Oregon Council on Developmental Disabilities

State Plan

For Federal Fiscal Year 2016

Submitted on: 2015-12-31 13:10:25

Oregon Council on Developmental Disabilities
540 24th Place NE
Salem, OR 97301
Section I : Council Identification


PART B:  Contact Person:  Jaime Daignault

Phone Number:  (503) 881-9525

E-Mail:  jaime.daignault@state.or.us

PART C:  Council Establishment:

(i) Date of Establishment:  1974-10-23

(ii) Authorization:  Executive Order

(iii) Authorization Citation:  Executive Order No. EO-74-18; continued by EO 02-24

PART D:  Council Membership [Section 125(b)(1)-(6)].

(i) Council Membership rotation plan:

The Council recommends self-advocates and family members for appointment to the Council by the Governor. Recommendations are made to reflect Oregon’s geographic, racial, ethnic, and disability diversity. Members serve up to two consecutive four-year terms. Former members who wish to be nominated for a third term may apply after waiting one full four-year period. Representatives of agencies with required representation on the Council are exempt from term limits or waiting periods.
## (ii) Council Members:

<table>
<thead>
<tr>
<th>#</th>
<th>Name</th>
<th>Code</th>
<th>Organization</th>
<th>Appointed</th>
<th>Term Date</th>
<th>Alt/Proxy State Rep Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Costello, Robert</td>
<td>A1</td>
<td>Office of Vocational Rehabilitation Services (OVRS)</td>
<td>2013-07-01</td>
<td>2017-06-30</td>
<td></td>
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<tr>
<td>2</td>
<td>Wells, Jeremy</td>
<td>A2</td>
<td>Oregon Dept of Education</td>
<td>2014-06-30</td>
<td>2017-09-30</td>
<td></td>
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<tr>
<td>3</td>
<td>Jacobs, Julie</td>
<td>A3</td>
<td>Aging and People with Disabilities</td>
<td>2015-12-16</td>
<td>2019-12-15</td>
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</tr>
<tr>
<td>4</td>
<td>Joondeph, Bob</td>
<td>A5</td>
<td>Disability Rights Oregon</td>
<td>2015-12-16</td>
<td>2019-12-15</td>
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<tr>
<td>5</td>
<td>Boy, Rob</td>
<td>A6</td>
<td>OHSU UCEDD</td>
<td>2012-04-01</td>
<td>2016-03-31</td>
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<tr>
<td>6</td>
<td>von Ravensberg, Heidi</td>
<td>A6</td>
<td>UO UCEDD</td>
<td>2013-07-21</td>
<td>2017-06-30</td>
<td></td>
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<tr>
<td>7</td>
<td>Rodriguez, Laura</td>
<td>A8</td>
<td>Maternal Child Health Title V, Center for Children &amp; Youth w/Special Health Needs</td>
<td>2015-12-16</td>
<td>2019-12-15</td>
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<td>8</td>
<td>Deal, Larry</td>
<td>A9</td>
<td>Independence Northwest</td>
<td>2014-03-07</td>
<td>2018-03-06</td>
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<td>9</td>
<td>Lansky, Anna</td>
<td>A9</td>
<td>Office of Developmental Disabilities Services</td>
<td>2015-04-08</td>
<td>2019-04-07</td>
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<td>10</td>
<td>Simpson, Becky</td>
<td>A9</td>
<td>Pathway Enterprises</td>
<td>2013-08-01</td>
<td>2017-07-31</td>
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<tr>
<td>11</td>
<td>Sneddon, Jeff</td>
<td>A9</td>
<td>Linn County DD Program</td>
<td>2012-01-10</td>
<td>2016-01-09</td>
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<td>12</td>
<td>Wilson, Bernie</td>
<td>A9</td>
<td>Albertina Kerr</td>
<td>2013-08-30</td>
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<td>13</td>
<td>Alrick, Daniel</td>
<td>B1</td>
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<td>2015-10-23</td>
<td>2019-10-22</td>
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<td>14</td>
<td>Joyce, Andee</td>
<td>B1</td>
<td></td>
<td>2012-10-20</td>
<td>2016-10-19</td>
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<td>15</td>
<td>Lawson, Jordan</td>
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<td>2015-10-23</td>
<td>2019-10-22</td>
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<td>Londahl, Kaaren</td>
<td>B1</td>
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<td>2013-08-10</td>
<td>2016-08-09</td>
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<td>17</td>
<td>Nicholas Kaasa</td>
<td>B1</td>
<td></td>
<td>2013-07-31</td>
<td>2016-08-09</td>
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<td>18</td>
<td>Sanchez, Julie</td>
<td>B1</td>
<td></td>
<td>2010-04-01</td>
<td>2018-03-31</td>
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<td>Tucker, Daniel</td>
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<td>2014-01-27</td>
<td>2018-01-26</td>
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<td>20</td>
<td>Kriloff, Sean</td>
<td>B2</td>
<td></td>
<td>2015-12-16</td>
<td>2019-12-15</td>
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<td>21</td>
<td>Palmer, Katherine</td>
<td>B2</td>
<td></td>
<td>2012-10-20</td>
<td>2016-10-19</td>
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<td>22</td>
<td>Salehiamin, Carrie</td>
<td>B2</td>
<td></td>
<td>2015-12-16</td>
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<td>23</td>
<td>Shockley, Caitlin</td>
<td>B2</td>
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<td>2015-12-16</td>
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<td>24</td>
<td>Sisk, Noelle</td>
<td>B2</td>
<td></td>
<td>2012-10-20</td>
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<td>25</td>
<td>Utzman, Stephanie</td>
<td>B2</td>
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<td>26</td>
<td>Cox, Monica</td>
<td>B3</td>
<td></td>
<td>2015-12-16</td>
<td>2019-12-15</td>
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<tr>
<td>27</td>
<td>Osburn, Sherri</td>
<td>C1</td>
<td></td>
<td>2010-09-01</td>
<td>2014-08-31</td>
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## PART E: Council Staff [Section 125(c)(8)(B)]

<table>
<thead>
<tr>
<th>#</th>
<th>Name</th>
<th>Position or Working Title</th>
<th>FT/PT %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Benson, Melinda</td>
<td>Program Coordinator, Inclusive Child Care Program (ICCP)</td>
<td>100.00</td>
</tr>
<tr>
<td>2</td>
<td>Bronson, Laura</td>
<td>Communications and Project Coordinator</td>
<td>100.00</td>
</tr>
<tr>
<td>3</td>
<td>Daignault, Jaime</td>
<td>Executive Director</td>
<td>100.00</td>
</tr>
<tr>
<td>4</td>
<td>Inac, Sieu</td>
<td>High Needs Child Care Specialist, Inclusive Child Care Program (ICCP)</td>
<td>100.00</td>
</tr>
<tr>
<td>5</td>
<td>Kessler, Beth</td>
<td>Family Engagement Coordinator</td>
<td>100.00</td>
</tr>
<tr>
<td>6</td>
<td>Kirby, Amy</td>
<td>Subsidy Coordinator, Inclusive Child Care Program (ICCP)</td>
<td>100.00</td>
</tr>
<tr>
<td>7</td>
<td>Majors-Thrash, Becky</td>
<td>Budget/Operations Analyst</td>
<td>100.00</td>
</tr>
<tr>
<td>8</td>
<td>Newport, Ryley</td>
<td>Advocacy Coordinator</td>
<td>100.00</td>
</tr>
<tr>
<td>9</td>
<td>Owens, Cynthia</td>
<td>Transition &amp; Employment Specialist</td>
<td>100.00</td>
</tr>
<tr>
<td>10</td>
<td>Sutton, Leslie</td>
<td>Policy Director</td>
<td>100.00</td>
</tr>
</tbody>
</table>
PART A: The designated state agency is:

Department of Human Services
500 Summer St. NE
Salem, OR 97301
phone: (503) 945, fax: (503) 581
email: Clyde.K.SAIKI@dhsoha.state.or.us

PART B: Direct Services. [Section 125(d)(2)(A)-(B)].

The DSA provides direct services to persons with developmental disabilities. (DHS contracts to provide service coordination, employment, day programs, residential, in-home, family, and adult support services. It directly manages 120 specialized residential beds. DHS includes the Office of Vocational Rehabilitation Services.)

PART C: Memorandum of Understanding/Agreement: [Section 125(d)(3)(G)].

The DSA has a Memorandum of Understanding/Agreement with the Council.

PART D: DSA Roles and Responsibilities related to Council. [Section 125(d)(3)(A)-(G)]

DHS collaborates with the Council on DD issues and provides in-kind office space, utilities, and administrative support services as well as fund management. DHS also has representation on the Council and on at least one of its standing committees.

PART E: Calendar Year DSA was Designated. [Section 125(d)(2)(B)]

1974
INTRODUCTION: A broad overview of the Comprehensive Review and Analysis conducted by the Council.

The Office of Developmental Disability Services (ODDS) provides DD waiver and Medicaid Community First Choice state plan (K plan) services to about 23,776 eligible children and adults. Oregon has two DD waivers serving both children and adults. Oregon is experiencing a workforce shortage.

