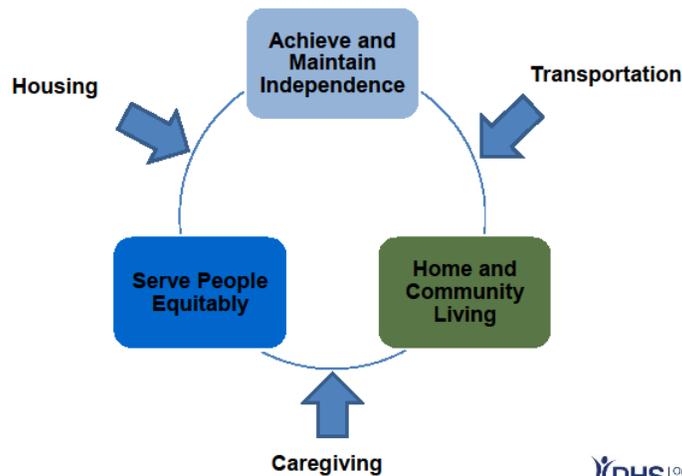
Senate Bill 21 – Final Report

Presented by:
The Department of Human Services
Aging and People with Disabilities Program

February 1, 2015



Senate Bill 21



SB 21 Report – Executive Summary

Senate Bill 21 required the Department of Human Services to develop a plan to improve and strengthen Oregon’s publicly funded long term care system. The plan was required to include strategies to serve seniors and people with disabilities in their own homes and communities, support their independence and to do so in an equitable, culturally responsive manner.

This report to the 2015 Legislative Assembly serves to meet the requirements of Senate Bill 21 (2013) by identifying proposed changes, areas of consensus, challenges and a time line for the implementation of the plan in whole or in part. In describing these proposed changes and proposed time line for implementation, this report identifies three objectives consistent with the requirements of Senate Bill 21.

In order to achieve the following objectives, the SB 21 Steering Committee placed a significant and overarching emphasis on strong research and data collection associated with each and an assurance that service equity will be central to each strategy moving forward.

Objectives:

- Support seniors and people with disabilities to stay in their own homes and communities.
- Support seniors and people with disabilities to achieve and maintain their independence.
- Serve all people and cultures equitably and in a manner they choose.

Each of these objectives includes a set of recommended strategies to achieve these three goals. The strategies include current and short, medium, and long term implementation milestones.

Throughout the discussion and prioritization of the many strategies, the Steering Committee made clear that an emphasis should be placed on three main areas: **Caregiving, Transportation and Housing**, with housing and transportation as

areas that are inexorably linked. These three areas are central in strengthening and improving upon Oregon’s model of supports and services so that seniors and people with disabilities can have a better quality of life, with independence, choice, and dignity.

The report proposes initial next steps and primary participants involved early in the implementation process. The Senate Bill 21 Steering Committee – which included stakeholder such as consumers, providers, consumer and provider organizations, two members of the House and two members of the Senate – worked with the Department of Human Services (DHS) Aging and People with Disabilities (APD) program to refine the objectives and propose strategies.

APD and the SB 21 Steering Committee in partnership with the stakeholders, advocates, and communities involved in the planning process of SB 21, respectfully submit this report, its recommendations, and implementation timeline to the 2015 Legislative Assembly for acceptance.

The final report and the Executive Summary are available at the following website: <http://www.oregon.gov/dhs/spwpd/LTC30SteeringCommittee/SB%2021%20Report%20-%20Final.pdf>, or by contacting Max Brown at max.brown@state.or.us or at (503) 945-6993.

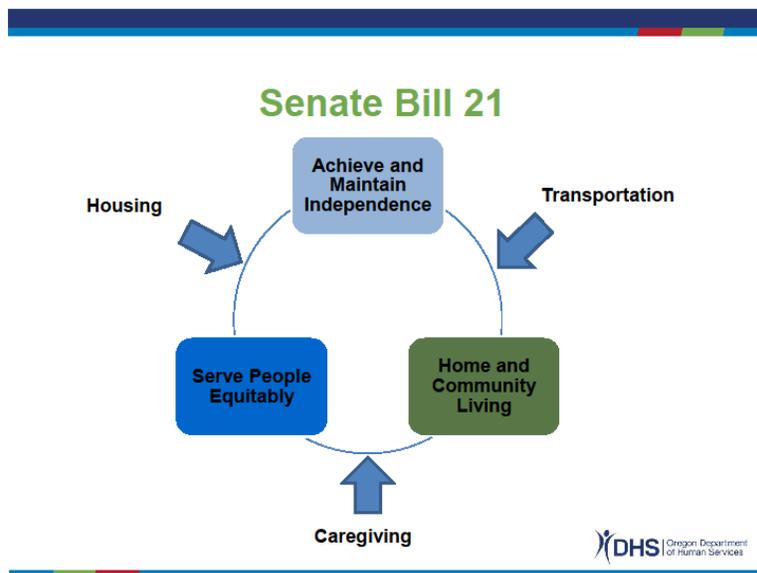


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Introduction

This report to the 2015 Legislative Assembly serves to meet the requirements of Senate Bill 21 (2013) by identifying proposed changes, areas of consensus and challenges and a time line for the implementation of the plan in whole or in part. In describing these proposed changes and proposed time line for implementation, this report identifies three objectives consistent with the requirements of Senate Bill 21.

In order to achieve the following objectives, the committee placed a significant and overarching emphasis on strong research and data collection associated with each and an assurance that service equity will be central to each strategy moving forward.

The 2013 Legislative Assembly passed Senate Bill 21, which requires the Department of Human Services (DHS) to develop a plan to strengthen and improve Oregon's publicly funded long term services and supports system. This report presents the plan required by the bill.

As required by SB 21, this report provides a set of strategies under the following three objectives:

- Strategies to serve seniors and persons with disabilities in their own homes and community settings of their own choosing, including but not limited to greater use of adult day centers and effective coordination with the health care system;
- Strategies designed to support independence and delay the entry of individuals into publicly funded long term services and supports, including but not limited to short stay respite care, medication management and support for family caregivers; and
- Strategies to serve individuals equitably in a culturally and linguistically responsive manner.¹

¹ Senate Bill 21A, page 1.

In addition to these sets of strategies, this report presents data and analysis on the primary causes of entry into publicly funded long term services and supports (LTSS), as well as significant cost drivers associated with the LTSS system, as required by SB 21. Finally, the report proposes a timeline for implementation of these objectives, in the form of short term, medium term, and long term strategies.²

The work entailed in SB 21 is informed by an acknowledgement that Oregon has been a national leader in long term services and supports for over 30 years. At the same time, SB 21 has given APD, stakeholders, and the public an opportunity to explore ways in which Oregon can build upon areas in which it is a model for the nation, as well as improve in areas to make the system better. What follows is an account of this planning process, followed by a roadmap forward for future action to strengthen and improve this model system.

² Ibid., pp. 1-2.

Process of the SB 21 Steering Committee

SB 21 mandated the formation of a planning committee of stakeholders and state legislators to develop a plan for publicly funded long term services and supports. Aging and People with Disabilities (APD) solicited applications from the stakeholder community in September 2013, and a group of fifteen stakeholders were selected to serve on the SB 21 Steering Committee. Stakeholders included consumers, providers, and organizations that represented and advocated for seniors and people with physical disabilities. The House Speaker and Senate President selected two legislators from their respective chambers, and the Steering Committee convened for a series of eleven meetings beginning in late October 2013.³

The Steering Committee agreed to the three aforementioned sets of strategies as their charge at the first and second meetings. The Steering Committee also agreed to establish subcommittees in order to manage the requirements of creating a plan under SB 21: the Data and Research, Assessment, Caregivers, and Service Equity Subcommittees. These subcommittees were chaired by Steering Committee members and included stakeholders outside of the Steering Committee as members. The subcommittees regularly updated the Steering Committee on their work and presented their findings and recommendations in July and August 2014. The scope, work and recommendations of each subcommittee are described below on page 6.⁴

After a brief overview of APD programs and services and how they address consumers' needs, the Steering Committee reviewed DHS's previous planning efforts for improving long term services and supports (LTSS) dating back to 2007. Common themes emerged from this review, including the need for:

- Improved education and outreach to consumers and their families about planning and options for LTSS in their communities;

³ A list of SB 21 Steering Committee members and staff are in Appendix A.

