

Oregon's Children with Special Health Care Needs  
*Five Year Needs Assessment Findings – October 2, 2020*

## **CHAPTER FIVE**

# Oregon Systems of Care for Children and Youth with Special Health Care Needs

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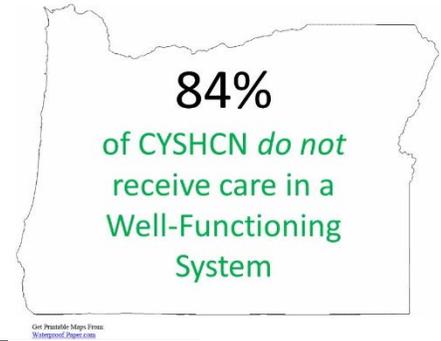
# Oregon Systems of Care for Children and Youth with Special Health Care Needs

## Oregon Title V Needs Assessment Chapter 5: Children and Youth with Special Health Care Needs

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A system of care is “a comprehensive spectrum of... health and other necessary services, which are organized into a coordinated network to meet the multiple and changing needs of children and their families” (Stroul & Friedman, 1986, p. 3). In Oregon, 84% of CYSHCN younger than 18 years *do not* receive care within a well-functioning system (CAHMI, 2020). This means that 84% of Oregon CYSHCN are missing one or more of the care elements shown in Exhibit 5.1.



### Exhibit 5.1. Elements of A Well-Functioning System for CYSHCN

- Adequate insurance
- Early screening
- Easy to access services
- Family partnership
- Medical home
- Preparation for transition to adult health care

Source: Child and Adolescent Health Measurement Initiative, 2020

Professional standards, i.e., the *Standards for Systems of Care Serving CYSHCN*, establish criteria for systems of care serving CYSHCN and their families (Association for Maternal and Child Health Programs [AMCHP] & National Academy of State Health Policy [NASHP], 2017). The “well-functioning system” composite measure reflects five of the eight standard domains: access to care, medical home, transition to adult health care, insurance eligibility and enrollment, and screening/assessment/referral. From previous chapters, we know that Oregon CYSHCN experience deficits in access to services, adequacy of insurance, components of medical home including culturally responsive care, and preparation for transition to adult health care.

This chapter describes aspects of Oregon’s system of care for CYSHCN from a state perspective. We begin with a short description of Oregon’s medical home program as it relates to CYSHCN, followed by ratings of key care areas for a subpopulation of CYSHCN served through Oregon’s Medicaid program. We then provide highlights of Oregon’s Medically Underserved Areas, after which we describe gaps in Oregon’s health care workforce, including gaps between the race/ethnicity of Oregonians and the health care providers who serve them. We conclude this chapter with findings from a root cause analysis focused on inadequate support and preparation for transition to adult health care for young adults with medical complexity.

### Medical Home Policy

The Oregon Health Authority’s Patient-Centered Primary Care Home (PCPCH) program “works with stakeholders across Oregon to set the standards for what high-quality, patient-centered primary care looks like. The program also identifies primary care homes, promotes their development, and encourage

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*Oregonians to seek care through recognized primary care homes”* (OHA Patient-Centered Primary Care Home Program, 2018). In our 2015 needs assessment we found that none of the program’s standards for PCPCH certification explicitly require addressing care for CYSHCN, but serving CYSHCN is one way a practice can meet Standard 5.C, Complex Care Coordination (Martin et al., 2015). This finding continues to hold true (OHA Patient-Centered Primary Care Home Program, 2018). However, if a clinic chooses to complete Standard 3.A, Preventive Services, the most recent standards require clinics to meet requirements specified in the national *Standards for Systems of Care for CYSHCN* (Association for Maternal and Child Health Programs [AMCHP], 2014).

## Public Insurance

More than one-third (36%) of Oregon CYSHCN younger than 18 years of age were publicly insured (Child and Adolescent Health Measures Initiative, 2020). As unemployment and financial hardship resulting from the COVID-19 pandemic continues to unfold, this percentage is likely to increase. Oregon administers its state Medicaid program, the Oregon Health Plan, via Coordinated Care Organizations and Open Card, a fee-for-service program. Through 2019, the Oregon Health Authority (OHA) contracted with fifteen CCOs. OHA uses health quality metrics to track their progress on health care accessibility, cost, quality, and eliminating health disparities (OHA, n.d.b). The metrics fall into two categories: (1) state quality measures that OHA agreed to report on to the Centers for Medicare and Medicaid Services as part of Oregon’s 1115 Medicaid waiver, and (2) Quality Incentive Pay-for-Performance Measures . CCOs receive additional payment based on performance (OHA, n.d.b). There are currently no metrics focused on CYSHCN.

*“A **coordinated care organization** is a network for all types of health care providers (physical health care, addictions and mental health care and dental care providers) who work together in their local communities to serve people who receive health care coverage under the Oregon Health Plan (Medicaid). CCOs focus on prevention and helping people manage chronic conditions, like diabetes. This helps reduce unnecessary emergency room visits and gives people support to be healthy”* (Oregon Health Authority, n.d.a).

OHA regularly administers the Consumer Assessment of Healthcare Providers and Systems (CAHPS) of Oregon Health Plan (OHP) members, including the Children with Chronic Conditions (CCC) survey items. Although the CCC survey results describe a subset of Oregon CYSHCN who are publicly insured – *not the population of CYSHCN who are publicly insured* – the results provide insight into the health care experiences of *some* CYSHCN who are insured through OHP.<sup>2</sup>

The CAHPS CCC items focuses on five areas of care: (1) Access to prescription medication, (2) Access to specialized services, (3) Getting needed information, (4) Having a personal doctor who knows the child, and (5) Coordination of care. Statewide aggregates (see Exhibit 5.5) show opportunity for improvement in Access to Specialized Services and Care Coordination.