According to November 2015 DHS caseload data, 23,776 adults receive a variety DD waiver and K plan services (5,738 receive case management only). Most adults (77%) live in their own homes or family homes. About 5,455 (23%) live in 24-hour settings: 2,603 in foster care; 2,754 in group homes; 98 in state-operated 24-hour Stabilization and Crisis Units (SACU).

Oregon settled the Lane v. Brown lawsuit to increase access to supported employment services for people with IDD. Current VR data show that over the past two years there has been a 42% increase in people with IDD applying to VR; an 86% increase in people with IDD entering an IPE; and a 56% increase in people with IDD exiting VR with a competitive job.

Approximately 6,737 children are enrolled in waiver and K plan services. About 300 are enrolled in case management only, suggesting they are waiting for eligibility. Three waivers provide in-home supports to 373 children with significant behavioral or medical support needs; 2,065 receive in-home services; 122 children receive general fund family support; 496 live in foster care; 157 live in residential settings.

Funding for EI/ECSE has not kept pace with increasing caseloads. A 2012 legislative report confirmed that children and families are not receiving recommended levels of service. An additional $5.4 million is required in 2016 to meet service recommendations and caseload increases.

Several non-profit family support organizations are located throughout our state. They provide support, education and resource referrals to families. Additionally, the Council coordinates the Oregon Consortium of Family Networks with funding from DHS. The eight Family Networks facilitate a family empowerment and support model in local communities utilizing the principles of asset-based community development. According to evaluation data, the Networks effectively help families to create a vision for their children experiencing disability that includes employment, graduation, relationships and inclusion in all aspects of community life.

Housing
Oregon is currently experiencing a shortage of affordable housing for low and middle income people and families, especially in rural areas. A recent study jointly sponsored by three state agencies found that people with disabilities face widespread barriers to housing choice. Barriers cited include widespread discrimination related to disability, limited resources to transition out of institutional settings and lack of housing to transition
into. Oregon’s K Plan allows expenditures for people transitioning from a nursing or mental health facility to a less restrictive community setting. However, funds cannot be used to assist with transition from group homes. The Fairview Trust was legislatively created with funds from the sale of institutional properties. The Council is supporting a work group to develop recommendations to the state for creative use of Trust funds to increase access to community housing for people with IDD. The Council also supports a work group to maintain Community Integration Project (CIP) Homes (valued at $71,400,000) as a housing resource within the DD system.

The Oregon Health Plan (OHP) provides healthcare coverage to about 1.1 million Oregonians are enrolled in the program. Sixteen local health care networks called Coordinated Care Organizations (CCOs) work for better health, better care and lower costs by focusing on prevention, chronic disease management, earlier interventions, and reduction of waste and inefficiency in the health system. According to a 2014 report, CCOs continue to show improvements in several areas of care.

PART A: State Information

(i) Racial and Ethnic Diversity of the State Population:

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Percentage of Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>White alone</td>
<td>85.2%</td>
</tr>
<tr>
<td>Black or African American alone</td>
<td>1.8%</td>
</tr>
<tr>
<td>American Indian and Alaska Native alone</td>
<td>1.2%</td>
</tr>
<tr>
<td>Asian alone</td>
<td>3.8%</td>
</tr>
<tr>
<td>Native Hawaiian and Other Pacific Islander alone</td>
<td>0.4%</td>
</tr>
<tr>
<td>Hispanic or Latino of any race</td>
<td>12.2%</td>
</tr>
<tr>
<td>Some other race alone</td>
<td>3.6%</td>
</tr>
<tr>
<td>Two or more races:</td>
<td>4%</td>
</tr>
</tbody>
</table>

(ii) Poverty Rate: 17.20

(iii) State Disability Characteristics:

a) Prevalence of Developmental Disabilities in the State: 546000

We use an estimated 1.4% prevalence rate recommended by the Human Services Research Institute to determine that of the 39,000,000 Oregonians, 546,000 have DD.

b) Residential Settings:

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Served</th>
<th>A. Number Served in Setting of 6 or less (per 100,000)</th>
<th>B. Number Served in Setting of 7 or more (per 100,000)</th>
<th>C. Number Served in Family Setting (per 100,000)</th>
<th>D. Number Served in Home of Their Own (per 100,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>379</td>
<td>137.300</td>
<td>10.700</td>
<td>211.200</td>
<td>19.400</td>
</tr>
<tr>
<td>2007</td>
<td>459</td>
<td>140.500</td>
<td>153.900</td>
<td>144.700</td>
<td>19.800</td>
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<tr>
<td>2005</td>
<td>392</td>
<td>131.000</td>
<td>146.800</td>
<td>95.200</td>
<td>19.100</td>
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c) Demographic Information about People with Disabilities:

<table>
<thead>
<tr>
<th>People in the State with a Disability</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Population 5 to 17 years</td>
<td>4.5%</td>
</tr>
<tr>
<td>Population 18 to 64 years</td>
<td>11.7%</td>
</tr>
<tr>
<td>Population 65 years and over</td>
<td>37.5%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race and Hispanic or Latino Origin of People with a Disability</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>White alone</td>
<td>13.5%</td>
</tr>
<tr>
<td>Black or African American alone</td>
<td>14%</td>
</tr>
<tr>
<td>American Indian and Alaska Native alone</td>
<td>18.8%</td>
</tr>
<tr>
<td>Asian alone</td>
<td>6%</td>
</tr>
<tr>
<td>Native Hawaiian and Other Pacific Islander alone</td>
<td>9%</td>
</tr>
<tr>
<td>Some other race alone</td>
<td>7.2%</td>
</tr>
<tr>
<td>Two or more races</td>
<td>11.7%</td>
</tr>
<tr>
<td>While alone, not Hispanic or Latino</td>
<td>14%</td>
</tr>
<tr>
<td>Hispanic or Latino (of any race)</td>
<td>7%</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Percentage with a Disability</th>
<th>Percentage without a Disability</th>
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</thead>
<tbody>
<tr>
<td>Population Age 16 and Over</td>
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<tr>
<td>Employed</td>
<td>34.2%</td>
<td>64%</td>
</tr>
<tr>
<td>Not in Labor Force</td>
<td>69.9%</td>
<td>28%</td>
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</table>

<table>
<thead>
<tr>
<th>Education Attainment</th>
<th>Percentage with a Disability</th>
<th>Percentage without a Disability</th>
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</thead>
<tbody>
<tr>
<td>Population Age 25 and Over</td>
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<tr>
<td>Less than High School graduate</td>
<td>18.3%</td>
<td>9.2%</td>
</tr>
<tr>
<td>High School graduate, GED, or alternative</td>
<td>31.9%</td>
<td>22.4%</td>
</tr>
<tr>
<td>Some college or associate's degree</td>
<td>35%</td>
<td>36%</td>
</tr>
<tr>
<td>Bachelor's degree or higher</td>
<td>14.7%</td>
<td>32.4%</td>
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<table>
<thead>
<tr>
<th>Earnings in the past 12 months</th>
<th>Percentage with a Disability</th>
<th>Percentage without a Disability</th>
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<tbody>
<tr>
<td>Population Age 16 and Over with Earnings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$1 to $4,999 or loss</td>
<td>36.2%</td>
<td>22.5%</td>
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<tr>
<td>$5,000 to $14,999</td>
<td>10.2%</td>
<td>9%</td>
</tr>
<tr>
<td>$15,000 to $24,999</td>
<td>17%</td>
<td>16.7%</td>
</tr>
<tr>
<td>$25,000 to $34,999</td>
<td>12.5%</td>
<td>13.4%</td>
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</table>

<table>
<thead>
<tr>
<th>Poverty Status</th>
<th>Percentage with a Disability</th>
<th>Percentage without a Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population Age 16 and Over</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below 100 percent of the poverty level</td>
<td>29.4%</td>
<td>11.7%</td>
</tr>
<tr>
<td>100 to 149 percent of the poverty level</td>
<td>14.5%</td>
<td>8.1%</td>
</tr>
<tr>
<td>At or above 150 percent of the poverty level</td>
<td>65.7%</td>
<td>80.2%</td>
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PART B: Portrait of the State Services [Section 124(c)(3)(A and B)]:

(i) Health/Healthcare:
Since 1993, the Oregon Health Plan (OHP) provides medical assistance to the uninsured with a 1115 waiver. The OHP uses a prioritized list of covered services to determine health care services. During the economic downturn, we have seen reductions in the availability of optional services like vision, dental and DME and
restricted access to publicly funded healthcare. However, recent federal initiatives to expand Medicaid are encouraging.

After passage Affordable Care Act, Oregon opted to expand the OHP using Medicaid dollars. Subsequent health care transformation efforts aim to reduce healthcare costs and expand healthcare access to thousands of uninsured Oregonians. As a result, the OHP offers tiered levels of financial participation and is managed by Community Care Organizations (CCO) charged to improve health, lower healthcare costs, and provide a better healthcare experience.

Additionally, Oregon has implemented a Health Insurance Exchange, called Cover Oregon, where individuals can shop for health insurance and receive eligibility determinations for the Oregon Health Plan effective October 1, 2013. While rollout of the website has been problematic, as of November 2013 Oregon has reduced its number of uninsured by 10%. We are currently waiting for full implementation to fully understand the implications of reform efforts.