⁴ Appendix A also has member lists for each Subcommittee.

- Building capacity and support for services for consumers not eligible for Medicaid LTSS, including stronger preventative programs for consumers before they have a higher level of need;
- More person-centered and person-directed services, with recognition of different service needs based on age, disability, demographic, cultural and geographical differences across the state.
- Development of age-friendly, accessible communities, which includes accessible transportation, housing, nutrition, social and vocational services, and inclusive community design; and
- Planning that includes well-defined objectives and time-bound strategies to achieve those objectives.⁵

Over the course of its meetings, the Steering Committee also reviewed current DHS and APD initiatives, as well as external factors, to inform its planning process. These included:

- APD’s initiatives from the 2013 legislative session, including: the nursing facility reduction package in House Bill 2216,⁶ the launch of the 1915(k) State Plan Option for home and community based services, the creation of the Innovations Fund;
- Funding initiatives in the 2013 Special Purpose Appropriation funding package, including: enhanced investments in Oregon Project Independence (OPI), the Special Transportation Fund (STF) through the Oregon Department of Transportation (ODOT), the Quality Care Fund (QCF), mental health for seniors and people with disabilities, the Public Guardian program and Adult Protective Services (APS), evidence-based health promotion

⁵ Previous reports reviewed include “Recommendations on the Future of Long-Term Care in Oregon,” Department of Human Services, Seniors and People with Disabilities, March 2007; “A Plan for Comprehensive Services to Seniors and People with Disabilities,” Department of Human Services, Seniors and People with Disabilities, September 2008; “Report for the House Bill 5030 (2011) Budget Note on Oregon’s Long Term Care System,” Department of Human Services, January 2012; Listening and Visioning Project on Long-Term Care, Phase I and Phase II, 2011-2012” Oregon Association of Area Agencies on Aging and Disabilities, Meyer Memorial Trust, and Oregon Community Foundation, 2013.

⁶ HB 2216 (2013).

programs for seniors and people with disabilities, and one-time caregiver training programs.⁷

- The Long Term Care/Coordinated Care Organization (LTC/CCO) Study Group Report, which outlined a model of coordinated care between the LTSS and medical services provided by CCOs, and included a proposed timeline for implementation of this coordination;⁸
- Discussion of new Home and Community Based Services (HCBS)⁹ and Department of Labor (DOL) regulations¹⁰, which, while outside the scope of the SB 21 Steering Committee’s work, nevertheless presented implications for current and future LTSS planning.

With a full discussion of previous LTSS planning efforts in Oregon and informed by current initiatives and external factors in LTSS planning, the Steering Committee began the process of building recommendations through the work of its subcommittees.

⁷ HB 5201 (2014).

⁸ “Report to the Centers for Medicare and Medicaid Services: Study Group Report on the Integration of Long Term Care into the Global Budgets of Oregon’s Coordinated Care Organizations,” Department of Human Services, Oregon Health Authority, and the Long Term Care/Coordinated Care Organization Study Group, December 2013, http://www.oregon.gov/dhs/cms/Meeting%20files/LTC_CCO%20Study%20Group%20Report%2012_20_13%20FINAL%20to%20CMS.pdf, accessed 28 January 2015.

⁹ Centers for Medicare and Medicaid Services, “Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers,” Federal Register, January 16, 2014, <http://www.gpo.gov/fdsys/pkg/FR-2014-01-16/pdf/2014-00487.pdf>, accessed 16 December 2014.

¹⁰ Department of Labor, Wage and Hour Division, Application of the Fair Labor Standards Act to Domestic Service, Final Rule, http://www.dol.gov/whd/homecare/final_rule.pdf, accessed 16 December 2014.

SB 21 Subcommittees: Work and Recommendations

As stated above, the Steering Committee formed four subcommittees to manage the planning work required by SB 21.

Data and Research Subcommittee

SB 21 required DHS to gather data on the primary causes of entry into, and the significant cost drivers associated with, publicly funded LTSS, including data on any differences that exist due to age and the location where services are delivered. The Data and Research Subcommittee worked with DHS staff in identifying these causes of entry and cost drivers.

DHS staff analyzed records of new Medicaid LTSS consumers from the *Oregon Access* database and other sources.¹¹ Major findings of the analysis included:

- A growing percentage of Medicaid LTSS beneficiaries are under the age of 65 (largely composed of people 50-65 years of age).
- While acute medical events appear to be an important driver for entry into the Medicaid LTSS system, about twice as many consumers entered the system from non-acute event causes, such as gradual loss of their abilities to perform activities of daily living, a chronic condition or illness, spend down, or loss of caregiver.
- There is a high prevalence of chronic health conditions such as cancer amongst beneficiaries of all ages.
- There are high rates of dementia among consumers aged 65 and over.
- The majority of system entrants are widowed, divorced or never married, and the number of female new entrants relative to males increases with age.
- Finally, and perhaps most importantly, approximately half of the consumers in the sample entered the system needing full assistance in at least one of the four activities of daily living – cognition, mobility, elimination, or eating

¹¹ DHS staff examined records of 513 consumers who became eligible for Medicaid LTSS during the period of October 2012 – November 2013. The consumers were stratified by age and then selected randomly, with the goal of having approximately 25 percent of the sample in each of the following age cohorts: 19-64; 65-74; 75-84; and 85 and over.

– and a significant portion of these individuals required full assistance in more than one activity.¹²

The Data and Research Subcommittee also examined data concerning the new entrants and Medicaid LTSS consumers as a whole to compare the sample and the population according to age, LTSS setting, geographic location, and other demographic data. Additional cause of entry and cost driver data included an analysis of assistance need for consumers at service priority level 3 (requiring full assistance with cognition, mobility, or eating), as well as the distribution of cost per consumer in community based, in home, and nursing facility settings.¹³

Building on and in addition to the work of the Data and Research Subcommittee, the Steering Committee also looked at national data and research studies to inform its work on targeting areas that may have a measurable impact on the well-being of individuals currently receiving LTSS as well as on their caregivers. For example, according to the *America's Health Rankings® Senior Report 2013*, Oregon has some of the highest rates of depression and chronic alcohol use amongst older adults in the nation.¹⁴ And among the findings of a 50-state scorecard released in June 2014, caregivers in Oregon also face significant stressors that negatively affect their health and ability to provide care.¹⁵

Assessment Subcommittee

The Assessment Subcommittee was charged with reviewing and identifying the strengths and weaknesses of the current assessment and eligibility system for

¹² A presentation of data regarding the causes of entry into Medicaid LTSS is available at <http://www.oregon.gov/dhs/spwpd/docs/Causes%20of%20Entry%20Analysis.pdf>, accessed 19 December 2014.

¹³ This analysis is available at <http://www.oregon.gov/dhs/spwpd/LTC30SteeringCommittee/SB%2021%20Data%20and%20Research%20Subcommittee%20-%20Revised%20analysis-3.pdf>, accessed 19 December 2014.

¹⁴ United Health Foundation, *America's Health Rankings® Senior Report, 2013*, <http://www.americashealthrankings.org/reports/Senior>, accessed 15 December 2014.

¹⁵ Susan C. Reinhard, Enid Kassner, Ari Houser, Kathleen Ujvari, Robert Mollica, and Leslie Hendrickson, *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers*, 2014, AARP, The SCAN Foundation, and the Commonwealth Fund, http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2014/raising-expectations-2014-AARP-ppi-ltc.pdf, accessed 15 December 2014.

Medicaid LTSS and making recommendations for improvements. The Subcommittee also reviewed broad recommendations for developing a new assessment tool from a previous DHS internal workgroup.