- The Access to Specialized Services composite is based on families’ ratings of the ease to get specialized medical equipment or devices, therapy, and treatment or counseling for their child in the last six months. The Access to Specialized Services statewide aggregate shows that less than 70% of CCC are able to well access specialized services; this result is statistically significantly lower than the

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<sup>2</sup> OHA oversamples member households having children with sets of condition diagnoses (Children’s Health Care Quality Measures Core Set Technical Assistance and Analytic Support Program, 2012). The survey then uses the Child and Adolescent Health Measurement Initiative CYSHCN screener to confirm that the child member has a special health care need (Agency for Healthcare Research and Quality, 2008).

2018 results (Center for the Study of Services, n.d.). Additionally, seven CCOs have percentages below the state average.

- The Coordination of Care composite is based on families’ reported ability to get the help they needed from their child’s doctors or other health providers in contacting their child’s school or daycare and whether anyone from their child’s health plan, doctor’s office, or clinic helped coordinate their child’s care among different providers or services (Center for the Study of Services, n.d.). The Care Coordination statewide aggregate shows that 78% of CCC receive coordinated care; this is a one percentage point increase from 2018 results, but is not statistically significant (Center for the Study of Services, n.d.). Seven CCOs have percentages below the state average.

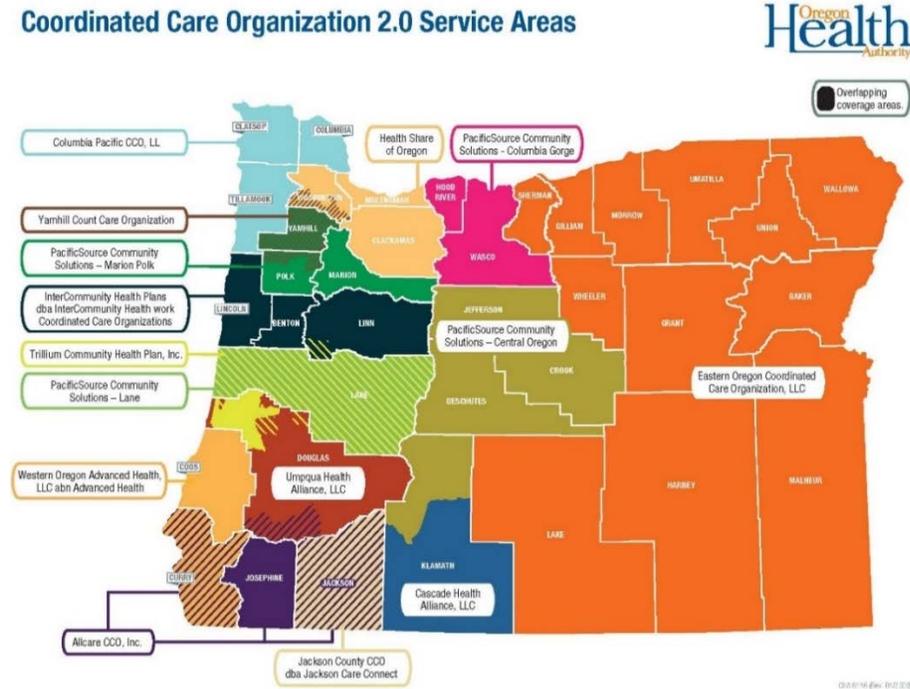
Two CCOs (AllCare Health Plan and Cascade Health Alliance) performed below the state average on *four of the five* CCC areas of care. Two other CCOs (Trillium Community Health Plan and Umpqua Health Alliance) performed below the state average on *three of the five* CCC areas of care. Prior to January 1, 2020, these CCOs served Medicaid-insured CCC in Curry, Jackson, Josephine, most of Klamath, Douglas, Lane, and parts of Benton, Coos, and Linn Counties. As of January 1, 2020, these CCOs will continue to serve part or all of the same geographic areas (see Exhibit 5.6).

Exhibit 5.5. 2019 Oregon CCO Scores for Children with Chronic Conditions’ Areas of Care

Survey Content Area	State Aggregate	High Score	Low Score	CCOs Below State Aggregate
Access to prescription medication	89%	97%	80%	<ul style="list-style-type: none"> <li>• AllCare Health Plan</li> <li>• Columbia Pacific</li> <li>• Trillium Community Health Plan</li> <li>• Umpqua Health Alliance</li> </ul>
Access to Specialized Services	69%	83%	48%	<ul style="list-style-type: none"> <li>• Cascade Health Alliance</li> <li>• Columbia Pacific</li> <li>• Eastern Oregon CCO</li> <li>• Fee For Service</li> <li>• Jackson Care Connect</li> <li>• Primary Health</li> <li>• Trillium Community Health Plan</li> </ul>
Getting Needed Information	91%	96%	87%	<ul style="list-style-type: none"> <li>• Advance Health</li> <li>• AllCare Health Plan</li> <li>• Cascade Health Alliance</li> <li>• Eastern Oregon CCO</li> <li>• Umpqua Health Alliance</li> </ul>
Personal Doctor Who Knows Child	87%	94%	78%	<ul style="list-style-type: none"> <li>• AllCare Health Plan</li> <li>• Cascade Health Alliance</li> <li>• Health Share</li> <li>• InterCommunity</li> <li>• Jackson Care Connect</li> <li>• Pacific Source – Central Oregon</li> <li>• Trillium Community Health Plan</li> </ul>
Coordination of Care	78%	87%	66%	<ul style="list-style-type: none"> <li>• AllCare Health Plan</li> <li>• Cascade Health Alliance</li> <li>• Fee For Service</li> <li>• Health Share</li> <li>• Pacific Source – Columbia Gorge</li> <li>• Primary Health</li> <li>• Umpqua Health Alliance</li> </ul>

Source: Center for the Study of Services (n.d.). Note: The total number of CCOs in 2019 was 15.