Regarding children, the OHP 1115 waiver agreement limits state responsibility to provide the treatment requirements of Early Periodic Screening Diagnosis and Treatment (EPSDT) to only those covered on the OHP prioritized list. This has been widely interpreted to mean that EPSDT itself has been waived. As a result, many children receive only limited testing and the mandate for EPSDT has not been aggressively enforced.

OHSU's Children's Development and Rehabilitation Center (CDRC), provides screening and clinical services to children with disabilities in several locations, and consults with local physicians. OHSU’s Title V Program, through an interagency agreement with the State Department of Public Health and County Health Care Departments, funds the CaCoon program, which provides limited in home support and care coordination for some children with disabilities throughout the state. Oregon’s children’s health care program, Healthy Kids, which encompasses the CHIP program and a provider tax funded expansion, serves over 85,000 children or 94.4 % of eligible children. Anecdotal information indicates many children with disabilities with private insurance lack coverage that fully addresses their health care needs.

Similarly, research and anecdotal information gathered in Oregon reflect a significant challenge to finding appropriate health care for adults with IDD. This problem is exacerbated by low OHP physician reimbursement rates, which act as a disincentive to provide Medicaid-funded healthcare. In response, the OCDD has a long history of ongoing legislative, policy and advocacy efforts to address these challenges. While past efforts have successfully led to modifications to the OHP to address disability concerns, we continue to advise current policy and practice. As a recent example, we engaged families and self-advocates to provide Cover Oregon input regarding website accessibility and procedures for people with disabilities.

With support from OCDD, the Oregon Commission on Autism Spectrum Disorder influenced passage of SB 365B during the 2013 legislative session. The bill created insurance coverage for Applied Behavior Analysis for children with autism and created a licensing mechanism for diagnosis and treatment of Autism Spectrum Disorders. Additionally, OCDD staff sits on the Oregon Medicaid Advisory Committee (MAC), a federally-mandated body which advises the operation of Oregon's Medicaid program. The MAC provides oversight and review of Oregon's administration of the OHP and makes recommendations to state agencies.

(ii) Employment:

Oregon was once a national leader in integrated employment during the mid-1980’s and 90’s, but fell far behind in the intervening years as the focus shifted to closing the institutions and addressing the waitlist. Without consistent attention, Oregon lost much of the knowledge, capacity, and demand for integrated employment. In
recent years, focus has again shifted to integrated employment. As evidence, Oregon’s Employment First policy was drafted and published in 2008; however, implementation has been slow. While expectations for integrated employment and demand for related services have steadily increased; the DD and VR service systems lack capacity to adequately address expectations and demands. This predicament has generated a great deal of frustration among job seekers and other system stakeholders.

In 2012, advocates filed a class-action lawsuit challenging Oregon’s failure to provide supported employment services to those segregated in sheltered workshops. Later, the US DOJ joined the lawsuit and the state entered into a federal mediation process. Unfortunately, a settlement was not reached. The anticipated court date is set for 2015.

In response, the Governor issued Executive Order 13-04, outlining plans to increase the funding and availability of supported employment services. The Order limits state support of sheltered workshops. At least 2,000 people are targeted to transition from sheltered work to integrated employment over a period of nine years. Advocates criticize the Order for low expectations for system change and that it does not address growing non-work programs. These programs continue to grow as students exit school without employment goals and families seek programs that will guarantee hours and transportation.

While these criticisms exist, the Order addresses significant system barriers to integrated employment. For example, DHS is directed to establish a comprehensive training and qualification system for job developers and employment specialists to increase capacity in Oregon’s communities to provide services that lead to regular jobs. Implementation also requires restructuring rates for day and employment services to incentivize supported employment and related services.

DHS publishes employment outcome data on its website. According to June 2013 data, 6,236 adults receive Comprehensive Waiver services. As of September 2013, 4,244 spend their days in sheltered workshops and non-work settings. Only 441 (10.4%) of these individuals are in individual integrated employment.

About 7,260 adults receive Supports Waiver services. According to March 2013 data, 3,277 adults use their funds for day services. Of this number, only 17% (537) have competitive jobs and 13% (432) receive individual supported employment. Meanwhile 27% (875) are in sheltered workshops.

As noted above, many youth transition from school without employment goals. We attribute this to wide-spread low expectations of students with disabilities for educational and employment attainment, poor interagency collaboration, and budget cuts that have resulted in the loss of many transition services. To address these issues, VR, ODE, ODDS, and the Council signed an MOU designed to improve outcomes. The document articulates the collective vision that all youth with disabilities leave school with a job or post-secondary education plan in place.

As a result of these efforts, ODDS released a new policy stating that students in both the Supports and Comprehensive programs are now able to access long-term supports to assist in achieving employment goals while they are still in school. Some school districts have engaged this policy to support students. However, additional policy clarification and guidance is needed to determine how student employment impacts the requirement of 990 hours of instructional time per year.

(iii) Informal and informal services and supports:
The Oregon Office of Developmental Disability Services (ODDS) funds a variety of formal DD services to over 21,000 children and adults. Services are provided through state contracted providers, Community Developmental Disability Programs (CDDP), or Adult Support Service Brokerages (Brokerage). Anyone found
eligible for DD services is entitled to service coordination/case management.

All adult services are funded through HCBS Waivers (Comprehensive and Supports) and the new Community First Choice State Plan [1915(k)] or "K Plan." Services are determined based on assessed need. Implementation of the K Plan required waiver revisions to move ADL and IADL services to the State Plan effective July 1, 2013. Employment, Community Inclusion and other specialized services remain under the waivers. K Plan services may not be capped so plan amount caps have been removed. We anticipate plan amount caps will be replaced with caps on specific waiver services.

Per June 2013 data, 13,496 adults receive in-home or 24-hour services under Oregon’s 1915(c) waivers. Of this group, 4,244 receive employment or day services. Formerly, access to out-of-home residential services required that an individual met crisis criteria. With implementation of the K Plan, people will access services per assessed need. With no strategies in place to constrain costs, we are concerned that 24/7 placements will grow despite no new money for these services.

About 7,260 Medicaid eligible adults are enrolled in Brokerage services. Under the new system, previous service plan caps (up to $21,562) have been removed. Brokerage customers either live in their family home or live on their own. Individuals with IDD with significant co-occurring mental health conditions, or who have committed crimes and are found not guilty by reason of "mental defect" may be confined to the Psychiatric Security Review Board program or the Oregon State Hospital. Currently 46 individuals are in the State Hospital. Individuals with co-occurring mental health conditions have limited access to community mental health services other than those received in the hospital.

About 5,702 children receive service coordination/case management services. Approximately 355 children and their families receive in-home supports through three Model Medicaid Waivers of ICF/MR, Nursing Homes, and Hospitals. These waivers are not funded to allow full capacity. They are available to children who meet the stringent eligibility criteria, irrespective of family income.

The State DD Program manages a specialized foster care program for children in collaboration with Oregon’s Child Protective Services (CPS) system. There are currently 544 children in DD foster care and 148 children in specialized residential programs. These children typically have co-occurring mental health, significant behavioral challenges, or involvement with the juvenile corrections system. Seventy-five percent of these placements come through CPS with other children entering voluntarily.

CDDP’s manage two family support programs with state general funds. The General Family Support Program supports 1,630 families of children under age 18. The program frequently provides respite with an average plan amount of about $625 per year. The Long-Term Family Support program funds 243 children with plans of up to $1000 per month. This program is for families with circumstances that require supports for the child to remain in the family home.

OCDD implements Family Networks to offer peer support, training, community capacity building, and technical assistance to families, individuals and providers. About 5,000 people are connected to Family Networks in four areas around the state. During the 2013 legislative session, DHS was awarded additional funding to expand the Networks. OCDD also maintains a Learning Community to pursue the paradigm shift from "family support" to "supporting families."

(iv) Interagency Initiatives:
Oregon has a number of interagency and collaborative structures that have resulted in successful
implementation of initiatives to improve community services to individuals with IDD and their families. These include the Oregon DD Coalition, the Oregon Self-Advocacy Coalition, the Oregon Commission on Autism Spectrum Disorder, the State Rehabilitation Council, the Oregon Commission on Disabilities, the Early Learning Council and the Inclusive Child Care Program. What follows is a description of each.

The Oregon DD Coalition is comprised of representatives from over 26 provider, family, self-advocate and advocacy organizations. ODDS leadership has historically engaged the DD Coalition in framing policy, as well as the planning and implementation of service initiatives. Outcomes of this collaboration have included the closure of all ICF/MRs, the creation of an adult support service system, the development of an individualized assessment process and rate restructuring, training programs, and waiver redesign. In 2013, ODDS leadership changed and the current director is not compelled to continue an advisory relationship. Coalition members continue to strategize about how to develop and re-establish a productive collaborative relationship with ODDS. OCDD provides staff support to the Coalition.

The Oregon Self-Advocacy Coalition (OSAC) was established with grant support from Portland State University. OSAC is a network of 17 local self-advocacy groups led by people with IDD. Their mission is to engage communities in advocating for the rights of people with developmental disabilities. In 2012, they published position statements on healthcare and employment. During fall 2013, the PSU grant expired and support for OSAC was transferred to the Council and a newly hired Self-Advocacy Coordinator.