The Assessment Subcommittee recommended that APD reconstruct its service priority level (SPL) framework in order to have better support for prevention and maintenance and/or improvement of function. The Subcommittee suggested keeping the numerical SPL system, with 18 levels of need for assistance and levels 1-13 for Medicaid LTSS eligibility.¹⁶ In the current system, the vast majority of consumers served are in four levels (1, 3, 7, and 10). The Subcommittee believed there can be better stratification through distinguishing individual needs and developing more person-centered plans.

The Subcommittee recommended that a better stratification of need would address consumers' needs more effectively at the lower and higher end of services. On one end of the scale, the Subcommittee found that the current assessment tool does not identify high need service plans because it is common to provide exceptions in these plans, meaning that these consumers require extra hours of service and therefore an exception to a payment limitation. On the lower end of the scale, low need plans do not include one-time interventions or preventive services. As such, the Assessment Subcommittee recommended redefining the SPL system in a manner that promotes early intervention and prevention services.¹⁷

Building on the recommendations developed by the internal DHS group on the assessment tool, the Assessment Subcommittee recommended that the tool should:

¹⁶ In Oregon's Service Priority Level System, one is assessed for services on a 1-18 scale, with SPL 1 as the highest level of need, and 18 as the lowest level of need. Consumers at SPL 1-13 qualify for Medicaid LTSS if they meet financial criteria. Oregon Project Independence serves individuals at SPL 1-18.

¹⁷ The Assessment Subcommittee designed a graphic to illustrate a proposed redesign of the SPL system, and the graphic is available at <http://www.oregon.gov/dhs/spwpd/LTC30SteeringCommittee/Assessment%20LTSS%20Prevention%20and%20Acuity%20Scale%20Final%203%2010%2014%20FINAL.pdf>, accessed 18 December 2014.

- Be consumer driven and person-centered to support consumer empowerment and responsibility for consumers' own health. The model should incorporate consumer activation and education as part of the assessment process;
- Include predictive modeling capacity, support the identification of risk, and allow for service planning that focuses on prevention;
- Allow for testing program changes in test environment;
- Allow for robust data collection, analysis and reporting at the state and local levels while providing the highest level of privacy protections;
- Have internal quality checks that help avoid the entry of conflicting data and provide alerts/suggestions to workers;
- Be easily modifiable and adaptable to meet changing needs over time; and
- Use the latest technology (features such as auto-fill, alerts, prompts and web-based, mobile devices) to minimize workload and maximize efficiency.

The Steering Committee voted to accept the Assessment Subcommittee recommendations at its March meeting. The Subcommittee's full recommendations and associated materials are included in Appendix B.

Service Equity Subcommittee

The Service Equity Subcommittee was charged with developing strategies to service individuals equitably, in a culturally and linguistically responsive manner. The Subcommittee was comprised of a large and diverse group of advocates, consumers, providers and other stakeholders who examined ways in which to achieve more equitable outcomes for Oregon's diverse communities. Not only did the Subcommittee explore equity in regard to communities of color; it also considered:

- Communities in which English is a second language;
- Younger people with disabilities (including individuals with a mental illness); and
- Communities in rural and frontier parts of Oregon.

In its formulation of strategies, the Subcommittee focused on the concepts of community engagement and cultural humility. These concepts were essential in crafting recommendations that proactively empower communities, rather than those that APD initiates in an attempt to rectify service equity issues in isolated cases. Subcommittee members felt strongly that strategies to empower underserved communities begin with APD reaching out to these communities, building lasting relationships, and maintaining strong connections through ongoing engagement and partnerships.

The Service Equity Subcommittee made the following recommendations:

- **Engagement, Collaboration and Trust:** Local and state staff should develop long-term relationships with members of each diverse community based on mutual respect and trust, and together, they should work to plan and develop policies and programs that ensure flexible, accessible, and culturally and linguistically responsive long term services and supports.
- **Service Provision for Diverse Populations:** Culturally and linguistically responsive services and supports should be available in every community throughout Oregon, regardless of how rural or remote, and consumers should be able to receive needed services in the place of their choosing.
- **Workforce Development:** Oregon's long term services and supports delivery system should have a knowledgeable and well-trained workforce that reflects the inherent diversity of each community, and long term services and supports should be provided by this workforce in a culturally-responsive, person-centered manner.
- **Collaboration with Other Agencies:** APD and other service partners (including OHA, Coordinated Care Organizations (CCOs), Centers for Independent Living (CILs), Addictions and Mental Health (AMH), Area Agencies on Aging (AAAs), and State Medicaid Offices) should actively collaborate to create a seamless long term service and support delivery system that is culturally and linguistically responsive. Agencies should continuously work in partnership to raise awareness of and to develop and disseminate best practices in serving diverse and underserved populations.

- **Accessibility:** Information about long term services and supports should be available in a variety of formats to meet individuals' diverse linguistic, literacy, and communication needs, and agencies should make this information available in locations visited and formats used by traditionally underserved populations.
- **Data Collection, Reporting and Investment:** APD should adhere 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.
- **Strengthening the Aging and Disability Resources Connection (ADRC) Network:** The Aging and Disability Resource Connection (ADRC) should have the capacity to equitably serve consumers from all diverse communities within Oregon and should be known as the first and primary contact for anyone in need of information and resources.

The SB 21 Steering Committee voted to accept the recommendations of the Service Equity Subcommittee in its July 2014 meeting. The full report of the Subcommittee's recommendations, along with a set of strategies for each recommendation, is in Appendix C.

Caregivers Subcommittee

The SB 21 Steering Committee formed the Caregivers Subcommittee because caregivers were deemed crucial in SB 21's mandate to serve consumers in their own homes and communities, to support independence, and to support all consumers equitably. The Subcommittee examined and discussed national and state data on both paid and unpaid caregivers, and framed its recommendations around caregiver issues such as workforce issues including recruitment and retention, training, technology, volunteers, and policy. The Subcommittee explored each of these areas with the following focus statement regarding its work:

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.

The Caregiver Subcommittee addressed recommendations common to all caregivers, as well as recommendations specific to the needs of paid and unpaid caregivers. These recommendations included:

- **Caregiver Support and Training:** Strengthen training through outreach and training specific to certain chronic conditions; access to training in rural and underserved areas; strengthen caregiver resources to address consumer needs, especially during periods of transition between care settings; and maintain a stakeholder group to research the needs of Oregon caregivers.
- **Respite:** Develop coordinated approaches to meet respite needs for caregivers, such as adult day services; develop person-centered, culturally responsive respite options; and fund Oregon's Lifespan Respite program.
- **Technology:** Support the use of assistive technology for caregivers or for consumers who can use the technology without needing caregiver support; analyze the possible cost-effectiveness of durable medical equipment; use technology to expand access to caregiver training; and create a workgroup that makes recommendations to the state and the private sector on the development and use of technology.
- **Volunteerism and Community Service:** Identify and develop volunteer resources that can ease the burden of caregivers, including local organizations; develop an approach to use vetted volunteers; and build upon successful volunteer-based programs to replicate best practices statewide.
- **Policy:** Implement federal allowance to have caregiver services when consumers are hospitalized; support the Oregon Behavior Risk Factor Surveillance System (BRFFSS) to get caregiver trend data for incidence and impact; support the development and expansion of the traditional health

worker workforce; continue support for the Innovations Fund to develop innovative support of caregivers and consumers.

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

The Caregiver Subcommittee recommended that 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
- Promote existing trainings more aggressively
- Expand access to trainings statewide
- Ensure unpaid caregivers are informed about caregiving and how to choose a useful training.

The SB 21 Steering Committee voted to accept the recommendations of the Caregiver Subcommittee at its August 2014 meeting. This subcommittee’s Summary and Recommendation report is in Appendix D.