Exhibit 5.6. Oregon Coordinated Care Organization Service Areas Beginning January 1, 2020



### Geographic Areas with Unmet Health Care Needs

The Oregon Office of Rural Health (ORH, 2019) identified the communities with the greatest unmet health care needs (see Exhibit 5.7). These results show that nearly all of these communities are located in counties whose CCOs scored below state averages on most of the CAHPS CCC composites (see Exhibits 5.4 and 5.5). Nearly one in five residents in most (11 of 14) of these counties is a child. CYSHCN and their families living in these communities likely experience considerable challenges accessing health care and related services.

Exhibit 5.7. Oregon Communities With Greatest Unmet Health Care Need Scores, 2019

Community <sup>1</sup>	Unmet Needs Score <sup>2</sup>	County Location <sup>3</sup>	Travel Time to Nearest PCPCH <sup>4</sup>	Primary Care Capacity Ratio <sup>5</sup>	Dentists per 1,000 <sup>6</sup>	ED Dental Visits per 1,000 <sup>7</sup>	Mental Health Providers per 1,000 <sup>8</sup>	ED Mental Health Visits per 1,000 <sup>9</sup>	138-200% of FPL <sup>10</sup>	Prev. Hosp. per 1,000 <sup>11</sup>	2019 County Child Popn <sup>12</sup>
Oregon (state)	49.2		12.4	1.24	0.49	4.3	1.33	17.5	12%	7.8	
Powers	27	Coos	31	0.0	0.0	3.4	0.0	17.5	13%	22.7	11,638 (18.4%)
Cascade Locks	28	Hood River	23	0.0	0.0	9.4	0.0	11.4	21%	10.9	5,848 (23.0%)
Drain/Yoncalla	28	Douglas	22	0.12	0.0	8.5	0.0	12.5	18%	12.7	20,350 (18.1%)
Port Orford	29	Curry	32	0.54	0.0	6.6	0.0	17.2	8%	15.5	3,048 (13.3%)
Chiloquin	30	Klamath	32	0.65	0.0	4.1	0.11	14.7	22%	9.4	13,294 (19.5%)
Glendale	30	Douglas	23	0.0	0.0	5.4	0.0	13.2	16%	9.5	20,350 (18.1%)
Blodgett / Eddyville	31	Benton / Lincoln	13	0.0	0.0	5.5	0.0	18.6	27%	4.1	14,348 (15.2%) / 28,087 (22.2%)
Swisshome/ Triangle Lake	31	Lane	28	0.09	0.0	4.6	0.9	13.0	14%	10.4	65,477 (17.3%)
East Klamath	32	Klamath	35	0.28	0.0	7.4	0.0	14.4	11%	11.2	13,294 (19.5%)
Shady Cove	33	Jackson	10	0.20	0.17	6.1	0.0	17.4	14%	15.8	43,759 (19.8%)
Yachats	33	Linn	12	0.0	0.11	7.6	0.28	15.9	10%	11.7	7,649 (15.9%)

Source: Oregon Office of Rural Health (2019).

<sup>1</sup>All of these communities have a "rural" geography designation.

<sup>2</sup>Lower scores indicate greater unmet need. The lowest (worst) score possible is 0; the highest (best) score possible is 90.

<sup>4</sup>Average drive time to the nearest Patient-Centered Primary Care Home (PCPCH) in minutes. The five communities with the longest travel times were Jordan Valley (77 min), Vernonia (38 min), East Klamath (35 min), Chiloquin (32 min), and Port Orford (32 min).

<sup>5</sup>Comparison of the estimated visits that primary care providers (i.e., general and family physicians, internists, obstetrician-gynecologist, pediatricians, primary care nurse practitioners, and primary care physician assistants) in the service area should be able to supply to the estimated primary care visits need by the population. The nine communities with no primary care provider FTE were: Applegate/Williams, Blodgett-Eddyville, Cascade Locks, Glendale, Glide, Jordan Valley, Powers, Scio, and Yachats.

<sup>6</sup>Comparison of local dentist patient care FTE to the local population.

<sup>7</sup>Visits to the Emergency Department (ED) with a principal diagnosis of dental problems that are not a result of trauma. ED visits for non-traumatic oral health conditions are often a result of limited access to a primary dental provider. Most of these visits result in opioid and antibiotic prescriptions, rather than definitive dental care" (OORH, 2019, p. 28). The five communities with the highest rates were: Warm Springs (18.1), Cottage Grove (10.8), Toledo (10.8), Madras (10.0), and Winston (9.8).

<sup>8</sup> Comparison of the sum of all Psychiatrist, Psychiatric Nurse Practitioner, Marriage and Family Therapist, Psychologist, Clinical Social Worker, and Psychiatric Physician Assistant FTEs to local population.

<sup>9</sup>“Visits to the Emergency Department (ED) with a principal diagnosis of mood disorders, anxiety disorders, alcohol, drug use, schizophrenia and other psychoses, suicide attempts and suicidal ideations. ED visits for Mental Health/Substance Abuse (MHSA) conditions are potentially preventable with adequate primary care. They are more than twice as likely to result in a hospital admission, and the increasing rate of MHSA ED visits in the past few years is highest among low-income populations” (OORH, 2019, p. 30). The five communities with the highest rates were: Portland Downtown (59.6), Warm Springs (59.3), Coos Bay (30.0), Seaside (28.7), and Portland Outer South (24.9).

<sup>10</sup> “The percentage of the local population that is above the Medicaid cutoff of 138% of Federal Poverty Level (FPL), but still too poor to afford health insurance on their own [unless health insurance is provided by their employer] (OORH, 2019, p. 22). The five communities with the highest 138%-200% rates were: North Lake (27%), Blodgett-Eddyville (27%), Canyonville (23%), Condon (22%), Chiloquin (22%), and Cascade Locks (21%).