The Oregon Commission on Autism Spectrum Disorder (OCASD) includes families, individuals on the Autism Spectrum, as well as representation from key state agencies, the Oregon House of Representatives and Oregon Senate. OCDD has an interagency agreement with DHS and ODE to staff the Commission. The Commission has engaged local and state education and human service programs that resulted in interagency agreements and service improvements for individuals with ASD and other developmental disabilities.

Council participation on the State Rehabilitation Council (SRC) has resulted in greater support for implementation of Oregon’s Employment First Policy. Members of the State Interagency Coordinating Council include Partners in Policymaking graduates.

The Oregon Commission on Disabilities includes family and self-advocate representation. Although the DD Program was combined at the state administrative level with Aging and Services to People with Physical Disabilities, there is little engagement with the State Independent Living Council or the Aging and Disability Resource Centers at the local level.

Governor Kitzhaber established the Early Learning Council (ELC) to streamline early education services. Several interagency groups were created during this process. The ELC consults with the State Interagency Coordinating Council to address early intervention and early childhood special education services to youth with disabilities. The Council facilitates these meetings. It is unclear whether the ELC will benefit children and youth with developmental disabilities.

OCDD has an interagency agreement with the Oregon Child Care Division and the Department of Education to operate the Inclusive Child Care Program (ICCP). Council staff implement training, technical assistance, and other supports to increase the capacity of community child care providers to serve children and families experiencing disabilities.

(v) Quality Assurance:
The monitoring of services to prevent abuse, neglect, sexual or financial exploitation, or violations of legal or
human rights is the responsibility of the County service coordinator or the Brokerage personal agent. The state level Office of Investigations and Training becomes involved at the request of the County in certain circumstances or when there is unexplained injury or death. The state is developing a statewide tracking system to monitor the employment of individuals who have been substantiated for multiple instances of abuse but whose actions have not reached the level of criminal prosecution. Counties are required to convene multidisciplinary teams (including law enforcement) to work on barriers to appropriate prosecutions of offenders. Finally, during the 2013 legislative session, funds were allocated to reinstate state-level QA positions that were eliminated due to budget reductions during the economic downturn.

Over the past three years, Oregon has invested significantly in trainings of direct care staff to increase the health, safety, and quality of life for individuals with IDD. Since 2010, over 10,000 direct care staff received a formalized training in several areas. The Oregon Intervention System (OIS) is designed to increase the confidence and ability of direct care staff to understand and appropriately respond to communication from individuals they are supporting, de-escalate tense situations, and protect themselves and the safety of the individuals they support. Other trainings focused on Individual Support Plans and Person Centered Thinking/Planning, Positive Behavior Supports, and Mandatory Abuse Reporting and Prevention. Oregon is currently updating its required core competencies for direct support staff working in 24 hour residential and day settings. Similar competencies are also being developed for personal agents and service coordinators. Additionally, the Home Care Commission is developing similar trainings for personal support workers who work with people in their homes.

CMS recently approved Oregon’s plan for the 1915(k) Community First Choice Plan “K Plan” which requires massive change in Oregon’s IDD Service System to accommodate the new services and requirements. This change also impacts system care provider capacity because the K Plan may open eligibility to thousands of children who do not currently receive services and also may offer new services to many of the approximately 21,000 people with IDD who currently receive services. OCDD is carefully monitoring this implementation to ensure that people receiving services continue to have supports that meet their needs, goals and preferences.

(vi) Education/Early Intervention:
The Oregon Department of Education (ODE) provides a seamless statewide system of free early intervention/early childhood education (EI/ECSE) services to children with disabilities, ages birth-five, and their families through Parts C and B of IDEA. There are currently over 11,876 children and families receiving EI/ECSE services. Funding has not kept pace with the 30% increase in the number of children with ASD and the increased costs to deliver services. In a formal budget study conducted by ODE and the Legislative Fiscal Office, children birth-five have experienced a 48% reduction in service hours since 2004 and children three-five have seen a 21% reduction in service hours. The 2013 Legislature provided new funding, however, it will not increase service levels for existing eligible children. Rather it will support case growth at current service levels. Oregon is currently reforming its Early Learning System and creating “hubs” to streamline services and ensure that children enter kindergarten ready to learn. Local hubs will coordinate health care, early childhood educators, human and social services, K-12 school districts, and the private sector to focus their efforts with a shared purpose. These efforts are complimented by a 2013 $20 million Race to the Top Early Learning Grant. The purpose of the grant is to improve quality and expand access to early learning programs in the state. Oregon is implementing several initiatives to improve the quality of early learning and development programs, provide better training of early childhood educators, and improve measurement of how well programs prepare children for kindergarten. OCDD has facilitated meetings and authored reports to the legislature and Oregon’s Early Learning Council about how to integrate children with disabilities in the Early Learning System.
Regarding K-12 education, Oregon has a history of funding struggles. However, the 2013 legislature increased K-12 funding by $1 billion or roughly 17.5%. Additionally, Governor Kitzhaber called a Special Session September 30, 2013 to address new revenue packages to fund even more education increases. K-12 education is funded primarily by state income tax through a complex statewide funding formula and comprises 53% of the state General Fund budget.

There are few specialized public or private schools for children with disabilities and a strong policy commitment to support students in their home school districts. The School for the Blind was closed in 2009 and there are currently 103 students at the School for the Deaf. Local Educational Service Districts (ESD’s) provide services to 197 school districts. The ESD’s often provide testing services, professional libraries, and specialized programs and services to students who have a disability. Recently, there has been increased scrutiny over the role and number of ESD’s as advocates for students with disabilities have challenged the quality of the often segregated programs and services provided to students with disabilities.

ODE also funds regionally based programs to provide more specialized services to districts or ESDs for students who have low incidence disabilities or disabilities where there is a need to increase instructional capacity, including students with orthopedic impairments, blindness or vision impairment; deaf or hard of hearing; medically fragile, traumatic brain injury, and ASD. School Districts are also able to access a High Cost Disability fund for students whose services exceed $30,000.

Over the past few years Oregon has made improvements to its academic standards, diploma options and transition responsibilities. More recently, the 2013 Legislature enacted two new laws directed at strengthening seclusion and restraint protections for students. These laws include improved standards and monitoring related to use of restraints and seclusion, prohibit new seclusion cells and required removal of existing cells by July 1, 2013.

(vii) Housing:
Optional, no information provided.

(viii) Transportation:
Optional, no information provided.

(ix) Child Care:
Safe, affordable child care is essential for families, yet finding care is often a struggle for families of children with disabilities. Oregon Child Care Research Partnership data, aligned with prevalence data for childhood disability, indicates that Oregon families are seeking paid care for at least 15,000 children with disabilities. Many of these children experience higher level or more complex care needs. Parents are often unable to find a child care placement that will accept their child; others lose child care placements when providers are unable to meet a child’s behavioral or other needs.

Six years ago 160 Oregon parents of children with disabilities responded to a survey on child care issues. 73% reported difficulty finding child care due to child’s disability or special needs; 53% had chosen not to work or to pursue further education due to difficulties finding or keeping child care.
Oregon’s child care subsidy program for lower income families includes provisions for higher rates for children with disabilities. This program is funded through state and federal dollars, and the state legislature has placed limits on the number of families receiving child care assistance. Since state child care subsidies are limited to families with very low incomes, the vast majority of Oregon families receive no assistance in meeting higher costs of care related to their child’s disabilities. Further, regulations explicitly prohibit disability-related funds, such as those targeted for respite care, from being used for employment related child care. Consequently, families are often left with no source of support and therefore have limited options for employment and community involvement.

OCDD administers the Inclusive Child Care Program (ICCP), in collaboration with the Oregon Department of Education’s Office of Child Care and the Department of Human Services Self-Sufficiency program. ICCP helps families of children and youth with disabilities to attain appropriate child care while parents are employed or in postsecondary education programs. ICCP also helps children and youth maintain placement in inclusive child care settings with their peers. The program conducts assessments for supports or accommodations in child care settings and facilitates individualized rates for eligible children with higher level needs. A December, 2012 survey found that 89.4% of participating parents said that it would have been difficult or very difficult (75%) to have child care without the assistance. 84% said that without the assistance it would be difficult or very difficult (66%) for their child to be in an inclusive setting with peers. ICCP also provides training and technical assistance to child care practitioners.

The ICCP is highly involved with Oregon’s child care community, including advisory and planning committees. ICCP subcontracts with Child Care Resource and Referral programs, to ensure statewide access to its services. ICCP’s work has identified a number of strategies to improve access to inclusive child care. Along with individualized financial assistance, these include ensuring that families and the child care community understand legal rights and responsibilities; consultation to child care providers; and embedding inclusive practices within early childhood systems planning.

(x) Recreation:
Optional, no information provided.

