Oregon's Children and Youth with Special Health Care Needs

Five-Year Needs Assessment Findings

Full Report – October 2, 2020

Oregon Center for Children and Youth with Special Health Needs

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Oregon Center for Children and Youth with Special Health Care Needs
Title V Needs Assessment
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How Are Oregon Children and Youth with Special Health Care Needs Faring?

Oregon Title V Needs Assessment Chapter 1: Summary of Findings.

The Oregon Center for Children and Youth with Special Health Care Needs, Sickle Cell Anemia Foundation of Oregon, and Latino Community Association[1]

Introduction

The Title V Maternal and Child Health Services Block Grant ("Title V") awards funds to every U.S. state and territory to serve women, children and adolescents, including children and youth with special health care needs (CYSHCN). The planning, implementation, and evaluation of strategies to serve these populations occurs in five year cycles. The cycle begins with a legislatively required statewide needs assessment. The Oregon Health Authority (OHA) Maternal and Child Health Section contracts with the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) to serve Oregon CYSHCN, and we conduct needs assessments for that population. CYSHCN are defined as children and youth "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138). The 2016-2017 National Survey of Children's Health (NSCH) estimates that approximately one in five (18.7%, 160,752) of Oregon's children younger than 18 years has a special health care need (CAHMI, 2020).

The National Survey of Children's Health is developed and administered by the U.S. Maternal and Child Health Bureau, in partnership with the U.S. Census Bureau. The NSCH collects data annually, using a sampling approach that allows results to be generalized to the national and state populations of children and youth. The survey provides states with essential surveillance data. Because CYSHCN are a subgroup of the larger child population, the sample size is often too small to produce reliable state-level estimates; this is particularly true for CYSHCN of Color. For example, we do not have an estimate of the number or percentage of Oregon CYSHCN who are African American/Black. Other data sources are needed to understand the needs and experiences of CYSHCN who are not White and their families.

We surveyed families of CYSHCN and youth with special health care needs for our 2015 needs assessment. Although we received a tremendous response, the results did not adequately represent CYSHCN and families of Color (Martin, Gallarde, & Hartzell, 2015). 2016-2017 NSCH results estimate that 303,111 Oregon children younger than 18 years are non-White: 22% Latinx; 9% Other race, non-Latinx; 3% Asian, non-Latinx; and 2%[2] Black, non-Latinx (CAHMI, 2020). If non-White children are just as likely to experience special health care needs as White children, then approximately 56,681 of these children experience special health care needs.

We worked with organizations that serve People of Color to test a participatory needs assessment approach (PNA) to our 2020 needs assessment. PNA involves the community in the needs assessment process. OCCYSHN had sufficient resources to conduct two PNA projects. We decided to seek one organization serving African

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[1] Suggested citation: Aiello, M., Bisso-Fetzer, C., Gallarde-Kim, S., Gonzales, O., Hairston, R.E., Martin, A.J., Porterfield, B., Roy, S., Smith, C., Taylor, M., and Vega-Juárez, R. (2020). *How are Oregon children and youth with special health care needs faring? Summary of findings. Oregon Title V needs assessment chapter 1: Children and youth with special health care needs.* Portland, OR: Oregon Center for Children and Youth with Special Health Needs.

[2] This estimate should be interpreted with caution; due to small sample size it may be unreliable (CAHMI, 2020).

American/Black families, and one organization serving Latinx families to test the PNA approach.[3] Through a competitive Request for Information/Proposal process, OCCYSHN awarded contracts to the Sickle Cell Anemia Foundation of Oregon (SCAFO) and the Latino Community Association (LCA) of Central Oregon. Our needs assessment findings are based on analysis of qualitative data collected through focus groups conducted by SCAFO and LCA with their respective communities, in addition to results of existing surveys (e.g., National Core Indicators, NSCH) and other OCCYSHN data collections.

Our PNA projects sought to collect data that described (a) the health and other care needs of Black and Latino CYSHCN, (b) the experiences families of Black and Latino CYSHCN had trying to get care for their child, (c) families' experiences trying to get culturally responsive care for their child, and (d) families' experiences with transition from pediatric to adult health care (for families whose child was 18 through 25 years of age).[4] We integrated findings from existing data collections (see Roy, Vega-Juárez, Gallarde-Kim & Martin, 2020) and stakeholder feedback on our Block Grant priorities (see Vega-Juárez & Martin, 2020) with those from our PNA projects. We organized our findings into five sections: Access to Care, Adequate and Continuous Insurance, Medical Home, Transition to Adult Health Care, and Protective and Risk Factors. Our summary begins with Access to Care.

Access to Care

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). A system of care serving CYSHCN and their families ought to ensure that CYSHCN have both geographic and timely access to in- and out-of-network primary and specialty care (AMCHP & NASHP, 2017). Further, it ought to have the following characteristics: "Reasonable access requirements and wait times… for routine, episodic, urgent, and emergent physical, oral, and mental health and habilitative services[5]"; same-day appointments for urgent care services; transportation assistance for families who need it; insurance that covers medically necessary services, and simplified authorization processes (AMCHP & NASHP, 2017, p. 8).