<sup>11</sup>Preventable hospitalizations are a set of inpatient discharges that may have been preventable had they been treated with timely and effective primary care. These include common conditions such as asthma, diabetes, hypertension, and pneumonia” (OORH, 2019, p. 26). The five communities with the highest rates of preventable hospitalizations were Powers (22.7), Wallowa/Enterprise (21.1), Reedsport (19.9), Warm Springs (18.2), and Coquille/Myrtle Point (17.1).

<sup>12</sup>Source: Portland State University Population Research Center (2019).

## Health Care Workforce

This section draws on findings from needs assessments conducted by the Oregon Health Authority Office of Health Analytics (OHA), Oregon Office of Rural Health (ORH), and the Oregon Center for Nursing (OCN). These studies provide an excellent perspective on the status of Oregon's health care workforce generally. A key limitation of this body of work is that it does not describe Oregon's pediatric workforce.

## Behavioral Health

Results of our 2015 needs assessment family survey showed that behavioral/mental health services are among the most difficult services for families of CYSHCN to access (Martin et al., 2015). Providers and care coordinators surveyed also identified a need for more behavioral/mental health services. Three of the four most frequently reported provider shortages were counselors/therapists, psychologists, and psychiatrists. As described in previous chapters, Oregon CYSHCN and their families need these providers, yet workforce shortages persist. For example, ten Oregon counties have no psychologists, three have no licensed clinical social workers, and three have no professional counselors/marriage or family therapists (OHA, 2019).

The Oregon Office of Rural Health (ORH) regularly reports on unmet needs for physical, oral, and mental health care in urban, rural, and frontier areas of the state.<sup>3</sup> ORH's 2019 analysis showed that the statewide average for mental health or substance abuse-related emergency department visits is 17.5 per 1,000 people per year, a rate that increased over the previous two years. Although the rate for urban areas is higher in general than that of rural and frontier areas (18.2 versus 16.3), the rates for Warm Springs, Coos Bay, and Seaside – rural areas – are very high (28.7 to 59.3). In addition, the statewide number of outpatient emergency department visits for suicidal ideation increased 96% from 2016 to 2018 (ORH, 2019). The Oregon Health Authority assessed Oregon's specialized behavioral/mental health workforce (i.e., behavioral/mental health care provided outside of primary care) (Hemeida et al., 2019). The results describe the availability and characteristics of the behavioral/mental health workforce generally, not specific to pediatrics. Key findings follow.

- *Oregon's behavioral/mental health workforce inadequacies result from provider shortages and geographic distribution. These same challenges face the U.S. generally.*
- *Multnomah County has almost twice as many provider FTEs as other Oregon regions. Gilliam and Sherman counties lack licensed prescribers and licensed providers.*
- *Discrepancies exist between the race/ethnicity of behavioral/mental health workforce and the race/ethnicity of Oregon's population. This discrepancy is particularly for Latino providers.*
- *"The outpatient clinical setting should be of particular focus when considering how to maximize the BH workforce. Outpatient specialty MH centers are saturated with patients from all levels of acuity, leading to excessive wait times that impact a patient's willingness to return for care. In order to improve the efficiency of the highly specialized workforce staffed in specialty MH clinics, the most complex patients with serious mental illness and those with more complicated medication regimens should be prioritized for this setting. Patients with mild to moderate BH conditions may be treated other lower-acuity settings such as integrated primary care clinics and school-based settings. After*

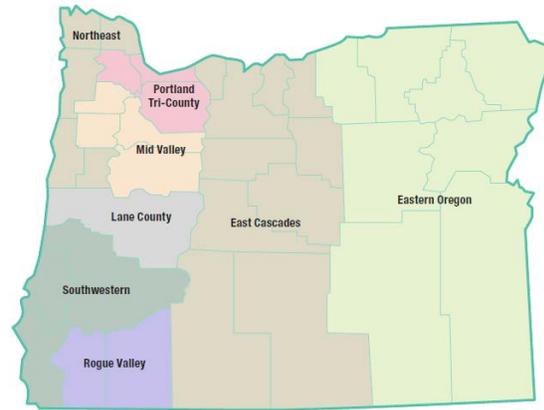
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<sup>3</sup>These reports are not specific to pediatric providers.

*patients' MH condition have stabilized or improved, services may be provided at the unlicensed provider or peer specialist level of care" (Hemeida et al., 2018, p. 55).*

The Oregon Employment Department (OED) developed a method to prioritize training resources for Oregonians to be competitive applicants for occupations that require post-high school training (Oregon Employment Department, 2018). OHA's 2019 analysis of OED data show that mental health counselor is one of Oregon's top 25 prioritized occupations for 2018-2028 in the following four regions: Eastern Oregon, Lane County, Portland-Tri-Counties, and Southwestern Oregon (see Exhibit 5.2). Mental health counselor is one of the top 50 prioritized occupations for the same time period in the Eastern Cascades and Rogue Valley regions (OHA, 2019).

Exhibit 5.2. Oregon Health Authority Health Care Needs Assessment Regions, 2018



Source: Oregon Health Authority (2019).

#### *Behavioral health providers of Color*

The Oregon Health Authority (OHA, 2018) analyzed the diversity of Oregon's health care workforce using licensing data from 14 health professional licensing boards.<sup>4</sup> Behavioral health care providers, which include psychiatric nurse practitioners, physicians and physician assistants, psychologist examiners, licensed professional counselors and therapists, and licensed clinical social workers, constitute nearly 9% of Oregon's health care workforce (OHA, 2018). OHA's analyses showed that racial and ethnic minority groups are underrepresented among behavioral health care providers. OHA (2018) reported a shortage of Hispanic/Latino behavioral health care providers compared to Oregon's Latino population (12.4%). With the exception of nurse practitioners, approximately 4% of Oregon's behavioral health care providers identified as Hispanic/Latino. Just 2.4% of nurse practitioners identified as Hispanic/Latino (OHA, 2018).

