

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

## **CHAPTER TWO**

# Compilation of Findings From Secondary Data Sources

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## Compilation of Findings From Secondary Data Sources

Oregon Title V Needs Assessment Chapter 2. Children and Youth with Special Health Care Needs  
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In this chapter we present findings from primary or secondary data analyses using seven data sources. Our findings rely heavily on the National Survey for Children’s Health. The sample from which the Federal Maternal and Child Health Bureau and U.S. Census Bureau collected data often is not large enough to reliably interpret CYSHCN estimates or reliably disaggregate CYSHCN findings by characteristics that help to identify disparities (e.g., ethnicity, race, socioeconomic status). We used footnotes to indicate when readers should interpret an estimate with caution due to small sample size. We also included results from other Oregon data sources that describe populations of CYSHCN, when those results were available; however, NSCH and 2015 Title V needs assessment results are the only that apply to Oregon’s population of CYSHCN. A brief description of the data sources used in this chapter follows.

1. *2016-2017 National Survey of Children’s Health (NSCH) combined data file.* The sampling frame of the NSCH changed in 2016, hence, the 2016 results are not comparable to those from the NSCH or the National Survey of Children with Special Health Care Needs (NS-CSHCN) from prior years. The 2016-2017 NSCH data are nationally representative of all non-institutionalized children in the United States from 0-17 years of age. CYSHCN are identified using five screener questions (Child and Adolescent Health Measurement Initiative, 2007). Other sources of data used in the report are described below.
2. *2016-17 National Core Indicators (NCI) Data.* The NCI Child and Family Survey (CFS) was administered to families who have a child with developmental disabilities who lives with the family and receives at least one service other than case management from the state developmental disability (DD) agency (National Core Indicators [NCI], 2018). A Child and Family Survey could be completed for an individual up to 22 years of age if they are still receiving “child” services. The NCI 2016-17 data also reported on needs (health care and others) for transition aged-youth in Oregon who have developmental disabilities (DD) and receive at least one service from the state DD agency other than case management (National Core Indicators [NCI], 2020). Although the Oregon sample size for transition-aged youth was small, it provided us with some valuable insights into the health care needs of the state’s transition-aged youth.
3. *2018 Children with Medical Complexity Collaborative for Improvement and Innovation Network Family of Young Adults with Medical Complexity Interview Results.* OCCYSHN leads Oregon’s team in a federally-funded Collaborative Improvement and Innovation Network (CoIIN) to improve the quality of care for children with medical complexity. Oregon’s project focuses on transition to adult health care for young adults with medical complexity (YAMC). OCCYSHN led the team in conducting an environmental scan on this topic, part of which included conducting interviews with families of young adults with medical complexity (YAMC) in Oregon. The data collection sought to understand their experience with health care transition.

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4. *2018-2019 OCCYSHN Shared Care Planning Family Survey.* Families of CYSHCN who received shared care planning through their LPHA are invited to participate in a survey about their experience and satisfaction with the shared care planning process.
5. *2018-2019 Oregon Department of Education (ODE) Data.* Per the Individuals with Disabilities Education Act (IDEA) 2004, ODE is required to summarize state-level data on aspects of special education which is reported to the U.S. Department of Education. ODE's report is divided into two sections: Part B (ages 3 – 21 years) and Part C (birth – 2 years). Part B provides information on the number of children served in special education, their education placements, personnel employed to serve students with disabilities, students exiting special education, discipline of students with disabilities, participation and performance on statewide assessments, and dispute resolution. Part C provides the number of children served in early intervention programs, their placements, children exiting early intervention, and dispute resolution.
6. *2019 OCCYSHN Shared Care Plan Information Form.* OCCYSHN contracts with local public health authorities (LPHAs) across the state to implement shared care planning to CYSHCN and their families. After each shared care planning meeting, LPHA staff complete this form online via REDCap. The primary purpose of this form is to enable OCCYSHN to track the number of new shared care plans developed, the number of existing shared care plans re-evaluated, the number of shared care plans that serve transition-aged youth (12 up to 21 years old), the number of shared care plans for transition-aged youth that included transition goals, and the number of children served.
7. *2019 Oregon Child Health Information Data System (ORCHIDS).* OCCYSHN's CaCoon program provides public health nurse home visiting care coordination for CYSHCN up to age 20 and their families. CaCoon is administered by LPHA nurses across the state. The purpose of ORCHIDS is to collect data for billing, program evaluation, and Title V reporting. LPHAs enter client demographics and data about each client's visit. Data entered into ORCHIDS include demographics, insurance type, referrals, risk factors, tier levels, and information about issues, outcomes, and interventions.
8. *2019 Oregon Healthy Teens (OHT) Survey.* OHT monitors the health and well-being of 8<sup>th</sup> and 11<sup>th</sup> graders statewide (Oregon Health Authority [OHA], 2019b). We used survey findings to identify the mental and emotional health needs of young school-going adults in the state.
9. *2019 Oregon Health Authority (OHA) Title V Survey of Partners.* OHA's Maternal and Child Health section fielded a survey to Title V Partners from across the state. The types of partners who completed the survey include community-based organizations, LPHA, OHA tribal grantees, and state agency staff. The survey asked partners to select the priority area that they would choose for Oregon Title V to focus on, if the state could only focus on one for each Title V population (women/mothers, infants, children, adolescents, and CYSHCN).

## Oregon Children and Youth with Special Health Care Needs

Nearly one in five (19%) Oregon children younger than 18 years have a special health care need (CAHMI, 2020). Approximately 18% are White, non-Hispanic and 17.5% are Hispanic (CAHMI, 2020).<sup>2</sup> Approximately 14% of CYSHCN are ages birth through five, 17% ages six through 11, and 25 % ages 12 through 17 (CAHMI, 2020). Oregon CYSHCN tend to live in two-parent families (63% in two-parent married families, 8% in two-parent unmarried families), although 20% live in a family headed by a single

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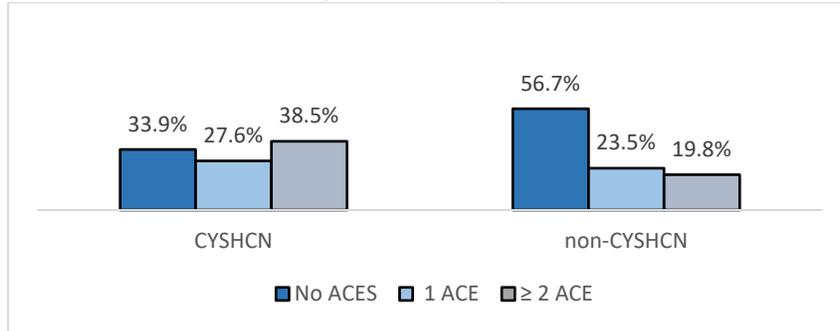
<sup>2</sup> The National Survey of Children's Health uses "Hispanic" on its questionnaire. When talking about NSCH findings, we use their term. When talking about findings from our collaboration with the Latino Community Association, we use their term, "Latino," to describe families from whom they collected data.

mother and 8% live in family with an other structure type (CAHMI, 2020).<sup>3</sup> The following sections describe characteristics of families of CYSHCN.

### Adverse Childhood Experiences

Oregon CYSHCN are about twice as likely to experience two or more ACEs than children without special health care needs (39% versus 20%, respectively) as shown in Exhibit 3.1 (CAHMI, 2020).<sup>4</sup>

Exhibit 3.1. Percent of Oregon Children By Number of Adverse Childhood Experiences (NSCH 2016-2017)



The Oregon Pediatric Improvement Partnership, Oregon Health Authority, and Department of Human Services (2018) analyzed data for 390,582 publicly insured Oregon children who were younger than 18 years during the July 2015 to June 2016 time frame. They identified children who experienced degrees of medical complexity (Complex Chronic Disease, and Non-Complex Chronic Disease; Simon et al., 2014) and number of social complexity factors (i.e., child receipt of TANF, foster care services, mental health care, substance abuse treatment, or experience of abuse or neglect; parent receipt of TANF, mental health care, substance abuse treatment; parent death; parent incarceration; parent disability; parent Limited English Proficiency). Children who experience medical complexity are a population of CYSHCN.