SB 21 Steering Committee Recommendations

During its August 2014 meeting, the Steering Committee worked on finalizing recommendations on a document titled “Long Range Vision for Oregon’s LTSS: SB 21 Destination Roadmap.” These recommendations were strategies toward achieving SB 21’s three objectives: serving consumers in their own homes and community settings of their own choosing; supporting independence and choice while delaying or avoiding entry into publicly funded LTSS; and serving consumers equitably, in a culturally and linguistically responsive manner. As members finalized a set of strategies to achieve all three objectives, **the Steering Committee agreed to a principle regarding consumer choice: all consumers have a right, a choice, and an entitlement to home and community based services as well as nursing facility services.** The Roadmap document follows:

Long Range Vision for Oregon Long Term Services and Supports:

Senate Bill 21 Destination Roadmap

Objective #1 - Support seniors and people with disabilities to stay in their own homes and the community.

Strategies:

- Ensure that all Oregonians have a right to choose whether they would like to receive long term services in their home and community or in a nursing home.
- Educate Oregonians about all options for receiving long term services and supports.
- Provide access to quality caregivers.
- Coordinate social and health systems to help consumers.
- Provide access to technology and other adaptive aids that support independence.
- Develop new models to call “home.”
- Ensure full access to transportation.

Objective #2 - Support seniors and people with disabilities to achieve and maintain their independence.

Strategies:

- Conduct more health and mental health prevention, promotion, and education.
- Address housing, social isolation, and other social needs.
- Access to help and information, including resources for personal financial planning.
- Focus on and support community planning for age- and disability-friendly communities.
- Support paid and unpaid caregivers.
- Ensure full access to transportation.

Objective #3 - Serve all people and cultures equitably and in a manner they choose.

Strategies:

- Build a culturally responsive workforce.
- Support for paid and unpaid caregivers in diverse communities.
- Earn trust by meeting with and hearing the needs of diverse communities.
- Collect data to improve service equity.¹⁸

¹⁸ The one-page document, entitled “Long Range Vision of Oregon Long Term Services and Supports,” is available at <http://www.oregon.gov/dhs/spwpd/docs/Long%20Range%20Vision%20for%20Oregon%20Long%20Term%20Services%20and%20Support.pdf>, accessed 19 December 2014.

After the August 2014 meeting, the Steering Committee reviewed a revised version of this document, which was finalized after feedback. The Steering Committee also reviewed a longer, more detailed, document on SB 21 Objectives and Strategies during and after the August 2014 meeting, which incorporated the elements of the shorter Roadmap document. After receiving feedback, APD finalized the longer document which stated the following recommendations:

- ***Create centralized, statewide mechanisms for recruiting for and improving the quality and portability of the LTSS workforce and ensure an adequate supply of caregiver support to meet consumer needs.*** This includes paid and unpaid care providers and requires coordination among higher education, community service, employment-related and labor organizations; it also overlaps with caregiver support and training and recognizes the anticipated trend of fewer family caregivers in the future.
- ***Plan for and monitor "emerging models of consumer-directed and person-centered service delivery," as all consumers have a right, a choice, and an entitlement to home and community based services as well as nursing facility services.*** Under Medicaid law, nursing facilities are a mandatory service of the state plan, and all eligible consumers are entitled to this benefit. Now, with the State Plan Option (k), eligible consumers in Oregon are entitled to home and community based services as well as nursing facility services, and over 85 percent of consumers choose home and community based services. The steering committee further recommends that it is Oregon's policy that all consumers have a right, a choice, and an entitlement to home and community based services as well as nursing facility services. As Oregon continues to innovate in long term service and support delivery, it will explore new models that are responsive to consumers' preferences and consumers' understanding of what independence, choice, and dignity mean to them. The goal is to provide a more person-centered approach to care throughout the long term care system. While Oregon is known for innovation, Oregon will commit to putting protections in place for current and future consumers regarding information, access, choice and full disclosure about where they live and receive services, and how new models will be monitored. Along with new models of service delivery, Oregon will explore improvements on its assessment tool, which too often falls short of providing services for those with lower service needs and – as evidenced by the number of exceptions –

services for consumers with very high needs. Financial supplementation strategies and transforming the roles of nursing facilities, away from their traditional purpose, will also be explored.

- ***Improve coordination of services between LTSS and health care systems and mental health and addictions services.*** This includes carrying out the CMS Study Group Report Recommendations including implementation of dual-eligible and pre-dual-eligible outreach and robust pre- and post-discharge planning and support for caregivers. It also includes improving care transitions regardless of payer or system and better coordination and service delivery of mental health and addictions services for older adults and people with disabilities.
- ***Promote, statewide, livable, accessible and age-friendly communities.*** This includes community planning to support universal home design/modification, age/people with disabilities-friendly community planning, mobility options that encourage walkability and wheelchair accessibility, access to healthy nutrition, recreational, and civic activities, and it requires state level coordination between the Oregon Department of Transportation, Department of Housing & Community Development and other state planning agencies. For all communities in Oregon – urban, rural and frontier – this includes transportation necessary to help people remain in their home, or in the least-institutional environment.
- ***Continue building, evaluating, and where necessary, modifying a statewide Aging and Disability Resource Connection (ADRC) infrastructure.*** This includes enhancing linkages to private and non-profit sectors, including private care delivery and employers/solo business owners.
- ***Enhance and promote innovative and evidence-based prevention services packages.*** This includes chronic disease self-management, medication management, money management, nutrition assistance, mental health and addictions services and unpaid caregiver support. Oregon will also explore the possibilities of a pre-Medicaid, prevention level of services for consumers who need one-time or infrequent supports and services and who are at risk of becoming eligible for full Medicaid Services.

- **Enhance and create sustained resources for systems of support, training, respite and other resources and policy protections for paid and unpaid caregivers.** These include: robust and sustainable funding for respite and adult day services; use of evidence-based approaches such as those examined by the Minnesota Dementia Study,¹⁹ and pre- and post-discharge support programs such as Housecall Providers; additional resources to provide continued funding for caregiver training initiatives for both paid and unpaid caregivers; promotion of career ladders for paid caregivers; the promotion of volunteerism in addressing the shortage of caregivers; and enhancement of available transportation options.
- **Support, encourage, and apply technologies and adaptive equipment designed to improve services and outcomes at all levels.** Examples include use of technologies by care providers to better deliver and coordinate care, purchase of adaptive equipment that reduces caregiver need and increases consumer independence, assist consumers to secure information and better self-manage care, and research to identify trends and analyze outcomes.
- **Create and invest in outreach and engagement to underserved communities.** This entails proactive relationship-building and long term collaboration with communities of underserved older adults and people with disabilities, including communities of color, LGBT consumers, individuals for whom English is not the primary language, and individuals living in rural and frontier areas of the state.
- **Develop a culturally and linguistically responsive workforce.** Providers, case managers, and others in the LTSS workforce will serve an increasingly diverse consumer population and the workforce must be developed with a service equity lens with regard to hiring, retention, promotion, career ladders, and workforce training.
- **Improve data collection, analysis and reporting on service equity.** This includes building capacity to have data that are granular and inclusive of diverse populations, as well as new analytical tools to evaluate and improve the delivery system to meet the needs of an increasingly diverse population.

¹⁹ MS Mittelman and SJ Bartels, "Translating Research into Practice: Case Study of a Community-Based Dementia Caregiver Intervention." *Health Affairs*. 2014, 33.4: 587-595.

Public Feedback: The SB 21 Community Tour

SB 21 required that APD conduct public hearings in all regions of the state to receive public input on the development of the plan.²⁰ With the above strategies finalized, APD organized public meetings across the state at which the public would review and prioritize these strategies. During the fall of 2014, there were 30 public meetings in 21 Oregon communities.²¹ Many of the same issues were also discussed at an AARP Oregon Tele-Town Hall call in November 2014.

Staff designed a brief Power Point presentation²² to inform the public of the work of the SB 21 Steering Committee and subcommittees and used the aforementioned Roadmap document to describe the three main objectives of SB 21 and the strategies the SB 21 Steering Committee recommended under each goal.