Approximately 1% of psychiatrists and licensed clinical social workers identified as Black/African-American (OHA, 2018). Black/African-Americans represent less than 1% of nurse practitioners, licensed professional counselors and therapists, and psychologists (OHA, 2018). Similarly, American Indian and Alaska Natives (AI/AN) and Native Hawaiian and Pacific Islanders (NH/PI) are the least represented among behavioral health providers. AI/AN represented from 0.1% to 0.7% of the behavioral health workforce, and for NH/PI the rate was 0.1% to 0.5% (OHA, 2018). Asian psychiatrists are the one group of behavioral health providers that is overrepresented (10.2%) compared to population size. (OHA, 2018).

#### *Physical and Oral Health*

The Oregon Health Authority (OHA) analyzed data from Oregon health care licensing boards to count licensed providers and examine changes in eighteen provider types over time. These analyses showed a 4% increase in the number of dentists between 2009-2010 and January 2018 (3,697 to 3,864), a 10% increase in physicians (14,646 to 16,124), 28% increase in registered nurses (43,015 to 55,316), a 63%

<sup>4</sup> Licensing boards collect data describing demographic characteristics of professionals at the time of license renewal; therefore, the results do not describe all currently active licensed professionals in Oregon (OHA, 2018).

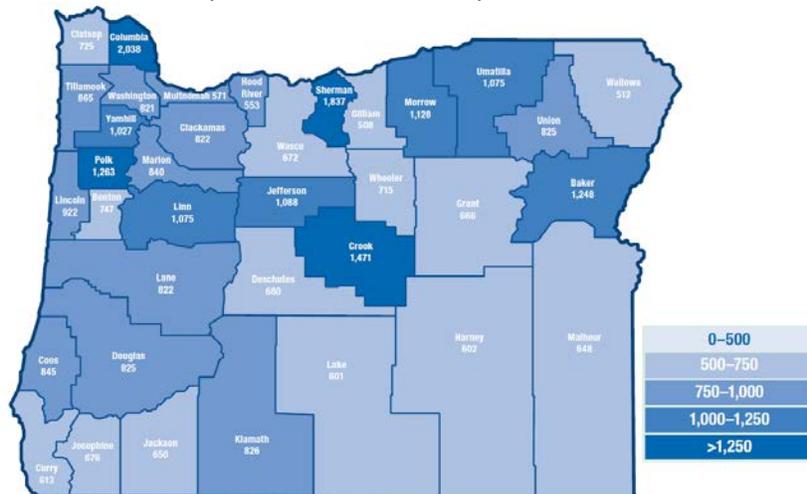
increase in physical therapists (3,139 to 5,113), a 78% increase in occupational therapists (1,269 to 2,260). During this time, Oregon’s population increased by nearly 8% (3,837,300 to 4,141,100)(OHA, 2019).

Despite these increases, some Oregon counties lack basic providers and provider types that Oregon families of CYSHCN often report needing, such as allied health providers (Gallarde-Kim, Bisso-Fetzer, Roy, et al., 2020; Gallarde-Kim, Smith, Roy, et al., 2020; Martin et al., 2015). For example,

- 15 counties have no audiologists.
- 5 counties have no occupational therapists, and 12 have no occupational therapist assistants.
- 3 counties have no speech language pathologists, and 5 have no speech language pathologist assistants.
- 3 counties have no pharmacists, and 2 have no pharmacy technicians.
- 2 counties have no dentists, and 2 have no dentist hygienists.
- 2 counties have no physical therapists, and 4 have no physical therapist assistants.
- 2 counties have no doctors of medicine (MD) or of osteopathic medicine (DO) (OHA, 2019).

OHA analyzed Health Care Workforce Reporting Program data (2019) to compute a resident to primary care provider ratio for each Oregon county (see Exhibit 5.3). Their results show that about one-third of Oregon counties have ratios at or greater than 1,000 residents to one primary care provider (Baker, Columbia, Crook, Jefferson, Linn, Morrow, Polk, Sherman, Umatilla, and Yamhill). A number of factors contribute to determining an appropriate size for a health care provider’s patient panel (Murray, Davies, & Bouchon, 2007; Weber, 2019), and county residents per provider does not equate to the number of patients per provider. It would be more helpful to understanding the system of care for CYSHCN if we had county-level data describing the number of pediatric primary care providers per child under age 18.

Exhibit 5.3. County Residents Per Primary Care Provider, 2016-2017



Source: Oregon Health Authority (2019) analysis of Health Care Workforce Reporting Program data submitted in 2016 and 2017.

In examining unmet need for physical, oral, and mental health care in urban, rural, and frontier areas of the state, ORH (2019) computes an unmet need score for primary care service areas that can range from 0 (worst, indicates greatest need) to 90 (best, indicates least need).<sup>5</sup> In 2019, the state average unmet need score was 49.2, and scores ranged from 27 to 73. As Exhibit 5.4 shows, the need in rural – excluding frontier – areas is almost 1.5 times that of urban areas (ORH, 2019). Results for rural areas

<sup>5</sup>Again, these reports are not specific to pediatric providers.

also show that the primary care demand exceeds capacity. Statewide, on average, there is about one-half of a dentist FTE available for every 1,000 residents; there is 1.3 mental health provider FTE available for every 1,000 residents; and 12% of the population have an income between 138% and 200% of the Federal Poverty Level, which inhibits families’ ability to purchase insurance (ORH, 2019).