Results showed that 6.1% of the children experienced Complex Chronic Disease (CCD) and 18.3% experienced Non-Complex Chronic Disease (NCCD). Of the 6.1% of CCD children, 2.4% experienced one or two, and 3% experienced three or more, social complexity factors (Oregon Pediatric Improvement Partnership, Oregon Health Authority, and Department of Human Services, 2018). Of the 18.3% of NCCD children, 7.2% experienced one or two, and 9.5% experienced three or more, social complexity factors (Oregon Pediatric Improvement Partnership, Oregon Health Authority, and Department of Human Services, 2018).

OCCYSHN and its local public health authority (LPHA) partners, serve CYSHCN whose families experience social complexity through home visiting and team-based shared care planning. In 2018-2019, 25 LPHAs served 1,192 CYSHCN and their families through OCCYSHN’s Care Coordination (CaCoon) public health nurse home visiting program. CaCoon public health nurses score clients using a “Tier Tool” to identify

<sup>3</sup> The Data Resource Center advises that consumers use caution when interpreting this estimate due to low sample size (<http://childhealthdata.org/browse/survey/results?q=6451&r=39&g=664>).

<sup>4</sup> The National Survey of Children’s Health collects data about the following adverse childhood experiences (ACEs): family finds it hard to get by on their income or cannot afford basics; parent or guardian divorced or separated; parent or guardian died; parent or guardian served time in jail; child witnessed domestic violence; child was the victim or witness of neighborhood violence; child lived with anyone who was mentally ill, suicidal, or severely depressed; child lived with anyone who had a problem with alcohol or drugs; and child was treated or judged unfairly because of his/her race or ethnic group.

the extent of their development, education, health, cultural and language, and basic needs. In 2019, most CaCoon clients and their families (n=894) had moderate needs. In 2018-2019, 21 LPHAs served 100 CYSHCN and their families<sup>5</sup> through team-based shared care planning, 65% of whom experienced social complexity.<sup>6</sup>

### Financial Hardship

Families of CYSHCN can bear significant financial burden for their child's health care in the form of out-of-pocket costs, foregone or lost work and higher routine expenses (Catalyst Center, 2017). This puts families of CYSHCN at risk of financial hardship, medical debt and poverty. About half the families of Oregon CYSHCN have lower household incomes and use public assistance.<sup>7</sup> These families also report greater problems paying medical bills than families of non-CYSHCN. Oregon families of CYSHCN experience financial hardship, and the sequelae of COVID-19 is likely to exacerbate this hardship.

- More than one-quarter (28%) of Oregon CYSHCN families have annual household income at 0-99% of the Federal Poverty Level (FPL), about one-fifth are at 100-199% FPL (21%), and nearly one-quarter are at 200-400% FPL (23%)(CAHMI, 2020). More than one-quarter (28%) have annual household income greater than or equal to 400% FPL (CAHMI, 2020). In 2017, the federal poverty level for a family of four was \$24,600 (Assistant Secretary for Planning and Evaluation [ASPE], 2017).
- Nearly half CYSHCN families received cash or food assistance. Cash and food assistance includes: (a) benefits from the Woman, Infants, and Children (WIC) Program; (b) cash assistance from government welfare program; (c) Food Stamps or Supplemental Nutrition Assistance Program benefits; or (d) free or reduced-cost breakfasts or lunches at school during the past 12 months. Nearly one-third (31%) received one or two types of assistance; 17% received three or four types of assistance (CAHMI, 2020).
- Almost one-quarter (20%) of CYSHCN with more complex health needs<sup>8</sup> had a family member who reduced their hours, stopped working, or both because of their child's health or health conditions (CAHMI, 2020).

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<sup>5</sup>Eighty-two percent of these children and families also were served through the CaCoon program.

<sup>6</sup>CYSHCN with social complexity, or their families, have experienced or currently are experiencing one or more of the following: adolescent exposure to intimate partner violence, child abuse/neglect – child welfare system involvement, child criminal justice involvement, child mental illness, child substance abuse, discontinuous insurance coverage, foreign-born parent, foster care, homelessness, low English proficiency, low parent educational attainment, parent criminal justice involvement, parent death, parent domestic violence, parent mental illness, parent physical disability, parent substance abuse, severe poverty, i.e., TANF eligible (Center of Excellence on Quality of Care Measures for Children with Complex Needs, University of Washington & Seattle Children's Research Institute, 2016).

<sup>7</sup> We lack state-level data to describe food security among Oregon CYSHCN. NSCH 2016-2017 results show that 11% of CYSHCN families nationwide reported that they could not afford enough to eat sometimes/often. About one-third (32%) of CYSHCN families nationwide reported that they could afford enough to eat, but not always the kinds of food they should eat.

<sup>8</sup> CYSHCN are identified as more complex if they have one or more of the following health conditions that has or is expected to last for 12 months or more: need or use more medical care, mental health, or educational services than is usual for same-age children; limited or prevented in anyway in their ability to do things that most same-aged children can do; need or receive therapy (e.g., occupational, physical, speech); or has any kind of behavioral, developmental, or emotional condition for which they need treatment or counseling.

- About 16% of CYSHCN with more complex health needs had a family member who avoided changing jobs because of concerns about maintaining health insurance for their child (CAHMI, 2020).
- We analyzed 2016-2017 NSCH data for Oregon CYSHCN whose families had expenses related to their child's health. We found that, regardless of insurance type, families of CYSHCN in Oregon were two times more likely to have problems paying their child's medical bills than parents of non-CYSHCN.

### Maternal Health

Mothers of CYSHCN tend to report good health, although about one in five report fair/poor physical health and one in ten report fair or more mental health. More than half (56%) of the families of CYSHCN with a mother in the household reported that the mother was in excellent or very good health (CAHMI, 2020). Slightly more than one-quarter (27%) reported that the mother was in good health (CAHMI, 2020). Less than one-fifth (17%) reported the mother's health was fair or poor (CAHMI, 2020). Two-thirds of families (66%) reported that the mother's mental health was excellent or very good (CAHMI, 2020). Nearly one-quarter (23%) reported that the mother's mental health was good (CAHMI, 2020). About one in 10 (11%) reported that the mother's mental health was fair or poor (CAHMI, 2020).

### Paternal Health

Fathers of CYSHCN also tend to report good health, although about one in ten report fair/poor physical health and about one in twenty report fair/poor mental health (CAHMI, 2020). More than half (67%) of the families of CYSHCN with a father in the household reported that the father was in excellent or very good health (CAHMI, 2020). About one-quarter (24%) reported that the father was in good health (CAHMI, 2020). A little less than one in 10 (7%) reported the father's health was fair or poor (CAHMI, 2020). More than half of families (79%) reported that the father's mental health was excellent or very good (CAHMI, 2020). Fifteen percent reported that the father's mental health was good. Six percent reported that the father's mental health was fair or poor (CAHMI, 2020).

### Neighborhood

Healthy People 2020 identifies the neighborhood and built environment as a social determinant of health. Neighborhood factors such as access to healthy food, quality of housing, crime and violence and environmental conditions can affect health outcomes (Healthy People, 2020). Nearly half (45%) of the families of CYSHCN reported living in a supportive neighborhood (CAHMI, 2020). Six in 10 (60%) families reported living in a safe neighborhood, and more than two-thirds (68%) reported living in a neighborhood with none of the following detracting elements: litter/garbage, rundown housing, and vandalism. Less than one-quarter (24%), however, reported living in a neighborhood with all of the following amenities: libraries, parks, recreation centers, and sidewalks (CAHMI, 2020). Nearly the same percentage (22%) live in neighborhoods with one or none of those amenities (CAHMI, 2020).

### Health Care Needs

This section summarizes the health care needs of CYSHCN in Oregon. As described below, Oregon CYSHCN experienced unmet health care needs primarily for mental and behavioral health care, preventive dental care, and hearing care. Children with developmental disabilities experienced unmet needs related to their disability, such as a lack of support workers for non-verbal children, and a lack of understanding from providers about needs related to disability. Family support continued to be an area of unmet need for families of CYHSCN in Oregon.