Following the slide show presentation, the participants were asked to take the Roadmap document and break into smaller groups to discuss the priorities and how they matched the needs of their local communities. The small groups of 3-6 people were tasked with ranking the strategies of each objective on a scale of 1-3, with 1 being the highest. They were also asked to identify strategies and needs of their communities they felt were missing from the Steering Committee's recommendations. At the end of each session, APD asked participants to complete a survey of the priorities, ranking their top three for each objective on a scale of 1 to 3, with 1 being the highest. It was the hope that through the private and anonymous surveys, attendees would be able to share further concerns about long term services and supports. In some instances, small group discussions only allow for the loudest voices to be heard. These surveys gave each community member the opportunity to share their thoughts.

²⁰ SB 21A, p.2.

²¹ A list of SB 21 Community Tour meeting sites is available at <http://www.oregon.gov/dhs/spwpd/docs/Senate%20Bill%202011%20Community%20Tour%20Official%20Master%20List.pdf>, accessed 19 December 2014.

²² The Power Point presentation is available at <http://www.oregon.gov/dhs/spwpd/docs/SB%202011%20Community%20Tour%20Presentation.pdf>, accessed 19 December 2014.

Over 200 surveys were completed by participants. APD staff recorded the strategies that received a one, two or three ranking on each survey. The survey results, survey comments, and summaries of small group discussions gave the Steering Committee some direction for the future, but there were some limitations based on the turnout at the public meetings. There was a larger turnout in the rural areas, making their priorities more prevalent in the analysis. In addition, the attendees who completed the survey were people who are already receiving supports, caring for someone who does, or are active in the field (such as caregivers, social service workers and government employees). Furthermore, while some community forums targeted to underrepresented groups were conducted, more extensive outreach to underserved communities would have provided more feedback on how services and supports would need to be adapted to changing demographics in the future. Nonetheless, these results reflect the priorities discussed in the SB 21 Steering Committee and subcommittees and also reflect feedback APD received in its series of public meetings across the state in the fall of 2012.

Here are the top three strategies marked as a first, second or third priority on the surveys APD received:

Objective 1: Priorities that support seniors and people with disabilities to stay in their own homes and communities:

1. Ensure full access to transportation.
2. Ensure that all Oregonians have an equal right to choose whether they would like to receive long term services and supports in their home and community or in a nursing home.
3. Educate Oregonians about all options for receiving long term services and supports.

Objective 2: Priorities for supporting seniors and people with disabilities to achieve and maintain their financial independence:

1. Address housing, social isolation, and other social needs.

2. Conduct more health and mental health prevention, promotion and education.
3. Support paid and unpaid caregivers.

Objective 3: Priorities to serve all people and cultures equitably, in a manner they choose:

1. Earn trust by meeting with and hearing the needs of diverse communities.
2. Support for paid and unpaid caregivers in diverse communities.
3. Build a culturally responsive workforce.

For strategies to support consumers staying in their own homes and communities, meeting participants prioritized transportation, the right to live in their own homes and community settings, education about options, and access to caregivers. For strategies to maintain independence, priorities included housing and other social needs, health promotion and education, support for caregivers, and transportation. Top prioritized strategies for service equity included earning trust with underserved communities, support for caregivers in these communities, and building a culturally responsive workforce. Overall, the results indicate high priorities given to access to services, support for caregivers, education, and building relationships between APD and the community.

The individual surveys asked meeting participants to provide feedback in their on the strategies they chose, as well as those that were missing. While caregiver, service equity and community relations were often cited in the surveys, the three most frequently mentioned priorities were economic insecurity and access to services, education and training, and housing. The pervasive themes that were captured in the group discussions were housing, caregivers, education, transportation, underrepresented communities, person-centered strategies, mental health needs, finances, and access to services and information. Transcripts of the flip charts and subsequent conversations were created to carefully identify the topic trends.

Meeting participants expressed both concerns and ways that the state can address them.

Economic Insecurity and Access to Services

Across the state, in rural and urban communities the most commonly identified barrier to keeping people independent is economic insecurity and barriers to access services, according to the surveys. Funding shortfalls affect meal and transportation programs, in addition to access to mental health services, social and housing needs and access to low cost quality caregivers. Many communities expressed dismay over seeing their loved ones and peers slip through the cracks as individuals made too much money to receive supports or were not receiving enough support to maintain independence, such as being able to make home modifications or have access to transportation to get to social events.

Underemployed and impoverished seniors faced tough choices, having to choose between housing costs and heating bills. Living in poverty decreases the likelihood of individuals aging in place.

While these concerns were expressed, solutions were also presented. Providing small stipends to volunteers to drive seniors and people with disabilities to medical appointments, shopping areas, and other social events would keep people active and give them access to the items needed to maintain independence. Providing low-cost training to all caregivers, and giving family caregivers a stipend were some other methods shared by Oregonians to keep seniors at home. The quality of caregivers was seen as essential by participants for keeping seniors healthy, informed and preventing isolation and abuse.

In the group discussions, access to resources was a common concern expressed in the community forums. Many of the communities experience a lack of affordable housing, adult day services, and employment options for seniors and people with disabilities. These factors put more stress on families whose caregivers and seniors needed to work outside the home. Economic viability was believed to be a key factor in keeping people independent and in their homes, with barriers being living on a fixed income and facing food insecurity. Existing programs, such as home-delivered meal programs or transportation supports, are not always available in rural areas.

Even when programs exist to relieve financial stress in these areas, they are not well-known among community members. For example, participants who shared stories of financial stress and need were unaware of the financial planning options provided by the Aging and Disability Resource Connection (ADRC), the location of the local DHS office and how to apply for and access Medicaid and other services. In some group discussions, participants talked about fear in talking with government agencies because they believed they had to deplete their savings to become eligible for services, or that DHS only provided “welfare.”

Education

According to many survey comments, training and education are not only essential for caregivers and providers, but education and access to information are also viewed as tools for empowerment, support and trust with government entities. Community forums and meetings give citizens the opportunity to engage with public employees and build relationships while receiving information on programs, classes and agencies that can assist seniors and people with disabilities with gaining access to resources. Participants identified the rural/urban divide that exists within Oregon. They felt that the tactics and strategies that are created in Salem do not work outside the Willamette Valley. Examples discussed included difficulty accessing the internet, long distances between towns, and how the cost to serve individuals increases the further one lives from the metro Area. Being informed about what options are available in their communities was a high priority.

Participants felt this could be achieved through training courses for caregivers, providers, local businesses and government agencies at community wide meetings. Having all entities involved would facilitate the coordination of services, build relationships, and increase trust between the community and government. Many participants were unsure of where the local APD offices were located and believed those offices to be solely for self-sufficiency services, such as Temporary Assistance for Needy Families and other cash assistance programs.

Training caregivers and medical personnel in a comprehensive manner would also help to deter abuse of consumers and achieve service equity by helping providers recognize and respect the choices their consumers make. Home has a different meaning to everyone, and knowing what options for home are can help the providers, consumers, and social service workers find the best solution for choice, dignity and independence.

Housing

Survey comments also frequently cited housing as a priority area. Community members in attendance desired to have options of living at home; however, in many areas housing was limited, particularly housing for low-income seniors and people with disabilities. The major concern was not having a choice, due to limited options. For example, some working adults feared their only choice was to put a loved one in a facility because adult day services were unavailable in rural areas and the primary caregiver had to work outside the home. Accessible housing for people with disabilities was also limited along the coast and central and eastern Oregon. The lack of wheelchair accessibility can keep people confined in their homes if corridors and stairs are a barrier. Home modification programs are not available making it difficult for consumers to age in place in a safe manner. Even if consumers are able to leave their homes, they may experience difficulty accessing transportation or navigating the community if the sidewalks and crosswalks are not accessible or safe for people with disabilities. Housing options may be far from bus stops and sites for recreation, nutritional and social needs. The coordination of services between government agencies, city planners, providers and social service workers is how participants see the development of age- and disability-friendly communities coming to fruition.