PART C: Analysis of State Issues and Challenges [Section 124(c)(3)(C)]:

(i) Criteria for eligibility for services:
Access to adult and children’s DD services, mental health services and increased services when an individual’s support needs change is limited by eligibility criteria. Eligibility criteria are largely used to keep costs down by limiting access to services. There are a number of areas where the Oregon eligibility criteria for DD services creates a barrier to individuals needing services including income level and diagnosis. Eligibility is determined at the county level with appeal rights to the state office. Efforts to change the eligibility language have been opposed by ODDS to prevent an increase in the number of individuals who successfully access services. Meanwhile, as a result of the K Plan, eligibility rules will be revised in 2013-2014. It is unclear whether these changes will loosen restrictions on access to services.

Eligibility for adult and children’s DD services is based on IDD that results in significant impairment in at least two areas of adaptive functioning: self-care, communication, cognition, mobility, self-direction, capacity for independent living, and economic self-sufficiency. An increasing number of eligibility applications from individuals
on the Autism Spectrum who do not have an intellectual disability, but may require significant levels of support, have resulted in numerous eligibility appeals. The requirement that an individual with a developmental disability, but no intellectual disability, must “require services similar to the support needs of an individual with intellectual disability,” often results in inconsistent interpretation. Additionally, many DD services have eligibility criteria designed to further restrict access.

Eligibility for the three children’s Model Waivers utilize a specific point-based criteria, including caregiver capacity measures, which limit access to most children. The largest of the Model Waivers, the Medically Involved Waiver, includes a point-based eligibility criterion in addition to a requirement for nursing home level care. This waiver, currently rolling up to full implementation, is running a two year waitlist. The Medically Fragile Waiver requires hospital level care, and the Behavior Waiver requires ICF/MR level care.

People with IDD continue to have difficulty accessing community based mental health services. While there are estimates that up to 30% of individuals with IDD experience mental health conditions, few receive appropriate services through the mental health system.

The K Plan includes in-home supports or residential services provided in supported living, group home, or foster care settings. These services Access to residential services through crisis has increased by 12.22% between 2007 and 2012. It is speculated that aging caregivers, combined with the pressures of the economy, contributes to more families seeking 24/7 supports. The Community First Choice option expands the ability to provide in home supports, and removes the requirement for accessing support through crisis eligibility.

Brokerages were created as the result of a waitlist lawsuit filed in 2000 and settled by providing universal access to a capped in-home benefit. Per June 2013 data, 7,260 Medicaid eligible adults receive Brokerage services. Prior to budget reductions in the 2010-2012 biennium, approximately 700 individuals who are not Medicaid eligible previously accessed Brokerage services with General Funds. These individuals now receive minimal case management through a CDDP. Effective July 1, 2013, these individuals are allowed choice of case management through a CDDP or Brokerage.

Currently, data available in other DHS services such as TANF does not capture disability-specific categories such as IDD.

(ii) Analysis of the barriers to full participation of unserved and underserved groups of individuals with developmental disabilities and their families:

OCDD continues to target its outreach to the unserved and underserved populations previously identified: families and individuals living in rural/frontier areas of the state and Latino individuals whose primary language is not English.

The geography and population distribution of Oregon presents significant ongoing challenges to providing equitable access to services statewide. Approximately 70% of Oregonians live in the Willamette Valley, which incorporates all of the urban population areas. The Valley runs down the western quarter of the state, and mountain ranges limit access to and from both the coast and the eastern part of the state. Of the 36 counties in Oregon, 11 meet the Federal definition of frontier. Not only is the population low and very widespread, but many of these areas may experience communication and transportation challenges. Many of the rural areas, with slightly higher population density, also share the challenges of long distances and lack of transportation systems which make easy access to services, trainings, and other events difficult for individuals and families. Many individuals find they have access to fewer services, and fewer providers of service, than are available in urban areas. This is felt by families in accessing medical services, as well as physical, occupational and speech
therapies. Families also find they have limited access to respite providers, accessible childcare, and adaptive recreation opportunities. Adults notice limited choice in recreational activities, supported employment providers, and adult direct service providers. Council members from these areas have been leaders in bringing the issues of the frontier and rural areas of Oregon to the larger DD community.

Currently Latinos are the largest single minority group in Oregon at almost 11% of the population. They are underrepresented in leadership positions in public and private agencies focused on IDD. Families continue to report difficulty in accessing the complex educational and social service systems in their communities, and the number of Latino adults currently receiving services do not align with the population data in the state. We believe this reflects a lack of awareness of what might be available, a reluctance to seek or accept services, a language barrier, and a lack of cultural appropriateness of the current service system.

The Council is committed to assuring that implementation of our State Plan goals includes overarching strategies to reach individuals and families in the rural and frontier areas of Oregon. We demonstrate this commitment in implementation of the Family Networks and our Partners in Policymaking program.

Due to Legislative support during the 2013 session, the Department of Human Services has doubled the funding available to the Council to grow and support Family Networks in Oregon. An emphasis has been placed on facilitating this growth within rural areas of the state, including Eastern Oregon. This will challenge the current model and require adaptation and ongoing learning. Family Networks in frontier areas will likely look different than those available in urban areas. Community development activities and potential partner development has already begun in both Eastern Oregon and along the Oregon coast. The Family Networks have also all been tasked with ensuring cultural competency and targeted outreach to families whose first language is not English. For most communities, this includes outreach to Spanish-speaking population. In the Portland metro area, the Family Network includes Russian-speaking families.

The Partners in Policymaking program enables the Council to directly target individuals from rural/frontier areas, and those who speak Spanish. We have seen strong leaders emerge from the Partners program over the past 20 years. Some of these leaders have started advocacy and support groups, or work for our partner agencies and organizations.

(iii) The availability of assistive technology:

The availability of assistive technology (AT) to adults and children with disabilities varies throughout the state. For adults with IDD, access to AT is limited to a few technology resource centers and several small AT service providers located primarily in urban areas around the state. These services are typically accessed through case managers or VR counselors.

Access Technologies, Inc (ATI) is Oregon’s statewide assistive technology program. It is sponsored by ODDS and the Rehabilitation Services Administration (RSA). The organization offers technical assistance, technology assessments, and training. It maintains a number of loan-able equipment, used equipment, and demonstration programs. Unfortunately, ATI has a very low profile in the DD community and has done little to make people aware of its services.

Individual Development Accounts (IDA) and the Fairview Trust and are other options to help people save and access more expensive adaptive home modifications and technology. The Trust was created with proceeds from the sale of institutional property. It provides grants for acquisition of AT and necessary home modifications. The Trust has not been available since July 1, 2011 when the legislature ruled to allocate half of the balance to fund day program services as a result of Oregon’s ongoing budget crisis. Funds have not been restored despite
ongoing advocacy of the DD community.

Availability of AT is more accessible to school-age children with disabilities. For example, the Coalition for Assistive Technology provides grants four times a year to a limited number of children with disabilities, allowing them to access AT for long term use. The Oregon Technical Assistance Program (OTAP) is the largest resource for children with disabilities. With funding from the Oregon Department of Education (ODE), OTAP provides AT information, training, and referral for children with disabilities. The program provides direct training for children and technical assistance to parents and teachers. It maintains a loan library and provides information on potential resources to those who need assistive devices and educational technology. As more school districts have developed their own assistive technology programs, OTAP has focused more on training school-based teams.

Despite these resources for children, educational assistive technology assessments are often difficult to access, particularly in the rural and frontier areas of the state. Further, the cost of devices may be prohibitive for families, and schools are sometimes reluctant to identify a need that they will have to fund. Finally, schools may require the child to leave the device at school during vacations and summers.

While AT resources are limited, new developments are promising. Electronic backup systems or devices to ensure the continuity of services and supports are now covered under Oregon’s new 1915(k) State Plan for both children and adults. Additionally, the Office of Developmental Disabilities Services (ODDS) is funding a project to develop core competencies for case managers. Included in the curriculum is a focus on AT counseling and determination of the most cost effective, appropriate technological supports for individuals. The curriculum is anticipated to be completed by December 2014. With these developments, we anticipate people with IDD will experience increased access to AT services and devices over time. However, far greater efforts to increase awareness and improve access to technology are needed.

(iv) Waiting Lists:

a. Numbers on Waiting Lists in the State:

<table>
<thead>
<tr>
<th>Year</th>
<th>State Pop. (100,000)</th>
<th>Total Served</th>
<th>Number Served per 100,000 state pop.</th>
<th>National Averaged served per 100,000</th>
<th>Total persons waiting for residential services needed in the next year as reported by the State, per 100,000</th>
<th>Total persons waiting for other services as reported by the State, per 100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>38.230</td>
<td>19008</td>
<td>497.140</td>
<td>212.400</td>
<td>0.000</td>
<td>54.030</td>
</tr>
<tr>
<td>2007</td>
<td>37.420</td>
<td>16031</td>
<td>428.010</td>
<td>198.400</td>
<td>0.000</td>
<td>52.700</td>
</tr>
<tr>
<td>2005</td>
<td>36.310</td>
<td>14796</td>
<td>407.440</td>
<td>184.000</td>
<td>0.000</td>
<td>38.280</td>
</tr>
</tbody>
</table>

b. Description of the State's wait-list definition, including the definitions for other wait lists in the chart above:
Oregon has an administrative rule for the maintenance of a centralized waitlist. County DD Programs (CDDP) are charged to maintain updated waitlist information, but there has been little accountability in this area for several years. Oregon does not currently have an adult waitlist that contains reliable data on the number of individuals waiting for specific services, or waiting for services other than what they are receiving. The best
waitlist data available captures only the number of individuals receiving no services except service coordination. Once having met DD eligibility, there are specific service waitlists based on the date the individual met the expressed eligibility criteria for the program and requested access.