### Mental/Behavioral Health Care

Access to mental and behavioral health care is an expectation of systems of care serving CYSHCN and their families (Association of Maternal and Child Health Programs [AMCHP] & National Academy of State Health Policy [NASHP], 2017). Both our 2010 and 2015 needs assessment findings identified access to mental/behavioral health care as a need for Oregon CYSHCN. For example, 2015 needs assessment findings showed that 24% of OCCYSHN family survey respondents had reported that mental or behavioral health services (e.g., Applied Behavior Analysis; autism counseling or services; behavior support; specialized counseling for children who are deaf and developmentally disabled, therapists, psychiatrists, and medical doctors that are reliable and understand Autism Spectrum Disorder) were one of three things that their child or family most needed but had a hard time obtaining (Martin, Gallarde, & Hartzell, 2015). Findings based on more recent data sources show an increasing trend in the mental and behavioral health needs of Oregon CYSHCN.

In Oregon, 45% of all CYSHCN had ongoing emotional, developmental and behavioral conditions, which is similar of the proportion of CYSCHN nationwide (44%) who had these conditions (CAHMI, 2020). Forty percent of Oregon CYSHCN, ages 3 through 17 years, received treatment or counseling from a mental health professional compared to one-third of CYSHCN nationwide (CAHMI, 2020). However, 6% of Oregon CYSHCN did not receive needed mental health care services (CAHMI, 2020).<sup>9</sup>

About one-third of Oregon 8th graders (32%) and more than one-third of 11th graders (39%) reported that their emotional and mental health is “fair” or “poor” in 2019 (OHA, 2019b). The percentage of Oregon 11th graders who reported feeling “sad or hopeless almost every day for 2+ weeks in a row” increased by 24% between 2015 and 2019 (29% vs. 36% respectively) (OHA, 2019b). An 18% increase was observed for 8th graders during the same time (27% vs. 32%) (OHA, 2019b). Survey results also showed an alarming increase in the percent of both age groups who seriously considered and actually attempted suicide during this period (see Exhibit 3.2). Oregon Healthy Teens Survey results showed that more than three-quarters of 8th (80%) and 11th graders (77%) reporting having unmet needs for emotional or mental health care in 2019.

Exhibit 3.2. Percentage of Oregon 8<sup>th</sup> and 11<sup>th</sup> Graders Who Considered and Attempted Suicide

|   | 2015 |      | 2017            |                  | 2019            |                  |
|---|------|------|-----------------|------------------|-----------------|------------------|
|   | 8th  | 11th | 8 <sup>th</sup> | 11 <sup>th</sup> | 8 <sup>th</sup> | 11 <sup>th</sup> |
| Seriously considered attempting suicide | 16.2 | 16.3 | 16.9            | 18.2             | 19.9            | 18.6             |
| Actually attempted suicide              | 8.2  | 6.2  | 8.7             | 6.8              | 10.0            | 7.4              |

Source: Oregon Healthy Teens Survey

The percentage of Oregon 11th grade students who report having serious difficulty concentrating, remembering, or making decisions because of an emotional, mental, or physical condition has increased by 35% between 2015 and 2019. Results of the Oregon Healthy Teen Survey showed that 20% of 11th graders reported these cognitive issues in 2015; 25% in 2017; and 27% in 2019 (OHA, 2019b). In addition, the percentage of Oregon 11<sup>th</sup> graders who reported difficulty doing errands alone (e.g., visiting a physician’s office or shopping) due to an emotional, mental, or physical condition also increased by one to two percentage points between 2015, 2017, and 2019: 7%, 9%, and 10%, respectively (OHA, 2019b).

<sup>9</sup> The Data Resource Center advises that consumers use caution when interpreting this estimate due to low sample size (<https://www.childhealthdata.org/browse/survey/results?q=5247&r=39&g=619>)

Children, youth, and young adults with developmental disabilities (DD) are a population within CYSHCN. National Core Indicator results showed that of Oregon young adults with DD, ages 18 through 22 years, 14% needed some support, and 3% needed extensive support, to manage *destructive* behavior. Further, 30% of these youth needed some support, and 8% needed extensive support, to manage *disruptive* behavior. Additionally, 14% of these young adults needed some support, and 5% needed extensive support, to manage *self-injurious* behavior.

National Core Indicator Child and Family Survey (NCI-CFS) results showed that 16% of families of children and young adults in Oregon with DD, who had access to mental health services, reported that the mental health professional sometimes/never understands the child's needs related to disability.

### Preventive Health Care

Children and youth with special health care needs, like children and youth without special health care needs, require preventive health care. Receipt of preventive health care and developmental screening are expectations of systems of care serving CYSHCN and their families (AMCHP & NASHP, 2017). Therefore, we report findings focused on three aspects of preventive care: primary care preventive health visit, dental care preventive health visit, developmental screenings, eye and hearing care.

Oregon CYSHCN under age 18 typically receive

- A preventive physical health care visit. Nine in ten CYSHCN visited a doctor, nurse, or other health care professional to receive a preventive check-up in the past twelve months (CAHMI, 2020). This percentage is similar to CYSHCN nationwide (89%)(CAHMI, 2020). National Core Indicator results show that 16% of young adults with DD ages 18 through 22 years did not have an annual physical exam in the past year.
- A preventive dental health care, although opportunity for improvement exists. Eight in ten CYSHCN visited with a dentist for any kind of preventive dental care within the last 12 months (CAHMI, 2020). This percentage also is similar to CYSHCN nationwide (85%)(CAHMI, 2020). Findings from our 2015 needs assessment suggested that preventive dental care is accessible to Oregon CYSHCN (Martin, Gallarde, & Hartzell, 2015). 2015 findings also indicated that CYSHCN with public insurance experienced greater difficulty accessing preventive dental care than privately insured CYSHCN due to a lack of dentists who accept Oregon Health Plan (Martin et al., 2015). Seventy-two percent of young adults with DD reported having a dental exam within the past 6 months, 19% reported in the past year, and 8% reported their last dental exam occurred more than one year ago.

Ninety-two percent of Oregon young adults ages 18 through 22 years with developmental disabilities had a primary care doctor; 8% did not (NCI, 2020).

More than half (60%) of Oregon children, ages 9 through 35 months, received a developmental screening using a parent-completed screening tool in the past year (CAHMI, 2020).<sup>10</sup> This was higher than the national average of 31% of children who received developmental screenings (CAHMI, 2020). However, 40% of children in Oregon, ages 9 through 35 months, did not receive developmental screening using a parent-completed screening tool in the past year (CAHMI, 2020).<sup>10</sup>

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<sup>10</sup> The Data Resource Center advises that consumers use caution when interpreting this estimate due to low sample size (<https://www.childhealthdata.org/browse/survey/results?q=5409&r=1&r2=39>)

Not all Oregon CYSHCN receive vision testing. Over three-fourths (78%) of Oregon CYSHCN under 18 received vision screening, however 22% did not (CAHMI, 2020). NCI survey findings showed that 9% of Oregon 18 through 22 year olds with DD had never had a vision screening, 20% received the last vision screening 5 or more years ago, and 69% had their most recent vision screening within the past 3 years (NCI, 2020). Results of the Oregon Healthy Teen Survey showed that 5% of 11th graders reported being blind or having serious difficulty seeing even when wearing glasses in 2015, in 2017, and in 2019 (OHA, 2019b).

A need exists for greater hearing testing. Results from the NCI survey showed that most (45%) of Oregon 18 through 22 year olds with DD had their hearing last tested five years earlier; 33% had a hearing test within the past five years; and 21% had never had a hearing test (NCI, 2020). The percentage of Oregon 11th grade students who report being deaf or having serious difficulty hearing has increased by 25% between 2015 and 2019. Results of the Oregon Healthy Teen Survey showed that 27% of 11th graders reported hearing issues in 2015; 32% in 2017; and 34% in 2019.

### Care Coordination

A meaningful proportion of Oregon CYSHCN and their families do not received needed care coordination. NSCH 2016-2017 results show that approximately one-third (32%) of the families of CYSHCN who needed care coordination did not receive effective care coordination, in contrast to about two-thirds (68%) who did receive it (CAHMI, 2020). NCI-CFS results showed that about one third (31%) of families of Oregon children with developmental disabilities said that service providers for their child did not work together to provide support, and about the same percentage (30%) said that they did not choose their case manager/service coordinator and could not change the case manager/service coordinator if they wanted (NCI, 2018).