Caregivers

One of the most commonly discussed and prioritized areas in small group discussions involved caregiver issues. Caregiver needs were addressed in three ways: paid caregivers, unpaid or family caregivers, and consumers' needs for caregiving professionals. Paid caregiver issues were of particular importance to

participants, as they recognized the increased demand for caregiver services. They expressed the desire to decrease the turnover rate among current caregivers and expand recruitment of caregivers into the labor force. Suggestions were given as to how to accomplish these goals, including increasing pay and recognizing the difficult and meaningful job that caregivers do. To diversify and increase the number of caregivers in the workforce participants addressed the need to change the perception of what a stereotypical caregiver looked like and suggested increasing recruiting efforts to groups underrepresented in the workforce, such as men and younger people. They felt as though the door was not open to quality caregivers who were non-traditional. In addition to opening jobs to younger people and men, participants would like to see training programs for veterans that would allow them to become caregivers.

Training and education of paid caregivers benefits both the workforce and the consumers, increases the awareness of the various preferences of consumers, and helps curb assumptions made about individual choice, better-supporting consumers in their decisions. Providing training and courses in various formats, accessible to a wide array of people, such as electronic and traditional classrooms, would benefit a wide range of caregivers to aid them in completing courses and increasing their skill set.

As caregivers complete mandatory trainings and courses, it is hoped that they will be able to provide quality and person-centered services. Consumers who are seeking a range of caregiver supports would be secure in knowing where to access information about potential caregivers who have passed a rigorous background check and screening process to prevent abuse.

Furthermore, consumers were concerned about the cost of caregivers and wanted to see more options for low-cost, quality caregivers. Many consumers were uncomfortable with the financial advice they were given to qualify for federal and state programs.

Due to caregiving costs being high, many consumers rely on family caregivers. Family caregivers often work outside the home, in addition to their caregiving

responsibilities. Family caregivers in attendance expressed the need for respite, adult day facilities and mental health services to keep them in the capacity as caregiver for as long as possible. Many caregivers were worried that they would undergo a crisis of their own while caring for a loved one without the extra support. Respite, stipends, and social and mental health services as resources were high priorities in rural areas where adult day centers did not exist for unpaid caregivers, such as La Grande.

Underrepresented Communities

The needs of underrepresented communities were another set of issues discussed frequently in small group discussions. For the purposes of the community tour, an underrepresented community was defined as one that is rural, a cultural, ethnic, racial, or sexual minority, as well as young people with disabilities. Many concerns were raised from members of these communities in regard to access to government and data, and the divide that exists between rural and urban Oregon. These sentiments were echoed by other underrepresented groups in terms of their access to policy decisions and building trust with government officials. Raising awareness and educating providers, agencies, and officials about the needs of varying communities across Oregon was the first step identified by most participants in building trust and increasing dignity for these communities throughout the state.

Many consumers viewed the four listed strategies of service equity (a culturally responsive workforce, supporting caregivers, earning trust of diverse communities, and data to improve service equity) as interdependent without one, you cannot achieve the other three. Data collection was seen as the foundation to success in achieving service equity. The data would have to be adaptable to different regions in order to work with existing resources, as resources are not as abundant in underrepresented communities. Once the data identified needs, the advocates, social service workers, providers, and officials could then go out in the communities and build relationships based on the results. In turn, a culturally and linguistically responsive workforce could be developed to provide a more

equitable distribution of resources among all communities in Oregon, including, respite and information and access to services that support individual choice.

Other Themes

While economic insecurity and access to services, education and housing were ranked highest on the individual survey comments, and caregivers and underrepresented communities were the most frequently prioritized in small group discussions, an underlying theme of collaboration, trust, and empowerment was expressed in survey comments in each area. Participants expressed the need for government agencies to work with local partners and community members in order to serve the needs of each community better, making outreach a foundation for all communities, not just the underrepresented communities. Once trust is established communities and individuals will know where to turn for resources, information and education. Educational resources will empower them to know their options and, hopefully, plan for their future needs for long term services and supports before a crisis occurs.

Proposed Short, Medium and Long Term Roadmap for the Future of Oregon's Long Term Services and Supports

SB 21 requires that DHS submit this report with a timeline for the implementation of the plan in whole or in part.²³ The implementation timeline below includes strategies in the current/short, medium and long term. These strategies reflect the work of the SB 21 planning process: the data and research into the causes of entry and cost drivers of Medicaid LTSS, the recommendations of the SB 21 subcommittees, the recommendations of the SB 21 Steering Committee, and the public feedback at the SB 21 community meetings.

Both APD and the SB 21 Steering Committee recommend that the 2015 Legislative Assembly accept these objectives and strategies, with three important areas of emphasis.

First, the SB 21 Steering Committee finds that implementing and monitoring progress on the strategies will require the availability of strong data and analytical and predictive modeling capability. Steps to accomplish this include:

- Developing a robust inventory of existing data, software, analysis and reporting systems;
- Developing, maintaining and continuously improving upon measurements of progress toward goals and objectives; and
- Building, improving, and maintaining data and research capability for data analysis and predictive modeling for future needs, including the necessary financial resources.

Second, the SB 21 Steering Committee finds that the commitment to service equity – serving Oregonians in a manner they choose – is a foundational principle that has not only its own set of strategies (under Objective 3) but also informs the strategies under Objectives 1 and 2.

Third, while there are ten strategies under Objectives 1 and 2 – supporting seniors and people with disabilities to stay in their own homes and communities, and to

²³ SB 21A, p. 2.

achieve and maintain their independence – the Steering Committee has identified **caregivers, housing and transportation** as the three highest priority areas to which future planning and implementation should be devoted, and the Steering Committee considers housing and transportation as inexorably linked. These three areas are central in strengthening and improving upon Oregon’s model of supports and services so that seniors and people with disabilities can have a better quality of life, with independence, choice, and dignity.

Current and short term strategies are for the 2015-2017 biennium, while medium and longer term strategies cover from 2015 through 2021 and 2025, respectively. The right hand columns indicate that the strategies may require administrative action by the state, stakeholder involvement and collaboration, legislative action, and/or federal action. Each strategy is followed by next steps and participating entities.

Objective #1 - Support seniors and people with disabilities to stay in their own homes and communities.

STRATEGY: Ensure that all Oregonians have a right to choose whether they would like to receive long term services in their home and community or in a nursing home.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Continue implementation of the K Plan Option to build on services in the consumer's own home and community.	x	x		
Medium Term	Build on capacity to serve individuals with high service needs in home and community settings, and improve Oregon's assessment tool to better reflect consumer needs along the spectrum of low to high needs for assistance.	x	x	x	x
Long Term	Explore strategies to mitigate barriers to increased housing options and to accessible communities.	x	x	x	

Next Steps: APD continue implementation work with K Plan Option.
Participating Entities: APD, Stakeholders

STRATEGY: Educate Oregonians about all options for receiving long term services and supports, and improve access to help and information, including resources for personal financial planning.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Continue to build a statewide ADRC infrastructure and Money Management program.	x	x		
Medium Term	Build capacity for robust options counseling to serve individuals who are not Medicaid eligible; explore successful financial planning initiatives for consumers and family members across the lifespan; continue to invest in low-cost programs to assist those facing economic insecurity.	x	x	x	x
Long Term	With a statewide ADRC infrastructure in place, fully implement a "no wrong door" approach to education, outreach, and information about options for every Oregon community, including resources for financial planning.	x	x		

Next Steps: APD and partners complete grant to fund the building of ADRC infrastructure.