The K Plan eliminates waitlists for services except for the Children’s Model waivers, which have limited enrollment numbers. Children who would otherwise qualify for those waivers may access in-home supports through a CDDP to meet their immediate needs.

c. To the extent possible, provide information about how the State selects individuals to be on the wait list:
K Plan implementation July 1, 2013 eliminated any waitlist for services through removal of all language in the Oregon Administrative Rules (OARs) regarding waitlists for services. Currently, individuals may access supports as needed once they have met Level of Care Criteria and have a functional needs assessment completed. Prior to K plan implementation, the OARs specified that to be on a waitlist: 1) the individual must be over the age of 15, and 2) must be deemed eligible for DD case management services. Then, an assessment is to be conducted to identify individual needs and wants; type of support requested; urgency of support; and level of support needed. With K Plan implementation, we anticipate increased request for services. However, it is currently unclear how or if any waitlist data will be tracked.

d. Entity who collects and maintains wait-list data in the State:
- [ ] Case management authorities
- [ ] Providers
- [X] Counties
- [ ] State Agencies
- [ ] Other:

e. A state-wide standardized data collection system is in place:
- [ ] Yes/No

f. Individuals on the wait list are receiving (select all that apply):
- [ ] No services
- [X] Only case management services
- [ ] Inadequate services
- [ ] Comprehensive services but are waiting for preferred options (e.g., persons in nursing facilities, institutions, or large group homes waiting for HCBS)
- [ ] Other:

Other services:

Other services description(s):
Implementation of the K Plan will allow access to services based on the assessed needs of an individual. Elimination of access through crisis eligibility will allow an individual’s assessed needs to be met. Effective July 1, 2013, individuals receiving in-home supports are not limited by funding. Additionally, the K Plan allows more children to become eligible for Medicaid services. Many children who receive case management only or general fund family support may now access K Plan services and supports as they become eligible. The amount and type of services provided will be based on the individual’s assessed support needs.

g. Individuals on the wait list have gone through an eligibility and needs assessment:

☐ Yes/No

Use space below to provide any information or data related to the response above:

All individuals must have DD eligibility in order to be considered for services. CDDPs use a Level of Care assessment and record review to determine eligibility. Additional testing occurs only when needed. Children birth-18 receive provisional eligibility. Permanent eligibility is determined at age 18 for intellectual disabilities or 22 for individuals who have a developmental disability, but have not been determined to have an intellectual disability. Eligibility disputes are resolved at the state level.

In June of 2010, over 19,000 adults and children were eligible for DD services in Oregon and have had a very basic needs assessment. Additionally, specific programs have eligibility criteria and may maintain a waitlist. Implementation of Community First Choice has eliminated waitlists for services effective July 1, 2013. As the system develops capacity, we anticipate adults and children will experience delays in eligibility assessments and access to services.

h. There are structured activities for individuals or families waiting for services to help them understand their options or assistance in planning their use of supports when they become available (e.g. person-centered planning services):

☑ Yes/No

i. Specify any other data or information related to wait lists:

Currently, all eligible adults and children have access to case management through a service coordinator or personal agent, even if they have no other service. Service coordinators are located in County DD Programs (CDDP) and personal agents are located in Brokerages. The quality of the service varies greatly from county to county, and service coordinator to service coordinator. In some areas of the state, individuals may receive significant levels of support from their service coordinators. Counties may facilitate activities, networking groups, organize relief care, conduct person centered planning, and connect individuals with community resources. In other situations, individuals may receive a yearly contact.

j. Summary of waiting list Issues and Challenges:

There is no reliable, aggregated data that reflects the kinds of services needed by people with DD in Oregon. Implementation of the K Plan results in an increase in federal matching funds by 6%, which reportedly, will be reinvested in to support increased access to services. Additionally, individuals are no longer required to meet
crisis criteria to access services effective July 1, 2013. The three Model Waivers for children are not funded for
capacity, and while only one has a wait list, there has been no analysis of what happens to the families or
children who fail to get access. Those children currently awaiting model waiver services who meet Level of Care
criteria may access K Plan and waivered services once deemed eligible for Medicaid.

(v) Analysis of the adequacy of current resources and projected availability of future resources to fund services:
Oregon, like many other states, is experiencing a growing disparity between workforce capacity and the
availability of resources for Medicaid-funded programs to address increasingly complex individual and family
needs and increased demands on service systems. DD program demographic projections show a steady
increase in the number of people with IDD seeking services over the next few years. Over half of these people
are children currently under age 18. Moreover, service data demonstrates that adults receiving Comprehensive
services have increasingly complex support needs and require higher cost service plans. Such individuals are
more likely to experience co-occurring mental health conditions and involvement with the criminal justice system.

As a result, we anticipate a significant increase in demand for services over time with little to no increase in
available funding. Additionally, the availability, quality, retention, and increasing cost of the direct support
workforce remains a growing issue. Meanwhile, funding for DD services continues to lie significantly below cost,
demand, and population growth. Other factors exacerbate this issue.

Oregon’s revenue is based primarily on income tax. There is no sales tax, and property taxes have a capped
growth rate. Additionally, Oregon has a tax anomaly called the “kicker” which returns income tax revenues to
taxpayers if the biennial income is greater than 2% over the state revenue projections. Thus, Oregon not only
experiences significant revenue reductions in times of economic and employment downturns but must return
revenues to tax payers if the economy recovers too quickly. Since 2007, Oregon has a rainy day fund that can
be employed to cushion public services from reductions during downturns when demand is often highest.
However, cuts are still made to public programs. As an example, in 2010, approximately 900 non-Medicaid
eligible General Fund Brokerage customers lost services as a result of budget reductions.

Another factor anticipated to drain resources is implementation of the Community First Choice Option or “K”
State Plan. Ironically, the K Plan is expected to bring in an additional 6% federal match to reinvest in DD
services. However, advocates argue that the costs of the K plan will surpass the 6%, contributing to funding
deficits. For example, as noted in Part B, Section iii of this report, the requirement to meet crisis level-of-care to
access high-cost out-of-home residential services has been removed. Now people may access services based
on assessed need with no strategies in place to limit costs. Without such limits, more families are likely to choose
costly out-of-home placements. We are already seeing individual service plan costs trending upward since the
October 1, 2013 start date of changes to service planning. It is unclear whether the K Plan will live up to
expectations.

All stakeholders agree that the current system is not sustainable. Families will continue to be the primary
caregivers throughout the lifespan and will need flexible service options and fair distribution of available services
among eligible Oregonians. It is clear that in addition to the creation of formal structures and programs to support
families, there must be increased attention to facilitating family-to-family supports, networking, creation of social
capital and community engagement.

(vi) Analysis of the adequacy of health care and other services, supports, and assistance that individuals with
developmental disabilities who are in facilities receive:

Oregon closed its last large public ICF/MR in 2010. There are no small or private ICF/MRs in Oregon. Additionally, no Oregon residents are being sent out of state for ICF/MR services. Oregon has actively sought to reduce the number of individuals with IDD in nursing facilities. Legislation was passed in 2009 to create a Model Waiver that would target the diversion of children from nursing facilities and assist children to return home from facilities. Three pediatric nursing facility wards were closed. In 2013, there were 58 children in nursing facilities for long term care. Each individual is evaluated yearly as to the appropriateness of the placement.

(vii) To the extent that information is available, the adequacy of home and community-based waivers services (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c))):

Oregon currently provides the majority of its DD services to over 21,000 adults and children with IDD through HCBS Waivers. Per June 2013 data, approximately 13,496 adults receive in-home or 24-hour services under either the Supports or Comprehensive 1915(c) waivers. Services are primarily provided by families as the primary caregiver with the individual remaining in the family home. With implementation of the new Medicaid State K Plan and the removal of benefit caps, access to waiver services is expected to increase for both adults and children.

Currently, only 355 children are supported via three Model waivers for those with significant medical and behavioral support needs. Anecdotally, there is a three-year wait to access these services. Other children entering the comprehensive system do so through voluntary placement by the family or involuntary placement through child welfare action. Those not found eligible for DD services or waiting for children’s waiver services receive limited General Fund or Long-Term Family Support or case management services through the County DD programs. As previously noted, children’s access to services is expected to increase under the new system with deeming of parental income and presumptive eligibility. As of July 1, 2013, access to waiver services for children is expanded with eligibility for Comprehensive waiver services. However, necessary infrastructure is not yet in place.

With implementation of the K Plan, adult access to services is expected to increase as well. Under the K Plan, all benefit caps in the Supports waiver have been removed. The capped benefit was an integral part of the strategy to delay or prevent individuals with IDD from entering higher cost 24-hour Comprehensive services. While growth is factored into the Supports Waiver budget, ODDS has indicated that if growth exceeds the projected budget, they will begin to run a waitlist. We anticipate ODDS will eventually implement caps to selected waiver services to control costs.