### Prescription Medication

In Oregon, 11% of CYSHCN used prescription medications, which is similar to the percentage of CYSHCN nationally (13%) who used of prescriptions (CAHMI, 2020). One-third (33%) of Oregon CYSHCN, ages 3 through 17 years, take prescription medication for ADD/ADHD, autism/ASD, or difficulties with emotions, concentration, or behavior (CAHMI, 2020). These results are similar to the percentage of CYSHCN nationwide (34%) using prescription medications for these conditions (CAHMI, 2020).

### Additional Health Care Needs

2015 needs assessment results showed that allied therapies, non-preventive dental care, home health care, specialty care, substance abuse treatment or counseling, palliative care, and Autism specific therapies were difficult to access for those who needed them (Martin et al., 2015). We lack more recent, Oregon-specific secondary data to describe these needs. Therefore, we highlight findings from our 2015 needs assessment or report national findings.

### Occupational, Physical, or Speech Therapy

Over half (51%) of families responding to OCCYSHN's 2015 needs assessment survey reported that accessing occupational therapy services and supports were either somewhat or very difficult for their CYSHCN (Martin et al., 2015). Nearly half (48%), of parents reported that physical therapy was either somewhat or very difficult to access for their CYSHCN. Similarly, nearly half (46%) reported that speech therapy was either somewhat or very difficult to access for their CYSHCN (Martin et al., 2015).

### *Non-Preventive Dental Care*

Findings from our 2015 needs assessment suggested that preventive dental care was more easily accessible compared to specialty dental care, over half (51%) of families responded that orthodontia or other specialty dental care was somewhat or very difficult to access as compared to 30% who reported difficulty accessing preventive dental care (Martin, 2014).

However, we do not have current data that describe access to specialty dental care. Nationwide, over half (51%) of parents reported that it was somewhat or very difficult to access orthodontia or other non-preventative dental care services for their CYSHCN (CAHMI, 2020).

### *Home Health Care*

Access to home health care will be a growing challenge for the systems of care that serve CYSHCN in Oregon. Seventeen percent of OCCYSHN 2015 family survey respondents reported that their child needed home health care (Martin, 2014). CYSHCN are living longer as a result of technological advances, so their numbers and the demand for a home health care workforce are increasing (Foster, Agrawal, & Davis, 2019). In addition, as adults live longer, they also will require more home-based care (Foster et al., 2019). Combined, these two trends will have a substantial economic impact on family caregivers and the demand for paid caregiving (Foster et al., 2019). In 2015, an estimated 43.5 million US adults provided unpaid, health-related care to an adult or child in the prior twelve months, providing an average of 24.4 hours of care per week (Foster et al., 2019). The number of hours of home health care needed for care of CYSHCN range from 20 to 30 hours per week to 24 hours per day for seven days per week (Foster et al., 2019). Medicaid spending for CYSHCN disproportionately goes to hospital care (47%) instead of home health care (2%) (Foster et al., 2019). Even when hours are approved for Medicaid payment, families reported having difficulty finding home nurses, which leads to either prolonged hospitalizations or exhausted family caregivers (Foster et al., 2019).

### *Specialty Care*

Over one-third (36%) of CYSHCN nationwide have seen a specialist other than a mental health professional within the last 12 months compared to 9% of non-CYSHCN (CAHMI, 2020). Also, 5% of CYSHCN nationwide did not receive needed specialist care as compared to 1% of non-CYSHCN (CAHMI, 2020). Results from OCCYSHN's 2015 needs assessment family survey showed that 39% of responding families reported needing, but having a hard time obtaining specialty medical care for physical health (e.g., audiology care; chiropractic care; genetic testing; occupation, physical, and speech therapy; prescriptions) (Martin et al., 2015). 2015 needs assessment results also showed that palliative care and Autism specific therapies were difficult to access for those who needed them (Martin et al., 2015).

### *Substance Abuse Treatment or Counseling*

Findings from our 2015 needs assessment suggested that the majority of families (60%) reported difficulty accessing substance abuse treatment and counseling for their CYSHCN (Martin, 2014). We lack more recent data about this. However, NSCH results showed that, less than 1% of children nationwide from ages 6 through 17 years currently have a substance abuse disorder (CAHMI, 2020). Less than 0.5% have been diagnosed with a substance abuse disorder in the past, but don't currently have the condition (CAHMI, 2020).<sup>11</sup>

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<sup>11</sup> The Data Resource Center advises that consumers use caution when interpreting this estimate due to low sample size (<https://www.childhealthdata.org/browse/survey/results?q=5306&r=1&g=664>)

## Health Care Equipment

Oregon CYSHCN experience challenges accessing necessary health care equipment. OCCYSHN's 2015 family survey collected data describing CYSHCN needs and ease of access for durable medical equipment (DME) and mobility devices. Results showed that 61% of families reported that it was somewhat or very difficult to access mobility aids for their CYHSCN (Martin, 2014).

Out of Oregon children with developmental disabilities, about one-third (31%) reported that they sometimes/seldom/never had the special equipment or accommodations that they needed (NCI, 2018). Twenty-two percent of children with DD used gestures or body language to communicate, 8% used communication aids or devices, and 2% used sign language or finger spelling. If their child did not communicate verbally, 27% of families reported difficulty accessing support workers who can communicate with their child (NCI, 2018).

## Education

Children and youth with special health care needs are children and youth first; therefore educational systems are a necessary entity within the systems of care for CYSHCN and their families. Missing school is deleterious to educational progress for CYSHCN in the same way that it is deleterious to the development of children and youth without special health care needs. About 15% of children and youth with special health care needs miss more than two weeks (11 or more days) of school (CAHMI, 2020). About 31% miss nearly one up to two weeks (4 to 10 days) of school (CAHMI, 2020). One-third (34%) miss one to three days of school, and about one in five (21%) miss no school (CAHMI, 2020). Results of OCCYSHN's 2015 needs assessment family survey showed that, on average, CYSHCN missed 12.95 days of school or work because of their health condition (Martin, 2014).

CYSHCN may be less engaged in school compared to children and youth without special health care needs.

- About half (49%) of families of CYSHCN reported that it is "definitely true" that their child cares about doing well in school, in contrast to 80% of families of non-CYSHCN (CAHMI, 2020).
- Thirty-nine percent of families of CYSHCN, versus 20% of families of non-CYSHCN, reported that it is "somewhat true" that their child cares about doing well in school (CAHMI, 2020).
- Twelve percent of families of CYSHCN, versus 2% of non-CYSHCN, reported that it was "not true" that their child cares about doing well in school (CAHMI, 2020).
- Nearly half (44%) of families of CYSHCN reported that it is "definitely true" that their child does all of their required homework, in contrast to 67% of families of non-CYSHCN (CAHMI, 2020).
- Nearly one-third (31%) of CYSHCN, versus 28% of non-CYSHCN, families reported that it is "somewhat true" that their child does all of their required homework (CAHMI, 2020).
- One quarter (25%) of CYSHCN, versus 5% of non-CYSHCN, families reported that it is "not true" that their child does all of their required homework (CAHMI, 2020).

A substantial proportion of Oregon children receive educational supports through Oregon Department of Education services. Of all Oregon children ages 1-17 years, 10% received services under a special education or early intervention plan (CAHMI, 2020). Out of Oregon CYSHCN ages 1-17 years, 30% received services under a special education or early intervention plan (CAHMI, 2020). Of Oregon students years enrolled in special education from ages 3 – 21,

- Latinos make up nearly one in four (24.8%) students in this category (ODE, 2018).
- Students identifying as two or more races account for 6.2%; Black 2.9%; Asian 2.1%; American Indian/Alaska Native 1.7%, and Native Hawaiian/Pacific Islander less than one percent (ODE, 2018).

Similarly, of those enrolled into an early intervention plan from ages 0 – 3 years,

- Latinos account for over one in five (21.7%) students in these programs (ODE, 2018).
- Students identifying as two or more races account for 4.8%; Black 2.1%; Asian 2.8%; American Indian/Alaska Native less than one percent; and Native Hawaiian/Pacific Islander also less than one percent (ODE, 2018).

### Family Supports

Twenty-four percent of OCCYSHN’s 2015 needs assessment family survey respondents identified quality respite care as 1 of 3 things that their family most needs but had difficulty obtaining (Martin et al., 2015). Twenty percent of families also reported that supports – such as activities with other families that have children with special health care needs, coaching on how to get around on buses, help shopping, housing and homelessness services, parent or sibling support groups, sleep, and time to relax – were 1 of 3 things that their family most needed but had difficulty obtaining (Martin et al., 2015).