STRATEGY: Provide access to quality caregivers and improve support for paid and unpaid caregivers.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Implement SB 1542, which provides access for private pay consumers to home care workers; fund evidence-based training opportunities for both paid and unpaid caregivers; fund continued growth of evidenced-based training resources to be available to paid and unpaid caregivers; continue to invest in the work of the Home Care Commission; fund Lifespan Respite by 2017.	x	x	x	
Medium Term	Create centralized mechanisms for recruiting, training, and improving the portability of the paid LTSS caregiver workforce; develop additional respite resources for paid and unpaid caregivers, including adult day services.	x	x	x	
Long Term	Build upon and sustain evidence-based training resources for all caregivers and career ladders and lattices for paid caregivers.	x	x		

Next Steps: APD and the Home Care Commission work with stakeholders to implement SB 1542.

STRATEGY: Coordinate social and health systems to help consumers.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Continue development of coordination between LTSS and CCOs through local LTSS innovator agents and Memoranda of Understanding (MOU) agreements.	x	x	x	
Medium Term	Develop and implement metrics of LTSS and CCO coordination to improve consumer outcomes and work with OHA, CCOs and partners for better Medicare-Medicaid alignment.	x	x		x
Long Term	Explore the development of services, for dual eligible and pre-dual eligible consumers, including preventive health, mental health and social services, who are at risk of Medicaid LTSS eligibility.	x	x	x	x

Next Steps: APD continue to work with local APD and AAA offices, OHA, and CCOs to develop coordination of care and LTSS in communities across the state.
Participating Entities: APD, Stakeholders, OHA

STRATEGY: Provide access to technology and other adaptive aids that support independence.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Develop a comprehensive survey of existing and developing assistive technology.	x	x		
Medium Term	Explore and implement options for supporting assistive technology for consumers and caregivers.	x	x	x	
Long Term	Seek strategies to use technology in the broader context of developing accessible and age-friendly communities in all areas of the state.	x	x	x	

Next Steps: APD research and work with stakeholders on a report on current and emergent assistive technology.

STRATEGY: Develop new models to call “home.”

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Continue to explore new models, such as housing with services and other forms of housing that exist in Oregon and other states, as well as protections for consumers in these models.	x	x	x	
Medium Term	Develop and implement changes in LTSS that reflect the new home and community based care federal regulations to better serve consumers.	x	x		x
Long Term	Continue exploring new models to call home, including services and supports to develop age-friendly and accessible communities and consumer protections in these models to ensure Oregonians can age in place.	x	x	x	x

Next Steps: APD to work with stakeholders and other state agencies in exploring new models through the Housing Policy Committee, as well as continuing current planning on the new home and community based services regulations.

STRATEGY: Ensure full access to transportation.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Continue enhancing resources to support existing programs, including ODOT's Special Transportation Fund.	x	x	x	
Medium Term	Develop volunteer and permanent staffing resources as well as capital investments for transportation services.	x	x	x	
Long Term	Continue building partnerships with state and local transportation agencies, including the exploration of sustainable public and private funding mechanisms for special transportation services and development of rural transportation options.	x	x	x	x

Next Steps: APD to build partnership with ODOT and local transit authorities and stakeholders to take inventory of current transportation resources.

Objective #2: Support seniors and people with disabilities to achieve and maintain their independence.

STRATEGY: Conduct more health and mental health prevention, promotion, and education.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Explore sustainable funding for programs, such as falls prevention and chronic disease self-management.	X	x		x
Medium Term	Utilize the ADRCs and other community partners, including CCOs, to provide outreach and education programs to consumers.	X	x		
Long Term	Sustain prevention, promotion and education programs in all communities across the state	x	x		x

Next Steps: Take inventory of successful past and present programs for health and mental health prevention, promotion, and education.

Participating Entities: APD, Stakeholders

STRATEGY: Address housing, social isolation, and other social needs.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Build partnerships with state and local housing agencies and successful local volunteer programs.	X	x		
Medium Term	Explore sustainable public and private funding for affordable housing and peer volunteer programs with state and community organizations, as well as the development of pre-Medicaid prevention services for one-time and infrequent supports.	X	x	x	x
Long Term	Build and sustain programs to decrease barriers to affordable and accessible housing, as well as programs to support employment, social programs and nutritional programs for consumers.	X	x	x	

Next Steps: APD to convene a group of stakeholders and housing entities and partners to take inventory of current resources.

STRATEGY: Focus and support community planning for age- and disability-friendly communities.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Explore models of age-friendly communities nationally and internationally, including communities with strong volunteer networks.	X	x		
Medium Term	Explore the possibilities of technologies to make housing, neighborhoods, and communities more accessible to seniors and people with disabilities.	X	x	x	
Long Term	Develop and adopt best practices for urban, suburban, rural and frontier age-friendly communities as they relate to community planning, housing, transportation, access to healthy food, and access to employment and other broad social and community participation.	X	x	x	x

Next Steps: APD to convene a group of stakeholders to take inventory of current volunteer programs, and have APD staff connect with research on age-friendly communities.

Objective #3 - Serve all people and cultures equitably and in a manner they choose.

STRATEGY: Build a culturally responsive workforce.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Develop community partnerships to build a strategy for workforce development.	X	x		
Medium Term	Develop intentional workforce recruitment, retention and training programs for providers and APD and AAA staff.	X	x		
Long Term	Develop relationships and mechanisms to continually improve upon programs to sustain a culturally responsive workforce	X	x		

Next Steps: APD work with stakeholders to take inventory of current efforts to build a culturally responsive workforce.

STRATEGY: Support for paid and unpaid caregivers in diverse communities.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Build relationships with underserved communities to get an understanding of caregiver needs.	X	x		
Medium Term	Develop mechanisms of training and support for paid and unpaid caregivers, as well as intentional, targeted recruitment, retention and promotion of paid caregivers in underserved communities.	X	x	x	
Long Term	Maintain and improve upon support systems for caregivers in diverse and underserved communities.	X	x		

Next Steps: APD initiate outreach to stakeholders, local offices and leaders in underserved communities to build relationships.

STRATEGY: Earn trust by meeting with and hearing the needs of diverse communities.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Continue developing relationships with diverse communities, both at the local and statewide level.	X	x		
Medium Term	Develop feedback mechanisms that are responsive to the needs and concerns of underserved communities.	X	x		
Long Term	Improve upon communication and continuous feedback to respond to the concerns of underserved communities.	X	x		

Next Steps: APD initiate outreach and dialogue with stakeholders, local offices and leaders in underserved communities.

STRATEGY: Collect data to improve service equity.

Timing	Actions	State Gov't	Stakeholders	Legislature	Fed. Gov't
Current/Short Term	Continue developing data systems to identify disparities in services to underserved communities, including continued implementation of HB 2134.	X	x		
Medium Term	Use both quantitative and qualitative data, as well as outreach and communication, to identify and address service disparities.	X	x	x	
Long Term	Improve upon data systems to address and be responsive to the growing diversity of Oregon's seniors and people with disabilities in the future and to monitor service quality.	X	x	x	

Next Steps: APD and DHS work to develop data systems under HB 2134, in partnership with stakeholders.

Conclusion

SB 21 provides a framework for planning through its three objectives for Oregon's older adults and individuals with disabilities: serving people in their own homes and community settings of their own choosing, supporting independence by delaying or avoiding publicly-funded long term care services, and serving people equitably, in a culturally and linguistically responsive manner, all while developing, building, supporting and maintaining strong research , data and reporting systems that inform and support ongoing goals of supporting choice, independence, and service equity for Oregon's seniors and people with disabilities. These objectives are rooted in the core principles and state statute of Oregon's system:

The Legislative Assembly finds and declares that, in keeping with the traditional concept of the inherent dignity of the individual in our democratic society, the older citizens of this state are entitled to enjoy their later years in health, honor and dignity, and citizens with disabilities are entitled to live lives of maximum freedom and independence.²⁴

APD, in partnership with the stakeholders, advocates, and communities involved in the planning process of SB 21, respectively submits this report and its recommendations and implementation timeline to the 2015 Legislative Assembly.

²⁴ Oregon Revised Statute 410.010(1).