Exhibit 5.4. Average Unmet Medical Health Care Need Scores By Geography, 2019

Geographic Area	Average Unmet Needs Score <sup>a</sup>	Number of Services Areas Below State Average	Primary Care Capacity Ratio <sup>b</sup>	Dentist FTE per 1,000 Population	Mental Health Provider FTE per 1,000 Population	Population Between 138% and 200% FPL
Oregon (statewide)	49.2		1.24	0.49	1.33	12%
Urban	60.7	1 of 26 (4%)	1.40	0.58	1.71	11%
Rural (without Frontier)	45.6	53 of 86 (62%)	0.93	0.33	0.62	13%
Rural (with Frontier)	46.3	60 of 104 (58%)	0.95	0.34	0.62	13%
Frontier	49.6	7 of 18 (39%)	1.37	0.39	0.57	14%

Source: Oregon Office of Rural Health (2019).

<sup>a</sup>Lower scores indicate greater unmet need. The lowest (worst) score possible is 0; the highest (best) score possible is 90. Total number of service areas is 130.

<sup>b</sup>Comparison of the estimated visits that primary care providers (i.e., general and family physicians, internists, obstetrician-gynecologist, pediatricians, primary care nurse practitioners, and primary care physician assistants) in the service area should be able to supply to the estimated primary care visits need by the population (ORH, 2019). A ratio less than one indicates that demand is greater than the supply (ORH, 2019).

ORH also found that

- *“The average travel time in Oregon to the nearest Patient Centered Primary Care Home (PCPCH) is 12.4 minutes. Twenty rural and frontier service areas do not have a PCPCH and the drive times for these areas average 26 minutes.*
- *Oregon has an average Unmet Need Score of 49.2 out of 90. All but 1 of the service areas that fall under this mean are either rural or frontier.*
- *Nine rural primary care service areas have 0 FTE of primary care providers available.*
- *Twenty-six rural and frontier primary care service areas have 0 dentist FTE.*
- *Oregon has an average non-traumatic dental Emergency Department (ED) visit rate of 4.3 per 1,000 people per year. The rate in rural Oregon is 5.6 per 1,000. Warm Springs, Cottage Grove, and Toledo have rates multiple times the state average (10.8 to 18.1).<sup>6</sup>*
- *Seventy-one rural and frontier service areas have less than 0.5 mental health provider FTE and 22 of those have 0 mental health provider FTE.*
- *The percentage of the population that is above the Medicaid cut off of 138% Federal Poverty Level (FPL) but still below 200% of the FPL (and therefore unlikely able to afford health insurance unless provided by an employer) is 12% in Oregon. North Lake,*

<sup>6</sup> Warm Springs is a community (population unavailable) located on the Warm Springs Indian Reservation in Jefferson County (East Cascades region in Exhibit 5.2). Cottage Grove is a community of 10,140 (Portland State University [PSU], 2019) located in Lane County near Interstate 5 (Lane region in Exhibit 5.2). Toledo is a community of 3,490 (PSU, 2019) located in Lincoln County (Northeast region in Exhibit 5.2).

*Blodgett-Eddyville, Chiloquin, Condon, and Canyonville have percentages as high as 22-27%.*

- *Oregon has a preventable hospitalization rate of 7.8 per 1,000 people. Rural and frontier service areas average 9.7 per 1,000. Powers, Wallowa/Enterprise, and Reedsport, have the highest rates, ranging from 19.9 to 22.7 (Oregon Office of Rural Health, 2019, p. 5).*

OHA's (2019) analysis of OED data describing the top 25 occupations prioritized for training needs for 2018-2028 by eight geographic regions (see Exhibit 5.2 above). The following ranked in the top 25 prioritized occupations in all eight regions: nursing assistants, registered nurses, medical assistants, medical secretaries. The following ranked in the top 25 prioritized occupations in seven of eight regions: dental assistants, physical therapists, and other physicians and surgeons (OHA, 2019).

Because CYSHCN by definition require more health care and related services than their peers, it follows that workforce shortages affecting Oregon's population generally would especially impact CYSHCN and their families. An important limitation to these results, however, is that they do not specifically describe pediatric providers. Data describing the pediatric workforce would help us better understand access to care challenges for CYSHCN.

#### *Physical and oral health providers of Color*

The Oregon Health Authority (2018) analyzed the diversity of Oregon's health care workforce using licensing data from 14 health professional licensing boards.<sup>7</sup> OHA found that Oregon's health care workforce does not reflect the increasingly racially and ethnically diverse state population (OHA, 2018). Health care professionals who identify as Latino are underrepresented, and those who are White and Asian are overrepresented, in nearly all health care profession types (OHA, 2018). Health care professionals who are Latino are more often represented in positions that require fewer licenses (OHA, 2018). Although women are overrepresented in many health care professional roles, men are overrepresented in those that require advanced training (OHA, 2018).

Primary care providers (i.e., nurse practitioners, physicians, physician assistants, and naturopathic physicians) represent 6% of Oregon's total health care workforce. With few exceptions, people of Color are underrepresented across all Oregon primary care provider (PCP) types (OHA, 2018). There is a gap between the proportion of Oregon's population who are people of Color and the proportion of providers of Color. Oregon's Hispanic/Latino population experiences the greatest gap. Hispanic/Latino people make up 12.4% of the state's population, although less than 5% of the state's PCPs identify as Hispanic/Latino (OHA, 2018).

The gaps between Oregon's population and PCP provider type for Black/African-American, AI/AN, and NH/PI are less pronounced than that of the Hispanic/Latino population. Black/African-Americans comprise 1.8% of Oregon's population, and percentages ranged from 0.8% and 1.9% of each PCP type that identified as Black/African-American (OHA, 2018). AI/AN represent less than 1% of Oregon's population, and percentages ranged from 0% to 0.5% of each provider type that identified as AI/AN (OHA, 2018). Similarly, NH/PI represent less than 1% of Oregon's population, and percentages ranged from 0.2% to 0.8% of each provider type that identified as NH/PI (OHA, 2018). In contrast to other racial and ethnic groups, Oregon's Asian population, which represents 4% of the state, reported an

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<sup>7</sup> Licensing boards collect data describing demographic characteristics of professionals at the time of license renewal; therefore, the results do not describe all currently active licensed professionals in Oregon (OHA, 2018).

overrepresentation (14.5%) of Asian physicians (OHA, 2018). In interpreting these results, it is important to note that they do not describe whether PCPs who identified as people of Color practice in the geographies where Oregon's people of Color live (OHA, 2018).