Although the following findings are specific to Oregon children with developmental disabilities, these results show similar trends in family support needs. NCI-CFS results showed that

- 22% of families of children with developmental disabilities in Oregon needed respite care but did not have access to it. Out of those who had access to respite care, 12% were not satisfied with quality of respite providers (NCI, 2018).
- Families needed additional respite care (50%), home or vehicle modification (44%), counseling services (30%), and family to family networks (24%) (NCI, 2018).

### Family-centered care

“Patient-and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care professionals, patients, and families...[it] assures that health care is responsive to priorities, preferences, and values of patients and their families” (Institute for Patient- and Family-Centered Care, n.d.). Many health care settings identify family-centered care as the standard of pediatric health care (Kuo, Houtrow, Arango, etc., 2012). About eight in ten (81%) of Oregon families of CYSHCN younger than 18 years report that they receive family-centered care as measured by the NSCH 2016-2017; nearly nine in ten (87%) of Oregon families of non-CYSHCN report receiving family centered care (CAHMI, 2020). However, when this overall finding is disaggregated by its component parts, results show that about two-thirds of CYSHCN families, and three-fourths, of non-CYSHCN families report “always” receiving these components of family-centered care:

- 60% of CYSHCN, and 68% of non-CYSHCN, families report that their child’s provider spent enough time with the child (CAHMI, 2020).
- 67% of CYSHCN, and 73% of non-CYSHCN, families report that their child’s provider listened carefully (CAHMI, 2020).

- 71% of CYSHCN, and 78% of non-CYSHCN, families report that their child's provider showed sensitivity to their values and customs (CAHMI, 2020).
- 62% of CYSHCN, and 76% of non-CYSHCN, families report that their child's provider provided information specific to parent concerns (CAHMI, 2020).
- 68% of CYSHCN, and 75% of non-CYSHCN, families report that their child's provider helped parents to feel like partners in their child's care (CAHMI, 2020).

NCI-CFS reported on families' experiences in accessing information to obtain services and supports for their children with developmental disabilities (NCI, 2018). A little less than one fourth (22%) of families reported that they did not have enough information to participate in planning services for their child (NCI, 2018). About one-third (34%) of families reported that the information about services/supports was not easy to understand (NCI, 2018). Also, 39% of families reported that they did not have enough information about other public services for which family is eligible (NCI, 2018). More than half of family members responded that they needed help with future planning related to Recreation (65%), Transition from school (63%), Finances (63%), Housing (54%) and Employment (54%) (NCI, 2018). More than half of family members (52%) also responded that when they asked for crisis/emergency services in the past year, they did not receive services when they needed (NCI, 2018). More than one-third (43%) of families responded that they did not discuss how to handle emergencies at their child's last service planning meeting (NCI, 2018). About 30% of families reported that they did not feel prepared to handle the needs of their child in an emergency such as a medical emergency or a natural disaster (NCI, 2018).

#### COVID-19 related outcomes for CYSHCN

Recent data showed that children with intellectual and developmental disabilities (IDD) had higher mortality rates from COVID-19 (Turk, Landes, Formica, & Goss, 2020). For children with IDD under 18 years of age, the case fatality rate was 1.6% vs. <.01% among those without IDD. The risk appears to be greater at younger ages. However, despite the higher risk, there has been limited reporting of COVID-19 trends for this population.

#### National Priority Areas

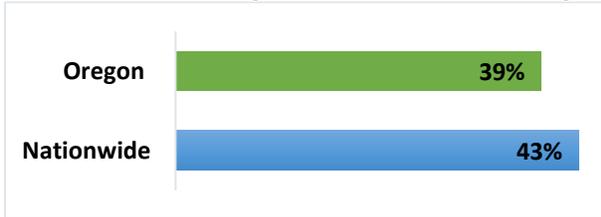
The Maternal and Child Health Bureau (MCHB) requires that each state select at least one national priority area per population served through the Title V Block Grant from its list of predetermined priority areas. MCHB has created measures for each of these priority areas using data available through national secondary data sources and ensures that state-level results are available for these measures. MCHB further requires that states develop and implement strategies, using Title V Block Grant resources, to address the selected priority areas. For the fiscal years 2021 through 2025 block grant cycle, MCHB identified receipt of care within a medical home, transition from pediatric to adult health care, and having consistent, adequate health insurance coverage. The following sections present findings from secondary data sources for each of these areas.

#### Medical Home

MCHB measures receipt of care within a medical home through NSCH survey items that collect data describing whether the child has a personal doctor or nurse and has a usual source for care, and whether the child and family receives family-centered care, gets needed referrals, and receives effective care coordination if needed (Child and Adolescent Health Measurement Initiative [CAHMI], 2020). The medical home concept was created for CYSHCN (American Academy of Pediatrics [AAP], 2020).

Most Oregon CYSHCN do not receive care within a medical home. Thirty-nine percent of CYSHCN received care that meets the NSCH definition of medical home (CAHMI, 2020). State-level results mirror those observed nationally (see Exhibit 3.3)(CAHMI, 2020). Additionally, Oregon CYSHCN with more complex health conditions are less likely to receive care within a medical home (35%) compared to those with less complex health conditions (52%)(CAHMI, 2020).<sup>12</sup>

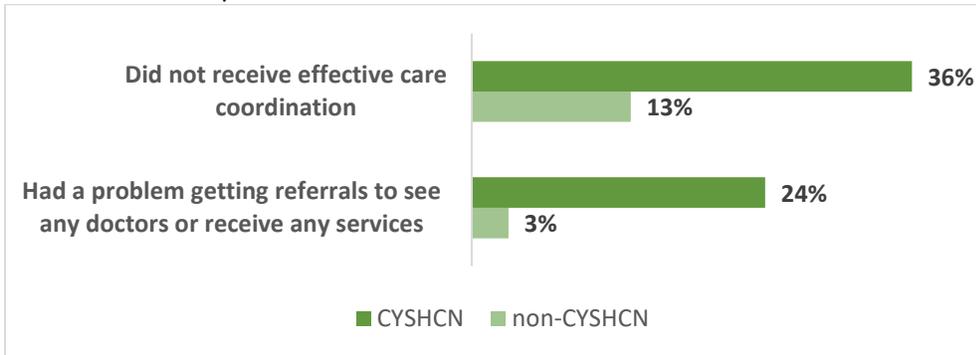
Exhibit 3.3. Percentage of CYSHCN, Birth Through 17 Years, Who Receive Care In A Medical Home



Source: National Survey of Children’s Health, 2016-2017

Examination of the individual components of medical home show that Oregon CYSHCN do not consistently receive needed referrals and effective care coordination when needed. Only one-third (36%) of CYSHCN receive effective care coordination when needed, and less than one-quarter (24%) receive needed referrals (CAHMI, 2020). Further, as shown in Exhibit 3.4, Oregon CYSHCN experience health care disparities with these types of health care compared to children and youth without special health care needs.

Exhibit 3.4. Percentage of Oregon CYSHCN Who Receive Needed Referrals and Effective Care Coordination Compared to Non-CYSHCN



Source: National Survey of Children’s Health, 2016-2017

*Children with Medical Complexity Served In Oregon Medical Homes*

Oregon’s state-level Patient Centered Primary Care Home (PCPCH) Program promotes clinical practice adoption of policies, procedures, and processes that support the receipt of care within the medical home. In 2016, researchers within the Oregon Health & Science University-Portland State University School of Public Health completed an evaluation of the PCPCH programs first three years of program implementation. Findings from the evaluation showed that the PCPCH program reduced total service expenditures by 4.2% and resulted in \$13 in savings in other services such as specialty care, emergency department and inpatient care for every \$1 increase in primary care expenditures related to the PCPCH program (Gelmon, Wallace, Sandberg, Petchel, & Bouranis, 2016). OCCYSHN contracted with Neal

<sup>12</sup> The Data Resource Center advises that consumers use caution when interpreting this estimate due to low sample size (<https://www.childhealthdata.org/browse/survey/results?q=5445&r=1&g=664>).