Appendix A: SB 21 Steering Committee and Staff Roster

SB 21 Steering Committee:

Senator Jeff Kruse
Senator Laurie Monnes Anderson
Representative Nancy Nathanson
Representative John Davis
Rodney Schroeder, Oregon Association of Area Agencies on Aging and Disabilities
Jim Carlson, Oregon Health Care Association
Ruth Gulyas, LeadingAge Oregon
Jerry Cohen, AARP Oregon
Leroy Patton, Elders in Action
Tina Treasure, State Independent Living Council
Joseph Lowe, Home Care Commission
Anne Bellegia, Rogue Valley Council of Governments Senior Advisory Council
Nancy Pierce, Governor's Commission on Senior Services
Mike Volpe, Oregon Disabilities Commission
Jim Davis, Marylhurst University
Margaret Neal, Portland State University
Daniel Torrence, Adult Foster Home Provider
Mary Jaeger, Long Term Care Ombudsman

SB 21 Data and Research Subcommittee:

Jerry Cohen, SB 21 Steering Committee
Jim Carlson, SB 21 Steering Committee
Mary Jaeger, SB 21 Steering Committee
Margaret Neal, SB 21 Steering Committee
Ruth Gulyas, SB 21 Steering Committee
Walt Dawson, Oregon Health Care Association

SB 21 Assessment Subcommittee:

Suanne Jackson, APD State Unit on Aging
Karen Kahl, APD Field
Ruth McEwen, Disability Advocate
Joseph Lowe, SB 21 Steering Committee

Suzy Quinlan, APD Medicaid Policy
Rodney Schroeder, SB 21 Steering Committee
Kati Tilton, Clackamas Area Agency on Aging
Tina Treasure, SB 21 Steering Committee
Mike Volpe, SB 21 Steering Committee

SB 21 Caregiver Subcommittee:

Anne Bellegia, SB 21 Steering Committee
Meghan Moyer, SB 21 Steering Committee
Jon Bartholomew, AARP Oregon
Dave Toler, Rogue Valley Council on Governments Area Agency on Aging
Cheryl Miller, Home Care Commission
Jan Karlan, APD State Unit on Aging
Mike Volpe, SB 21 Steering Committee
Tina Treasure, SB 21 Steering Committee
Roxanne McAnnally, Home Care Commission

SB 21 Service Equity Subcommittee:

Jim Davis, SB 21 Steering Committee
Daniel Torrence, SB 21 Steering Committee
Julian Spalding, Rogue Valley LGBT Elders
Leroy Patton, SB 21 Steering Committee
Edna Nyamu, Oregon Community Health Worker Association
Phaedra Duarte, Oregon Home Care Commission
Amal Jama, Anatoli Adult Day Center
Lee Po Cha, Asian Family Center
Felicia Akubuiro, Multnomah County Adult Care Home Program
Ellen Garcia, Providence ElderPlace
Georgena Carrow, Advocate
Melissa Egan, LGBT Elder Housing
Ellen Greenlaw, Clackamas Disability Services Advisory Council
Galina Burley, Clackamas County
Andrew Riley, Center for Intercultural Organizing
Dennis Elliott, Advocate
Philipos Ghaly, Marylhurst University

Jason Mak, DHS Office of Equity and Multicultural Services
Elizabeth O'Neill, APD State Unit on Aging
CJ O'Connor, Advocate
Ryan Yency, Advocate

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Mike McCormick, APD Director
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Bob Weir
Max Brown
Ann McQueen
Naomi Sacks
Jeannette Hulse
Theresa Powell
Rebecca Arce
Cynthia Vargo
Deborah White
Jill Gray
Annie Woo
Brenda Autry

Appendix B: Assessment Subcommittee Report and Recommendations

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

<u>General Style/Approach:</u>	<u>Automation/Technology:</u>	<u>Components/Content:</u>
<ul style="list-style-type: none"> • <u>Doesn't re-ask things that don't change over time</u> • <u>Prompts for right questions and diagnosis at right time, good conversational flow</u> • <u>Intuitive to use</u> • <u>Prompts conversation with consumer</u> • <u>Simple for consumer to use and engages consumer</u> • <u>Easy to use and navigate</u> • <u>Role based access</u> • <u>Works to support consumer empowerment and</u> 	<ul style="list-style-type: none"> • <u>Web based with Internet capability in the field, tablet with touch screen with ability to capture signatures in the field, send material to consumers</u> • <u>Oracle platform (<i>reconsider based on Cover OR?</i>)</u> • <u>Master file of information accessible to all programs that need that information (such as financial data) with modules serving individual program data needs</u> • <u>Connects, imports and exports to other systems, data resources (providers,</u> 	<ul style="list-style-type: none"> • <u>Includes person-centered, consumer friendly approach and be strengths based</u> • <u>Captures more information relevant to service planning including capturing support information when assessing each need, equipment used or needed</u> • <u>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</u>

<p><u>responsibility</u></p> <ul style="list-style-type: none"> • <u>Consider using only 4 ADLs for consumers in facilities or make a streamlined assessment for those in facilities</u> • <u>Maintain highest level of security and consumer privacy protections</u> • <u>Always allows for exceptions</u> • <u>Focus on identifying risks and opportunities for preventative services</u> 	<p><u>medical systems, etc.)</u></p> <ul style="list-style-type: none"> • <u>Alerts, auto navigation to direct to other data fields as appropriate, pop-ups with relevant info</u> • <u>System auto sends or connects to consumers, providers, other programs and resources for referrals</u> • <u>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</u> • <u>Auto translation</u> 	<p><u>these</u></p> <ul style="list-style-type: none"> • <u>Simplified navigation between elements (service planning, client details, assessment)</u> • <u>Simplified in-home plans / hrs. assignment, records # of hours assigned per worker, more automation of multiple caregiver plans</u> • <u>Best practice for cognition, dementia, traumatic brain injury, mental health, assessments- use externally validated tools and scales, train staff for use</u> • <u>Consider inclusion of a self-assessment component</u> • <u>For categorically eligible – requires only functional assessment & planning once</u>
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	<ul style="list-style-type: none"> • <u>Voice recognition</u> • <u>Video/picture capacity</u> • <u>Excellent search functionality across narratives, comments and other data fields</u> • <u>Has robust reporting capacity to meet program planning, development, integrity/quality assurance, transparency and predictive modeling needs at state and local levels</u> • <u>Has internal consistency and quality assurance checks built in so staff is unable to enter inconsistent information, or they get alerts to check</u> • <u>Auto generated, short summary of past service plans available at all times</u> 	<p><u>eligibility is determined</u></p> <ul style="list-style-type: none"> • <u>Exceptions continue if condition doesn't change</u> <ul style="list-style-type: none"> ○ <u>Look at existing data first and prompt or auto approval</u> ○ <u>Build in auto exceptions</u> • <u>Risk alerts</u> <ul style="list-style-type: none"> ○ <u>"Percolator" model- if an event occurs in other data systems (such as a hospital claim, an alert is generated</u> • <u>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</u>
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	<ul style="list-style-type: none">• <u>Has ability to make small changes without having to re-work entire assessment or create a new one</u>	<p><u>conversation with consumers</u></p> <ul style="list-style-type: none">• <u>Provides on the spot educational tools for consumers at the time of assessment (ex. 3 minute video)</u>• <u>Quality Assurance functions- checks for conflicting, unusual data (ex. multiple workers with extensive hours)</u>• <u>Includes all necessary information to meet rule, waiver, state plan and other required elements</u>
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Appendix C: Service Equity Subcommittee Report and Recommendations²⁵

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.

²⁵ A full version of the report is available at <http://www.oregon.gov/dhs/spwpc/docs/Caregivers%20Subcommittee%20Report.pdf>, accessed 30 January 2015.

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.²⁶ (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.

²⁶ 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>

- 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.

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.

Appendix D: Caregivers Subcommittee Report and Recommendations²⁷

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

²⁷ A full version of the report with supporting documents is available at <http://www.oregon.gov/dhs/spwpd/docs/Caregivers%20Subcommittee%20Report.pdf>, accessed 30 January 2015.

- 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
- 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 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
 - 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?