Based on OHA's 2018 analysis of Oregon's health care workforce, oral health care providers make up approximately 2% of Oregon's health care workforce. Most racial and ethnic minority groups are underrepresented in oral health care providers. The gap between the population's racial/ethnic identity and dentists' racial/ethnic identity is greatest for Hispanic/Latinos. Three percent of dentists identified as Hispanic/Latino. Less than 1% of dentists identified as Black/African-American, AI/ANs, or NH/PIs. Asian dentists are overrepresented (13.3%) relative to the size of Oregon's Asian population.

### Language spoken

In Oregon, English remains the dominant language spoken among the health care workforce. According to OHA (2018), 20% of Oregon's health care professionals reported speaking languages other than English. Spanish is the most commonly reported non-dominant language spoken among the health care workforce; more than 10% of health care professionals reported an ability to speak Spanish (OHA, 2018). Of these:

- About 40% reported either advanced proficiency (21%) or being a native speaker (18%)
- 69% reported that they used Spanish while providing patient care
- Only 5% of these providers are certified to use Spanish while providing patient care
- 39% have training in medical terminology (OHA, 2018).

After Spanish, French is the second most commonly reported non-dominant language used by health care professionals (OHA, 2018). Almost 6% of the health care workforce reported other Indo-European spoken languages (most languages of Europe, Indic languages of India, and languages spoken in Iran) (OHA, 2018). Nearly 5% of the health care workforce reported speaking Asian and Pacific Island languages, including Chinese, Hmong, Japanese, Khmer, Korean, Lao, Tagalog, Thai, and Vietnamese (OHA, 2018).

### Education-Based Care

The *Standards for Systems of Care for CYSHCN* (AMCHP & NASHP, 2017) identify education representatives as important members of a child's care team. Special Education, including Early Intervention (EI) and Early Childhood Special Education (ECSE), programs provide essential services to CYSHCN and their families. Additionally, school nurses are important partners in supporting the health care needs, and monitoring the health of, CYSHCN. In this section, we summarize findings from the Oregon Secretary of State Audits Division and a survey of Oregon school nurses to describe challenges facing education partners in the system of care.

### Special Education

The Oregon Secretary of State (OSOS) Audits Division conducted an audit of the Oregon Department of Education (ODE) in 2020, to determine whether ODE can better support early childhood through school-age children and youth who experience disability, a subpopulation of CYSHCN. During the 2018-2019 academic year, the Oregon Department of Education identified over 80,000 students in kindergarten through grade 12 as experiencing disabilities (Oregon Secretary of State [OSOS], 2020), which was 14%

of the Oregon students.<sup>8</sup> The audit found that “only 33.4% of children eligible for [Early Intervention and Early Childhood Special Education] services received the recommended specialized consultation services at least one time per week” (OSOS, 2020, p. 9). In addition, the rate of children eligible for Early Childhood Special Education (ECSE) services who received adequate levels of service varied depending on the child’s level of need. That is, only 0.7% of children with high needs, 6.2% with moderate needs, and 61.6% with low needs received adequate service (OSOS, 2020).

Growing caseloads and a lack of funding present barriers to providing these services. According to the audit, “funding has never been sufficient to meet the level of adequacy called for in ODE’s EI/ECSE service model since...it was first developed” (OSOS, 2020, p. 12). Districts sometimes use funds from their general education budgets to cover special education service costs (OSOS, 2020). Education Service Districts cannot afford to hire enough special education teachers, making the demands on the teachers they do hire so high that it is hard to retain them; the turnover rate for special education teachers is 20.4%, compared to 13.7% for all teachers (OSOS, 2020). Rural Oregon districts are further challenged to provide special education services in that they compete with urban areas for a limited supply of teachers (OSOS, 2020). Additionally, the shortage of primary care and child care providers may play a part in some children not being referred early for evaluation and services, as these providers often are professionals who refer children and families to EI/ECSE (OSOS, 2020).

### School-Based Nursing

In 2019, OHA’s Adolescent and School Health Section (ASH) surveyed Oregon school nurses about their ability to serve youth with individualized education plans (IEPs) and received 72 responses. Eighty-two percent of respondents reported that they were responsible for 1,001 to 3,500 students; 18% reported being responsible for 1,000 or fewer students. Nearly all respondents worked for school districts (60%), education service districts (26%), or local public health authorities or health departments (8%).

Respondents most often reported the following barriers to providing school health services to students with IEPs: not enough nurses (70%); not enough time (61%); lack of coordination with school staff in planning for the student (61%)(Oregon Health Authority Public Health Division Adolescent and School Health [ASH], 2019). Respondents also reported difficulties communicating with providers (43%) and with parents (42%); school staff resistance to delegation (36%); lack of time to chart/document (36%); lack of professional development and technical assistance (26%)(ASH, 2019). Twelve respondents (16%) listed the following other barriers: school nurses not invited to IEP meetings or made aware that a student with medical issues has an IEP; access to student medical records; language barriers for families that do not speak English; lack of time to train school staff and students; staff turnover; and school resistance to “outside the box” solutions (ASH, 2019).