Wallace to replicate these analyses for a population of Oregon CYSHCN: children with medical complexity (CMC). We used the Complex Chronic Disease (CCD) category of the Pediatric Medical Complexity Algorithm (PMCA; Simon et al., 2014) to identify CMC in Oregon All Payers All Claims data.<sup>13</sup>

#### Prevalence of Children with Medical Complexity

Nearly seven percent (6.8% or 74,254) of children ages 21 and younger in the sample experience complex chronic conditions (Wallace, 2020). More than one-fifth (22%) of the sample age was birth through 5 years; nearly one-quarter (24%) was six through 11 years; nearly one-third (32%) was 12 through 17 years; and more than one-fifth (22%) was 18 through 21 years (Wallace, 2020). Fifty-one percent of the sample was male, and 49% was female (Wallace, 2020).

The broad professional community focused on CYSHCN and children with medical complexity often assume that children who experience medical complexity typically are insured through public insurance programs. Our results showed that two in five (43%) children with medical complexity are completely privately insured (Wallace, 2020). Often, professionals perceive the children with medical complexity live closer to urban areas to access care; however, our results showed that similar proportions of insured children who use health care services experience medical complexity in frontier (6.1%), rural (6.7%), and urban (6.9%) areas (Wallace, 2020).

#### Health Care Costs

Results showed about a 10.1% reduction in overall expenditures for CMC who received primary care within a PCPCH compared to CMC who received care in non-PCPCH (Wallace, 2020). The unadjusted (raw) expenditures were reduced by \$154.66 (Wallace, 2020). Although all service categories (primary care, specialty care, mental health, radiology, lab, pharmacy, emergency department and inpatient care) showed decreased expenditures associated with the PCPCH program, only the primary care, specialty care and pharmacy categories were individually statistically significant. Large percentage reductions (15.5%-22.1%) were found for lab, pharmacy, and inpatient care; the remaining services areas had reductions that ranged from 3% to 6% (Wallace, 2020).

The overall expenditures were progressively reduced from year 1 to years 2 and 3 by \$119.58 and \$177.92 or 7.8% and 11.7%, respectively (Wallace, 2020). Both effects were statistically significant. Effects by service category showed some similarities and distinct differences. Large reductions in expenditures for lab, pharmacy and inpatient were apparent in both years, ranging from approximately 12% to 25%, albeit only pharmacy (both periods) and lab in year 1 were statistically significant (Wallace, 2020). Primary care, specialty care, mental health and emergency department all had small to moderate increases in year 1 ranging from 0.7% to 7.0%, although only the increase in primary care was statistically significant (Wallace, 2020). In years 2 and 3, each of these services showed larger decreases,

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<sup>13</sup>The Oregon All Payers All Claims database contains “administrative data collected by insurers for purposes related to issuing coverage and making payments” (Oregon Health Authority, 2020). Data describe most Oregon residents (Oregon Health Authority, 2020). The study period for the PCPCH analysis encompassed four study years over the period October 1, 2010 through September 30, 2014. The October 2011 through September 2014 period reflects the first three years of the PCPCH program after the earliest PCPCH practice designation date of October 1, 2011. An additional year of “pre-“ data, from October 2010 to September 2011 was included to provide a minimum of one year’s data prior to the earliest designated PCPCHs. PCPCH practices identified in the study were limited to those with initial designation dates prior to September 2014 and with continued designation through September 2014. Data from one large health system were excluded from analyses due to data reliability concerns. These criteria yielded 510 PCPCH practices and 40,205 children and youth through the age of 21 years who had complex chronic disease.

ranging from 5.3% to 11.3%, with both the primary and specialty care decreases statistically significant (Wallace, 2020).

Results also showed larger, and statistically significant, overall expenditure reduction in rural versus urban areas: \$200.41 versus \$129.89, or 14.4% and 8.1%, respectively (Wallace, 2020). In examining reductions by specific service types, the largest reductions were generally in lab, pharmacy and inpatient care ranging from 12.3% to 28.8% (Wallace, 2020). Pharmacy reductions were statistically significant in rural and urban areas, however, lab reductions were statistically significant for the rural areas only. Rural areas had larger reductions in specialty care and radiology, 12.7% and 11.5% respectively, compared to urban areas, 4.1% and 2.5% respectively (Wallace, 2020). Specialty care reductions were statistically significant; the urban radiology reduction was not. Primary care expenditures increased by 2.9% rural areas, in contrast to the 6.5% reduction in urban areas. Both were statistically significant (Wallace, 2020).

### Health Care Utilization

Wallace's (2020) analyses showed reductions in health care costs, although the probability of any service use remained virtually unchanged. Service specific changes were mixed in direction, generally of small magnitude and largely not statistically significant. Radiology and lab use had the largest reductions, 3.5% and 2.4% respectively. Emergency department use had the largest increase (4.8%) and was the only statistically significant specific service result. All other service rates of changes were between 0.1% and 1.5%.

From baseline to year 1, overall probability of service use increased and was statistically significant (Wallace, 2020). Only two services, mental health and radiology, showed declines in use. Primary care, specialty care, pharmacy and emergency department use all showed statistically significant increases during this time (Wallace, 2020). For years 2 and 3, overall probability of service use showed a very slight decline but was not statistically significant (Wallace, 2020). Only three services showed increases in use – mental health, emergency department and inpatient care – none of which were statistically significant. Specialty care, radiology and lab showed statistically significant declines in use (Wallace, 2020).

Probability of service use for CMC served in PCPCHs and non-PCPCHs in rural and urban areas was largely unchanged for both groups, however there are distinct underlying differences in patterns by service type. For the urban areas, the changes in service use are generally small (less than 3.5%). Service use predominately decreased, with the exception of inpatient care, however, the changes are not statistically significant. In the rural areas there is a mix of increased and decreased use. Primary care, mental health and emergency department all show statistically significant increases in use; radiology shows a statistically significant decrease in use.

Findings from these analyses show that a greater percentage of CMC rely solely on private insurance, which suggests that strategies to improve the systems of care for Oregon CYSHCN and CMC ought to engage private insurers. Given that roughly equal proportions of Oregon children living in frontier, rural, and urban areas experience medical complexity, strategies to improve systems of care for Oregon CYSHCN and CMC need to account for differences in systems of care in these geographies. Lastly, findings suggest that cost decreases are associated with CMC receiving care within a medical home, and decreases in cost do not necessary accompany decreases in service use. These findings suggest that further research is needed to better understand whether the quality of care provided to CMC in medical home meets medical home standards (AMCHP & NASHP, 2017), and whether cost and service utilization vary as a result of quality.

## Transition to Adult Health Care

MCHB measures receipt of services necessary to transition to adult health care also through NSCH survey items. These items collect data describing whether the doctor spoke with the youth privately without an adult in the room during the last preventive check up, a discussion about transition to adult health care happened if it was needed, and the doctor actively worked with the youth to gain skills and understand changes in their health care. (CAHMI, 2020). If family survey respondent affirms that the youth received *at least one of the three*, then the youth is considered to have received services necessary to transition to adult health care (CAHMI, 2020). NSCH 2016-2017 results show that in Oregon, *fewer than one in five* (17%) youth with special health care needs ages 12 through 17 years (YSHCN) received services necessary to transition to adult health care.

- Half of Oregon YSHCN did not have time alone with a provider during their last preventive check-up.<sup>14</sup> Similarly, more than half (54%) of YSHCN nationwide did not have time alone with a provider (CAHMI, 2020).
- Over one-third (35%) of Oregon YSHCN did not learn skills to manage their own care from their health care providers or did not understand the changes in health care at age 18.<sup>15</sup> This is in comparison to 29% of CYSHCN nationwide, whose providers did not help them to manage their own care or understand the changes in health care at age 18. Only 14% of Oregon CYSHCN discussed with their health care providers about the shift to an adult health care provider compared to 17% of CYSHCN nationwide.<sup>16</sup>

Arguably, YSHCN most need support to prepare to transition to adult providers. Although Oregon youth generally do not receive transition services, a slightly smaller percentage of YSHCN receive transition services compared to non-YSHCN (see Exhibit 3.5). Of the YSHCN who did not receive services,

- 86% had more complex needs (CAHMI, 2020).
- 86% of CYSHCN had emotional, developmental, behavioral conditions (CAHMI, 2020). This result is consistent with reports from families, of young adults with medically complex conditions, who stated that pediatric behavioral/mental health providers did not provide their young adults, or the family, with notice about care discontinuing at age 18 years (Roy, Valdez, Trejo et al., 2020).