About 7,260 adults are served under the Supports Waiver. Prior to the K Plan, the Adult Supports waiver provided a capped benefit up to $21,562 per year based on an assessment of the individual’s support needs. There is currently no formal waitlist. However, informal estimates suggest that approximately 300 eligible youth are waiting to access Brokerage services.

The 24-hour Comprehensive waiver includes residential and day services for 6,236 adults with IDD. Comprehensive services are provided in the individual’s home, group homes, residential programs or foster care. Approximately 106 individuals receive services in homes operated by the state for individuals who have had difficulty in other community comprehensive services.

ODDS and system stakeholders have strategized to create new service models to address the needs of individuals requiring more or different supports than are currently available through Brokerage services but do not require the more costly 24-hour comprehensive model. Under the new system, individuals no longer need to
meet crisis criterion to access comprehensive services and should receive access to services based on assessed need.

Analysis of state data indicates that individuals between the ages of 18 to 26 are most at risk for crisis, but current services do not adequately acknowledge the strengths or address the needs of this demographic. There is hope that the K Plan will eventually address the needs of this and other people with IDD by allowing people who need more services and supports to receive them. However, with no apparent strategies in place to distribute resources fairly and limit excess, there are significant concerns that the new system will reduce the number of people served over time and create a growing waitlist for services.

PART D: Rationale for Goal Selection [Section 124(c)(3)(E)]:

Since the original plan was submitted, OCDD has contracted with an independent evaluator. With her input on how to more effectively and efficiently evaluate our work, the Council has amended its goals and objectives. The specific rationale for each revised goal is listed below.

1. Education
The majority of Oregon students with IDD currently exit school unprepared for employment or to pursue further education and training. This is due, in part to the limited expectations of many families, teachers and others, prevalence of dated education practices, and lack of current knowledge of best practice among educators. The journey to employment and continuing education must begin with young children and their families. It must include tools that facilitate empowerment, expand vision, and refine the strategies to get there. Recent changes in diploma options, implementation of the Governor’s Executive Order 13-04 on employment of youth and adults with IDD, the transition MOU between OCDD, DHS, VR and ODE, and access to long-term funding while students are still in school, provide opportunities to youth with IDD not previously available. We will continue work in this area to maintain momentum for systems change towards our goal.

2. Employment
This goal was amended to include attainment of employment, not just the desire for employment. Although the Council feels it is not OCDD’s responsibility to get people jobs, it is our role to support efforts toward that end. Employment provides everyone with opportunities for social connections, a feeling of self-worth, and the ability to support a desired lifestyle. Limited expectations for people with IDD and employment continue to exacerbate other barriers such as the current policy and practice barriers, shortage of qualified job developers, myths about the impact of earned income on public benefits, etc. In response to the Lane v. Kitzhaber lawsuit, the state has committed to increasing access to integrated employment with implementation of the Governor’s Executive Order 13-04 on employment for people with IDD. Council activities will continue to focus on building greater demand for employment while collaborating with state leaders to design policy and practice to increase the capacity of the system to support competitive employment outcomes and reduce barriers to employment.

3. Community Inclusion
Demographic and fiscal data demonstrate Oregon trends towards increased service demand to match a growing population of people with IDD requiring services with complex support needs, increased reliance on families as primary caregivers across the lifespan, and shortage in the availability of qualified direct support professionals. In this context, the current DD service system is unsustainable. Additionally, there is growing recognition that Medicaid-funded services cannot address the needs of the whole person. Most recently, these trends are exacerbated by unintended consequences of rapid State K Plan implementation with little stakeholder input and
lack of vision and direction. As a result, the Council believes we must pursue strategies to improve the current service system, build capacity for advocacy by families and self-advocates to influence policy and practice, explore alternative ways of supporting people with IDD and their families, and work to increase community engagement to build inclusive communities.

4. Health, Safety and Quality of Life
Current trends and changes to the DD service system present both opportunity and risk to the health, safety and quality of life for people with IDD. In response, the Council believes it is critical to closely monitor and contribute to systems change efforts through recommendations to policy, rule and statute changes, and to ensure the process respects and values and voices of people and families experiencing IDD and other system stakeholders.

PART E: Collaboration [Section 124(c)(3)(D)]
(i) As a Network:

The Oregon AIDD Network includes OCDD, the UCEDD at Oregon Health Sciences University (OHSU), the UCEDD at the University of Oregon (UO), and Disability Rights Oregon (DRO). The Network agency directors meet at least quarterly and at the beginning of each year to discuss current efforts and plan joint projects. We recently initiated a monthly communications project. Each partner takes turns producing a monthly communication with relevant information to the field.

(ii) With each other: (e.g. Describe the plans the Council has to collaborate with the UCEDD(s). Describe the plans the Council has to collaborate with the P&A.)

OCDD provides staff support and policy analysis for the Oregon Commission on Autism Spectrum Disorders. Through this work, we are engaged with the UCCED at the University of Oregon related to their expertise around Autism. We collaborate with OHSU to conduct interviews required to implement the Oregon National Core Indicators. Both UCEDDs support self-advocacy groups and participation in OSAC, the statewide self-advocacy organization funded by OCDD. Additionally, we collaborate with OHSU, members of the Oregon Self-Advocacy Coalition and others to develop a “health card.” The card is a tool that people with IDD can use facilitate communication with their doctors related to health, wellness and prevention activities.

Finally, we have a long-standing relationship with DRO regarding legislative and other policy issues. We frequently collaborate to address changes to Oregon statutes on developmental disabilities, administrative rules and identifying critical barriers that may be best addressed through legal avenues.

(iii) With other entities: (e.g. network collaboration with other entities in the State, including both disability and non-disability organizations, as well as the State agency responsible for developmental disabilities services)

AIDD Network members meet monthly during DD Coalition meetings to address policy issues with the ODDS,
act as a sounding board on initiatives and plan activities related to DD issues. Further, Both DRO and the Council staff the DD Coalition policy committee whose advocacy efforts increase during legislative session. The Coalition has been a major participant in all activities and initiatives that impact people with IDD and families for many years. In this capacity, members have sponsored legislation, testified at hearings, supported advocacy on issues, and provided trainings to direct support professionals, self-advocates, and families.

OHSU and Council staff are members of the planning committee to implement Oregon’s National Core Indicators project in partnership with ODDS. Finally, several Network members participate in the Oregon Human Services Coalition, a broad-based human services coalition.

We also revived the Partners in Oregon on Diversity and Disability (PODD) group. We meet regularly to discuss opportunities to enhance diversity within each of our organizations and in our respective activities. This year, our discussions resulted in joint commitment to conduct a listening tour beginning in winter 2015 and convene a disability and diversity summit during fall 2015. Our overall goal is to increase cultural competence of our organizations. As a result, we hope to increase our interactions with diverse groups in our state plan activities, develop infrastructure for ongoing outreach and communication to diverse communities statewide, and identify strengths and local assets of diverse communities, barriers to engagement and strategies to develop and maintain critical relationships.
Section IV : 5-Year Goals  [Section 124(4); Section 125(c)(5) and (c)(7)]

GOAL # 1: Education

There is an increase in the number of students with I/DD in Oregon who exit secondary education prepared for and qualified to pursue continuing education and/or competitive employment.

Area(s) of Emphasis:

- Quality Assurance
- Education and Early Intervention
- Child Care
- Health
- Employment
- Housing
- Transportation
- Recreation
- Formal and Informal Community Supports

Strategies to be used in achieving this goal:

- Outreach
- Training
- Technical Assistance
- Supporting and Educating Communities
- Interagency Collaboration and Coordination
- Coordination with related Councils, Committees and Programs
- Barrier Elimination
- Systems Design and Redesign
- Coalition Development and Citizen Participation
- Informing Policymakers
- Demonstration of New Approaches to Services and Supports
- Other Activities

Objective: 1.1

Typical child care or out of school time care facilities have the knowledge and resources to support children with diverse abilities and needs.

Activities

- Develop Leadership and Advocacy Skills
- Conduct Direct Advocacy and Influence Policy Decisions
- Develop Sustainable Models of Informal and Formal Supports
- Facilitate Collaboration and Raise Awareness

Timeline

2-5 Years
Objective: 1.2
Individuals with I/DD are provided opportunities and support for inclusive participation in school and the broader education community.

Activities
- Develop Leadership and Advocacy Skills
- Conduct Direct Advocacy and Influence Policy Decisions
- Develop Sustainable Models of Informal and Formal Supports
- Facilitate Collaboration and Raise Awareness

Timeline
1-5 Years

Objective: 1.3
Policies and systems are in place that facilitate access to and remove barriers to appropriate and inclusive education.

Activities
- Develop Leadership and Advocacy Skills
- Conduct Direct Advocacy and Influence Policy Decisions
- Develop Sustainable Models of Informal and Formal Supports
- Facilitate Collaboration and Raise Awareness

Timeline
1-5 Years

Intermediaries/Collaborators Planned for this goal (if known):
- ✔ State and P&A
- ✔ University Center(s) for Excellence
- ☐ State DD Agency
GOAL # 2: Employment

Increase in the number of individuals with ID/DD in Oregon who achieve competitive employment.