Fifty-seven percent of respondents reported requesting records or other care records from behavioral/mental, oral, primary or specialty health care providers for more than half of the students with IEPs with whom they work. Respondents reported that it is “usually” or “always” easy to coordinate with the following types of care providers to meet the needs of students with IEPs:

- Primary care providers (69%)
- Occupational, physical, or speech therapists (66%)

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<sup>8</sup>Based on the Fall enrollment for the 2018-2019 school year (581,730 students kindergarten through 12<sup>th</sup> grade) as reported by the Oregon Department of Education (<https://www.oregon.gov/ode/reports-and-data/students/Pages/Student-Enrollment-Reports.aspx>).

- Pediatric specialists (65%)
- Early Intervention staff (52%)
- Behavioral and mental health providers (40%)
- Dentists (25%)
- Adult-oriented primary care providers for coordinating transition care (23%)
- Naturopathic doctors (20%)
- Vocational or rehabilitation program staff (18%)
- Respite care providers (13%)
- Day care providers (8%)
- Chiropractors (3%)(ASH, 2019).

When asked for the three greatest challenges they experience attempting to coordinate care for for students with IEPs, nearly half of the respondents described difficulties working with families of these students. Examples included the family being unresponsive or not following through, refusing or being slow to sign releases of information, not providing up-to-date provider information, and not seeing the need for help. Nearly half of the respondents also described difficulties working with health care providers. Examples included getting a timely response for information, getting information about prescriptions and care plans, and receiving a provider request that is unrealistic for the school context. About one-quarter of respondents described challenges with school-based colleagues, including administrators. Examples included not understanding the role of the school nurse, not seeing a need for nurse involvement, and not communicating or involving them in IEP meetings. Nearly one-quarter also described a lack of time for them to coordinate, plan, and train and supervise other staff, and overwhelming caseloads that prevented them from attending meetings or doing the other activities (ASH, 2019).

About half (51%) of respondents reported they did not have access to a shared care plan for students with IEPs. One-third (33%) reported they did have access to a shared care plan, and 15% did not know. About 20% reported that they had been included in the shared care plan development for more than half the students with IEPs that they served. Almost half (48%) reported that they had been involved in shared care plan development for none or almost none of the students with IEPs (ASH, 2019).

### Transition to Adult Health Care

OCCYSHN led Oregon's participation in the HRSA-funded, Boston University-led Children with Medical Complexity (CMC) Collaborative Improvement and Innovation Network (CoIIN). Families of young adults with medical complexity (YAMC) report being ill-prepared for the transition from pediatric to adult health care. We conducted an analysis of the root causes underlying this lack of preparation. We used a fishbone diagram to organize the causes, which we categorized into People, Place and Technology, Policies, and Procedures and Materials (Martin et al., 2019). A brief discussion of the system of care-related findings from each category follows.

#### People

This category describes gaps in capacity, knowledge, or skills on the part of providers (pediatric and adult primary care, specialty care, and mental health) involved in the transition from pediatric to adult health care.

### *Pediatric Providers*

Our analysis identified that pediatricians do not typically refer patients to adult providers or otherwise help them with the transition to adult health care because:

- Health care transition is a new concept to pediatric providers. Primary care providers (PCP) do not yet understand what early conversations should entail. Families of YAMC with mental health conditions reported that their child's mental health providers did not know or were not tracking that their child's care will cease once the child turns 18 years old. Additionally, some child psychiatrists will not see a youth who is older than 18 years.
- Pediatricians do not know which adult providers care for medically complex youth. They lack staff resources to find an adult PCP who will accept their patient, or to dedicate care coordinator time to transition issues. In addition, adult provider choices may be limited by pediatric provider preference to refer YAMC to internal medicine rather than family medicine. Pediatric providers may perceive that the knowledge of internal medicine providers better aligns with the needs of YAMC.
- Pediatric practices sometimes expect that adult primary care is helping the YAMC locate adult specialists, which is not always the case (Martin et al., 2019).

### *Adult Providers*

Our analysis identified that adult physical health providers may not accept YAMC because the providers lack understanding or familiarity with their conditions or are uncomfortable working with them. Some adult psychiatrists will not take patients younger than 24 years, which limits the number of mental health providers available to work with 18 to 24 year old YAMC. Our analysis also identified that providers who work with YAMC could develop more successful relationships with YAMC and their families if they understood:

- The developmental needs of young adults.
- The value of patient and the family knowledge of the YAMC's condition and history.
- How to work with YAMC who have developmental and intellectual disabilities.
- How to work with family members of YAMC, such as acknowledging the family member's expertise and input.
- The process to obtain durable medical equipment (Martin et al., 2019).

### *Policies*

The policy issues we identified primarily focus on payment challenges. For example, under a fee-for-service payment system, providers lose money caring for YAMC when longer appointments are required. A provider can make more money billing for two 20-minute visits with two separate patients than one 40-minute visit with a single patient. A second payment issue is that insurance payers do not pay adequately, if they pay at all, for care coordination CPT codes.

Other policy issues that contribute to inadequate support and preparation for transition to adult health care include:

- A lack of policy on transition in health care settings results in inconsistent provision of care. Some practices provide a warm hand-off to adult providers, others do not.

- Adult mental health systems may require new or additional diagnostic evaluations at age 18 years to sustain mental health services. As there can be waits of up to two years for diagnostic appointments, YAMC experience lapses in care.
- Some hospitals do not permit pediatricians to admit patients who are older than 21 years, which interferes with receipt of care.

### Procedures and Materials

Our root cause analysis also identified that providers lack standardized procedures to help YAMC transition to adult health care. This contributes to inadequate support and preparation. YAMC often do not have a care plan, emergency plan, or condition-specific materials for a new adult health care provider. Adult providers do not have established relationships with the patient's pediatric care team for consultation.

### Technology

Primary care and specialty providers may not have access to the same patient health and care information. Sometimes the providers do have access, but are not aware because the information is buried in the electronic health record (EHR). Because EHR systems do not include transition elements, providers cannot use technology to promote a focus on transition.

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