Neither receipt of care within a medical home nor consistency of insurance coverage appeared to improve these results. Out of Oregon CYSHCN who did not receive transition services:

- 86% received care in a medical home (CAHMI, 2020).
- 82% had consistent insurance coverage (CAHMI, 2020).

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<sup>14</sup> The Data Resource Center advises that consumers use caution when interpreting this estimate due to low sample size (<https://www.childhealthdata.org/browse/survey/results?q=5483&r=39&g=664&r2=1> )

<sup>15</sup>The Data Resource Center advises that consumers use caution when interpreting this estimate due to low sample size (<https://www.childhealthdata.org/browse/survey/results?q=5484&r=39&g=664&r2=1>)

<sup>16</sup> The Data Resource Center advises that consumers use caution when interpreting this estimate due to low sample size (<https://www.childhealthdata.org/browse/survey/results?q=5485&r=39&g=664&r2=1>).

### *Additional Transition to Adult Health Care Provider Support*

The following NSCH items are not part of the MCHB national transition to adult health care priority measure. The items, however, describe supports that facilitate transition.

- Less than half (41%) of Oregon YSHCN have actively worked with their provider to think about and plan their own future, similar to 40% of YSHCN nationwide (CAHMI, 2020).
- Over three-fourths (78%) of Oregon YSHCN have a provider that has worked with them to make positive choices regarding their health. Oregon state results mirror national results (CAHMI, 2020).
- Only 46% of Oregon CYSHCN have discussed with someone to obtain or keep some type of health insurance coverage as they become an adult compared to half of CYSHCN nationwide (CAHMI, 2020).<sup>17</sup>

Transition plans, or care plans that include transition goals, co-produced by YSHCN, family members, and youth are standard of care for CYSHCN transition (AMCHP & NASHP, 2017; Got Transition, 2020). Opportunity exists in Oregon to increase the percentage of YSHCN who have such plans.

- NSCH 2016-2017 results show that only one in ten Oregon YSHCN with more complex health needs has an up-to-date written plan to meet specific health goals and needs compared to 18% nationwide.<sup>18</sup> In comparison, 2% of Oregon CYSHCN with less complex health needs have a written plan compared to 8% of CYSHCN with less complex needs nationwide (CAHMI, 2020).<sup>17</sup>
- NCI-CFS survey results showed that the majority of families (66%) of youth with developmental disabilities responded that their child did not have a transition plan (NCI, 2018).
- In 2018-19, LPHA's held 21 shared care planning meetings for YSHCN age 12 up to 21 years. Of those, only 9 shared care plans included goals that addressed health care transition planning. Examples of those transition goals include building skills for YSHCN to manage their own health care, obtaining more information about preparing for transition to adulthood, and working with adult services to ensure a successful transition.

### *Transition, Young Adults with Medical Complexity, and Their Families*

Results from the environmental scan conducted for Oregon's CMC CoIIN project suggested that Oregon young adults with medical complexity (YAMC) and their families are not adequately prepared for, or supported in, the transition from pediatric to adult health care (Martin, Bakewell, Trejo, et al., 2019). Four key themes emerged from analysis of qualitative data collected from families of YAMC, aged 18 through 22 years: (a) Absence of transition guidance, (b) Limited adult provider options, (c) Consequences of poor transition, and (d) Difficulty working within adult health care (Roy, Valdez, Trejo et al., 2020). Families described having little to no notice about transitioning out of pediatric care; one parent likened their experience to being "*dropped off over the edge of a cliff*" (Roy, Valdez, Trejo et al., 2020). Health providers gave little, if any, direction to families about next steps. As a result, families initiated a range of actions, such as networking with other families to find specialists and applying pressure to the insurance provider to get needed medications (Roy, Valdez, Trejo et al., 2020). Exhibit 3.5 represents the journey that the family of a YAMC takes to attempt to identify a single adult provider

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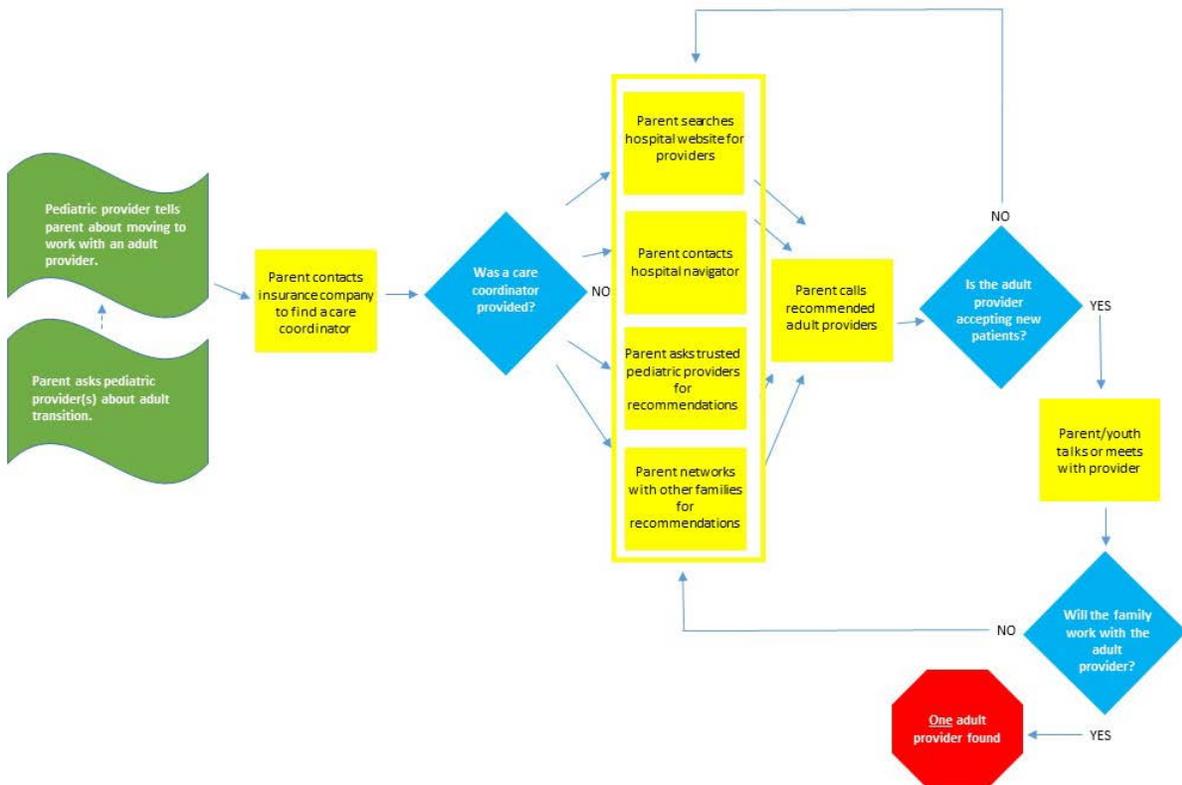
<sup>17</sup> The Data Resource Center advises that consumers use caution when interpreting this estimate due to low sample size (<https://www.childhealthdata.org/browse/survey/results?q=5491&r=39&r2=1&g=664>).

<sup>18</sup> The Data Resource Center advises that consumers use caution when interpreting this estimate due to low sample size (<https://www.childhealthdata.org/browse/survey/results?q=5490&r=39&r2=1&g=665>).

for their young adult. YAMC often work with multiple health care providers, therefore, families must replicate this journey for as many adult providers as their young adult needs. Some difficulties experienced by families in finding an adult provider were limited options provided by insurance and not being accepted by the potential adult provider because of the complex of the YAMC’s conditions (Roy, Valdez, Trejo et al., 2020).

Due to poor handling of transition, there were adverse effects such as gaps in needed care, decline in health status and costly alternatives such as hospitalizations (Roy, Valdez, Trejo et al., 2020). . Families described challenges working with adult providers due to providers’ limited familiarity with caring for young adults with complex medical conditions (Roy, Valdez, Trejo et al., 2020). They also described not feeling heard by adult providers regarding their concerns about the young adult’s health status and lack of support from the provider on other issues such as guardianship, release of information and obtaining medical equipment (Roy, Valdez, Trejo et al., 2020).