Area(s) of Emphasis: Strategies to be used in achieving this goal:

- Quality Assurance
- Education and Early Intervention
- Employment
- Formal and Informal Community Supports
- Outreach
- Training
- Technical Assistance
- Supporting and Educating Communities
- Interagency Collaboration and Coordination
- Coordination with related Councils, Committees and Programs
- Barrier Elimination
- Systems Design and Redesign
- Coalition Development and Citizen Participation
- Informing Policymakers
- Demonstration of New Approaches to Services and Supports
- Other Activities

Objective: 2.1

Individuals with I/DD have a vision for, pursue and achieve post-secondary education, training and integrated community employment.

Activities

- Develop Leadership and Advocacy Skills
- Conduct Direct Advocacy and Influence Policy Decisions
- Develop Sustainable Models of Informal and Formal Supports
- Facilitate Collaboration and Raise Awareness

Timeline

2-5 Years

Objective: 2.2

Policies and systems are in place that facilitate access to and remove barriers to integrated
community employment.

Activities

- Develop Leadership and Advocacy Skills
- Conduct Direct Advocacy and Influence Policy Decisions
- Develop Sustainable Models of Informal and Formal Supports
- Facilitate Collaboration and Raise Awareness

Timeline

2-5 Years

Intermediaries/Collaborators Planned for this goal (if known):

- ✔ State and P&A
- ✔ University Center(s) for Excellence
- ✔ State DD Agency
GOAL #3: Community Inclusion

Increase in the number of individuals with ID/DD in Oregon who experience full community participation, exercise choice in their lives, and contribute to their communities.

**Area(s) of Emphasis:**
- ✓ Quality Assurance
- ✓ Education and Early Intervention
- ✓ Child Care
- ✓ Health
- ✓ Employment
- ✓ Housing
- ✓ Transportation
- ✓ Recreation
- ✓ Formal and Informal Community Supports

**Strategies to be used in achieving this goal:**
- ✓ Outreach
- ✓ Training
- ✓ Technical Assistance
- ✓ Supporting and Educating Communities
- ✓ Interagency Collaboration and Coordination
- ✓ Coordination with related Councils, Committees and Programs
- ✓ Barrier Elimination
- ✓ Systems Design and Redesign
- ✓ Coalition Development and Citizen Participation
- ✓ Informing Policymakers
- ✓ Demonstration of New Approaches to Services and Supports
- ✓ Other Activities

**Objective: 3.1**

There is an efficient, active and sustainable model for engaging individuals with I/DD and the DD community.

**Activities**

- Develop Leadership and Advocacy Skills
- Conduct Direct Advocacy and Influence Policy Decisions
- Develop Sustainable Models of Informal and Formal Supports
- Facilitate Collaboration and Raise Awareness

**Timeline**

2-5 Years

**Objective: 3.2**
There is an efficient, active and sustainable model for engaging communities and supporting families with children with I/DD.

Activities

- Develop Leadership and Advocacy Skills
- Conduct Direct Advocacy and Influence Policy Decisions
- Develop Sustainable Models of Informal and Formal Supports
- Facilitate Collaboration and Raise Awareness

Timeline

2-5 Years

Objective: 3.3

Families and individuals with I/DD access programs, activities, services and supports in community.

Activities

- Develop Leadership and Advocacy Skills
- Conduct Direct Advocacy and Influence Policy Decisions
- Develop Sustainable Models of Informal and Formal Supports
- Facilitate Collaboration and Raise Awareness

Timeline

1-5 Years

Objective: 3.4

Families and individuals with I/DD are empowered to advocate for policy and systems change, and inclusive communities.

Activities

- Develop Leadership and Advocacy Skills
- Conduct Direct Advocacy and Influence Policy Decisions
- Develop Sustainable Models of Informal and Formal Supports
- Facilitate Collaboration and Raise Awareness

Timeline
Objective: 3.5
Policies and systems are in place that facilitate access to and remove barriers to community via DHS/ODDS services (e.g., case management, brokerage services, waivers, family support program, etc).

Activities
- Develop Leadership and Advocacy Skills
- Conduct Direct Advocacy and Influence Policy Decisions
- Develop Sustainable Models of Informal and Formal Supports
- Facilitate Collaboration and Raise Awareness

Timeline
2-5 Years

Intermediaries/Collaborators Planned for this goal (if known):

- [ ] State and P&A
- [X] University Center(s) for Excellence
- [X] State DD Agency
GOAL # 4: Health, Safety, Quality of Life

Increase in the number of individuals with ID/DD in Oregon who experience health, safety and quality of life consistent with the values expressed in the DD Act and by ADD.

Area(s) of Emphasis:

- Quality Assurance
- Education and Early Intervention
- Child Care
- Health
- Employment
- Housing
- Transportation
- Recreation
- Formal and Informal Community Supports

Strategies to be used in achieving this goal:

- Outreach
- Training
- Technical Assistance
- Supporting and Educating Communities
- Interagency Collaboration and Coordination
- Coordination with related Councils, Committees and Programs
- Barrier Elimination
- Systems Design and Redesign
- Coalition Development and Citizen Participation
- Informing Policymakers
- Demonstration of New Approaches to Services and Supports
- Other Activities

Objective: 4.1

Individuals with I/DD are active and informed participants in their health and wellness and practice self-determination in their lives.

Activities

- Develop Leadership and Advocacy Skills
- Conduct Direct Advocacy and Influence Policy Decisions
- Develop Sustainable Models of Informal and Formal Supports
- Facilitate Collaboration and Raise Awareness

Timeline

2-5 Years

Objective: 4.2
Policies and systems are in place to facilitate access and promote health, safety, and quality of life for individuals with I/DD.

Activities

- Develop Leadership and Advocacy Skills
- Conduct Direct Advocacy and Influence Policy Decisions
- Develop Sustainable Models of Informal and Formal Supports
- Facilitate Collaboration and Raise Awareness

Timeline

2-5 Years

Intermediaries/Collaborators Planned for this goal (if known):

- ✔ State and P&A
- ✔ University Center(s) for Excellence
- ✔ State DD Agency
Section V : Evaluation Plan  [Section 125(c)(3) and (7)]

- Outline how the Council will examine the progress made in achieving the goals of the State Plan.
- Explain the methodology, which may be qualitative or quantitative, that will be used to determine if the needs identified and discussed are being met and if the Council results are being achieved.
- Describe the Council's role in reviewing and commenting on progress towards reaching the goals of the Plan.
- Describe how the annual review will identify emerging trends and needs as a means for updating the Comprehensive Review and Analysis.

Our evaluation and data collection efforts align with our goals and respective outputs, outcomes, and objectives outlined in our logic models. Goals describe the ultimate achievement envisioned for individuals with I/DD in the specific content area (e.g., employment), which is likely to occur in the long-term and in collaboration with other organizations and agencies.

Outputs are activities that result from program stream planning and implementation efforts (evidence of movement toward expected outcomes, objective and goal). These may include events, stakeholder meetings, and resources developed. We will use both quantitative and qualitative data to describe our achievements.

Objectives describe the interim changes that are required in order to achieve five year plan goals (evidence of movement toward our ultimate goal). We will use data like tools, materials or policy changes to measure progress towards our objectives.

Outcomes are the short and long-term changes or impact for individuals, organizations and/or systems (evidence of movement toward objective and goal). We will use qualitative and quantitative state agency data to determine impact.

This period, we refined our internal tracking systems to collect better data for annual federal reporting but also to make decisions about our work. Program staff record work per objective on a quarterly basis using an internal form created with help from our evaluation contractor. The form is based on PPR performance measures and our five year plan goals and objectives. We used this strategy to complete our FY 2013-14 annual report and are pleased with the results. Staff will review resulting compiled data in the coming year for decision making. Going forward, staff will also begin entering quarterly reporting data directly into DD Suites each quarter to further streamline this process.
### Section VI: Projected Council Budget [Section 124(c)(5)(B) and 125(c)(8)]

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Section VII : Assurances  [Section 124(c)(5)(A)-(N)]

Written and signed assurances have been submitted to the Administration on Intellectual and Developmental Disabilities, Administration for Community Living, United States Department of Health and Human Services, regarding compliance with all requirements specified in Section 124(c)(5)(A-N) in the Developmental Disabilities Assistance and Bill of Rights Act of 2000:

☑ Assurances submitted

Approving Officials for Assurances

☑ For the Council (Chairperson)
☑ For DSA, when not Council
PART A: How the Council made the plan available for public review and comment and how the Council provided appropriate and sufficient notice in accessible formats of the opportunity for review and comment.

The Council provided many opportunities for public input on the plan goals and intended outcomes. Once the goal categories were identified, Council staff met with partners and stakeholders to gather input. We used this information to revise goals and administer a survey to the general public. The survey was posted to the Council website for 45 days and advertised in the Oregonian, our statewide newspaper. We also distributed the survey via email to a network of more than 2,000 individuals. Completed surveys were returned via SurveyMonkey, mail, fax or completed in person through public forums with self-advocates.

PART B: Revisions made to the Plan after taking into account and responding to significant comments.

There were no substantive changes to the content of our 5 year plan goals or evaluation plan due to public review data this period.