Exhibit 3.5. Workflow of A Family’s Experience Transitioning Their Young Adult with Medical Complexity To One Adult Provider, October/November, 2018



Source: Oregon Center for Children and Youth with Special Health Needs Children with Medical Complexity CoIIN

Although our environmental scan and root cause analysis primarily identified system of care barriers to transition to adult health care, some patient and family barriers also were revealed (Martin, Bakewell, Trejo, et al., 2019). We discuss the system of care barriers in Chapter 5 of the 2020 Needs Assessment, and list the patient and family barriers below.

- “YAMC can lack ability to successfully advocate for themselves, which results in lapses in care or insurance coverage.

- YAMC may lack capacity to fully or partially fulfill responsibility for their health care.
- Parents often lack understanding that health care transition is a consideration for their child’s health care and/or of the incremental steps to take to begin to prepare themselves and their children for transition.
- Parents of young adults with medical complexity often lack time to proactively think this far ahead when addressing the day to day needs of their child.
- Concurrent transitions (to adult health care, work, independent living) compound the barrier to adult health care. This relates to Quality of Life.
- Parents are reluctant to give up their caregiver role” (Martin, Bakewell, Trejo, et al., 2019).

### Adequate and Continuous Insurance Coverage

Finally, MCHB also measures adequate and continuous insurance coverage through NSCH survey items. These items collect data describing whether the child was continuously insured in the past 12 months, and whether the child has current insurance that is adequate for the child’s health care needs (CAHMI, 2020). If family survey respondent affirms that the child was continuously insured or that they had adequate insurance for their health care needs, then the child is considered to adequate and continuous insurance. (CAHMI, 2020). NSCH 2016-2017 results showed that the majority of CYSHCN in Oregon (97.8%) were insured at the time of the survey (CAHMI, 2020; see Exhibit 3.6). The majority of CYSHCN were *consistently* insured in the past year, however, 7% of CYSHCN were currently uninsured or did not have coverage for periods of time in the past year.<sup>19</sup> Although nearly all CYSHCN had consistent insurance for the past year, nearly one-third (30%) lacked *adequate* insurance to meet their needs. In comparison, 22% of non-CYSHCN had inadequate insurance coverage (see Exhibit 3.7)(CAHMI, 2020).

Exhibit 3.6. Percent of Oregon CYSHCN Insured At Time of Data Collection



Exhibit 3.7. Percent of Oregon CYSHCN Whose Insurance is Consistent and Adequate



Source: National Survey of Children’s Health

Of all Oregon CYSHCN, more than one-third (36%) had public insurance, half (51%) had private insurance, about one in ten (11%) had both public and private insurance,<sup>20</sup> and 2% were uninsured.<sup>21</sup>

<sup>19</sup> The Data Resource Center advises that consumers use caution when interpreting this estimate: it has a 95% confidence interval width exceeding 20 percentage points or 1.2 times the estimate and may not be reliable. <https://www.childhealthdata.org/browse/survey/results?q=5392&r=39&g=664>

<sup>20</sup> The Data Resource Center advises that consumers use caution when interpreting this estimate: it has a 95% confidence interval width exceeding 20 percentage points or 1.2 times the estimate and may not be reliable.

<sup>21</sup> The Data Resource Center advises that consumers use caution when interpreting this estimate: it has a 95% confidence interval width exceeding 20 percentage points or 1.2 times the estimate and may not be reliable.

Additional insurance-focused statistics for Oregon CYSHCN from the Child and Adolescent Health Measurement Initiative (CAHMI, 2020) follow.

- For Oregon CYSHCN who had *private* health insurance, 29% reported that their current insurance was inadequate.
- In comparison, only 14% of CYSHCN who had *public* insurance reported inadequate insurance.
- For 27% of Oregon CYSHCN, the out-of-pocket costs for health care were sometimes or never reasonable, compared to 20% of non-CYSHCN.
  - About a quarter (24%) of Oregon CYSHCN had more than \$1000 in out-of-pocket costs for health care in the past 12 months, out of which 4% had more than \$5000 in out-of-pocket costs.
  - Fifteen percent of Oregon CYSHCN had problems paying their medical bills compared to 8% of non-CYSHCN.
  - The majority of families, who stated that their child did not receive needed care, reported that the reason was issues related to cost.<sup>22</sup>
- For 17% of Oregon CYSHCN of ages 3-17 years, their health insurance sometimes or never offered benefits or services for behavioral and mental health needs.

#### Title V Partner Survey Results Specific to Medical Home

Nearly 170 partners responded to the CYSHCN survey section, and most (43%) selected transition to adult health care as the priority on which to focus for Oregon CYSHCN (Oregon Health Authority [OHA], 2019a). On average, respondents rated transition to adult health care as having a “large” impact on the overall health of CYSHCN in their community and having a “large” impact on health equity among CYSHCN (OHA, 2019a). Respondents also rated that Title V resource allocation at both state and local level would have, on average, a “large” impact on transition to adult health care (OHA, 2019a).

Nearly one-third (31%) of partners selected medical home as the priority focus for Oregon CYSHCN, and almost one-third (27%) selected adequate and continuous insurance (OHA, 2019a). All respondents also rated the transition and insurance priority areas as having a “large” impact on the overall health of CYSHCN in their community, having a “large” impact on health equity among CYSHCN, and that Title V resource allocation would have a “large” impact on medical home and insurance coverage (OHA, 2019a).

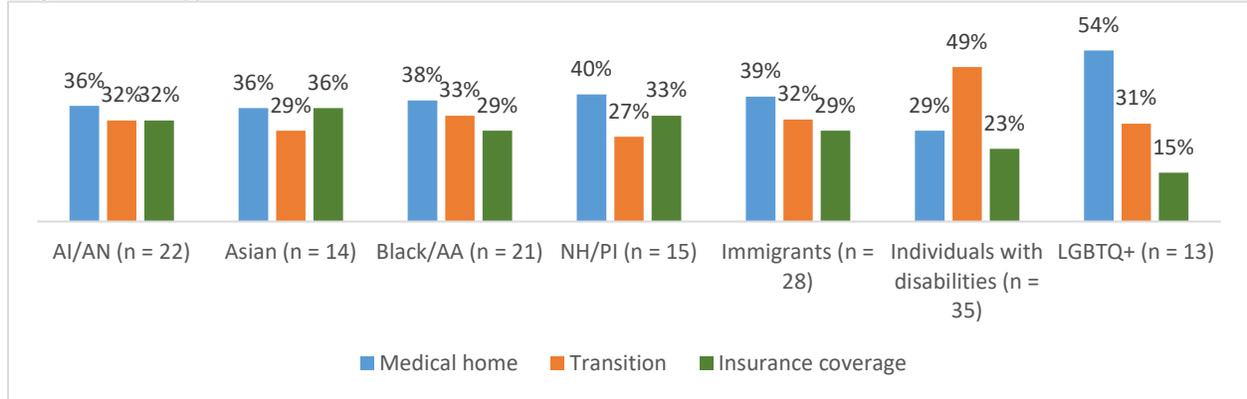
When survey results were disaggregated by partners representing organizations that primarily served American Indian/Alaska Native, African American/Black, Native Hawaiian/Pacific Islander, and immigrant communities, results showed that these partners favored the medical home as the priority for Oregon CYSHCN (see Exhibit 3.8)(OHA, 2019a). Equal percentages of partners representing organizations that served the Asian community responded that the medical home and insurance coverage were the most important priority for CYSHCN (OHA, 2019a). Organizations that served individuals with disabilities most often selected transition to adult health care as the CYSHCN priority (OHA, 2019a).

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<https://www.childhealthdata.org/browse/survey/results?q=5400&r=39&g=664>

<sup>22</sup>Other reasons were (listed from highest frequency to lowest frequency): did not get appointment when needed, not eligible for service, service unavailable in area, transportation issues and doctor’s office not open when child needed care (CAHMI, 2020).

Exhibit 3.8. Percentage of Respondents Selecting Each National Priority Area by Respondent Organization Type



Source: Oregon Health Authority Maternal and Child Health Section Title V Partner Survey.

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