Our needs assessment showed that Oregon CYSHCN experience challenges accessing

- **Behavioral/mental health care**. *This has been a persistent challenge identified in Oregon Title V Block Grant five-year needs assessments for the last 15 years.* Although we lack data specifically describing pediatric providers, this challenge is likely due in part to behavioral/mental health provider shortages and geographic maldistribution (Hemeida et al., 2019). Mental health counselor is a prioritized occupation[6] for

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[3] PNA has been used in California to conduct a county-level maternal and child health needs assessments (Wang & Pies, 2004). Given available resources and that PNA is a new approach for OCCYSHN, we chose to first focus on African American/Black and Latinx communities with the understanding that if the project was beneficial to the community organizations and OCCYSHN, OCCYSHN will conduct PNA projects with other Communities of Color as part of its ongoing needs assessment activities.

[4] SCAFO determined that "Black" was the appropriate racial term to use for families we recruited for our project as we sought to be inclusive of all Black cultures. LCA determined that "Latino" was the appropriate ethnic term to use for the families we recruited for our project as that is how their community describes itself. We use these terms in the remainder of the chapter.

[5] "The National Association of Insurance Commissioners (NAIC) defines habilitation services as "health care services that help a person keep, learn, or improve skills and functioning for daily living" (AMCHP & NASHP, 2017, p. 8).

[6] The Oregon Employment Department (OED) Workforce and Economic Research Division (2018) developed a methodology to prioritize training resources to prepare the workforce to meet the needs of positions that will be created

2018-2028 in all areas of the state except in the Northeast and Mid-Valley regions (Oregon Health Authority, 2019). Ten Oregon counties have no psychologists (Oregon Health Authority, 2019). Gaps are particularly prominent for behavioral/mental health providers who identify as non-White (Gallarde-Kim, Smith, Roy, et al., 2020; Oregon Health Authority, 2018b).

- **Care specific to children with developmental disabilities**. Providers lack an understanding of how to work with children who experience developmental disability, including those who are non-verbal.
- **Care coordination.** Families of CYSHCN continue to report that they need more effective care coordination.

Families of Oregon CYSHCN who are Black or Latino experienced long wait times to get appointments when they were seeking diagnoses for their children. They also experienced long waits for allied therapy appointments (e.g., occupation, physical, and speech therapy).[7] Some families of Black CYSHCN reported that scheduling appointments so far out is problematic for them, because important family matters that conflict with making the appointment may come up in the interim. Some families of Black CYSHCN reported using the emergency department because they could access care for their child more quickly than through other care channels.

Families of CYSHCN who are Black and Latino described shortages of all kinds of health providers. Families of Latino CYSHCN in Central Oregon also identified a lack of quality care locally. They described needing to travel to get quality care, most often to Portland.

Data Limitations

We lack data describing how hard it is to access pediatric specialty/subspecialty care. NSCH 2016-2017 data that describe difficulties accessing specialty care cannot be disaggregated by CYSHCN. Results from Oregon's 2019 Consumer Assessment of Healthcare Providers and Systems (CAHPS) show that Children with Chronic Conditions (CCC)[8] insured through Medicaid experience challenges accessing specialty care – defined as specialized medical equipment or devices, therapy, and treatment or counseling for their child in the last six months (Center for the Study of Services, n.d.). Some local public health nurses who work with CYSHCN and their families have previously reported that their clients had trouble accessing pediatric specialty/subspecialty care (Martin et al., 2015). Families of Black and Latino CYSHCN described challenging experiences accessing such care (Gallarde-Kim, Bisso-Fetzer, Roy, et al., 2020; Gallarde-Kim, Smith, Roy, et al., 2020). However, we cannot generalize these findings to the entire CYSHCN, CYSHCN who are Black, or CYSHCN who are Latino populations.

Additionally, we do not have data to adequately describe the following:

- The need for preventative oral health care for CYSHCN of Color. Oral health, along with behavioral/mental and physical health, is foundational to child well-being; poor oral health contributes to negative educational and health outcomes.
- The need for home health care for CYSHCN. Access to home health care will be a growing challenge for systems of care serving Oregon CYSHCN as technological advances extend the lifespan of medically

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by economic growth, retirement, and other factors. Masters-level mental health counselor was ranked 9th in statewide prioritization for training among top high-wage, high-demand health care health care occupations (OED, 2018).

[7] Oregon Health Authority (2019) found that five counties have no occupational therapists, and 12 have no occupational therapist assistants; and 2 counties have no physical therapists, and 4 have no physical therapist assistants.

[8] Children with Chronic Conditions are a subset of CYSHCN.

complex CYSHCN (Foster, Agrawal, & Davis, 2019). Medicaid funds are disproportionately used for hospital care compared to home health care. When home health care is approved for Medicaid payment, families report having difficulty finding nurses to provide the care, which leads to either prolonged hospitalizations or exhausted family caregivers (Foster et al., 2019).

Early Intervention and Early Childhood Special Education

During the 2017-18 school year, Early Intervention and Early Childhood Special Education (EI/ECSE) caseloads increased by at least 10,000 to 15,000 cases per month, and they are projected to increase in subsequent school years (Oregon Secretary of State Audits Division, 2020). Education services districts (ESD) and subcontractors reported these increases as an obstacle to providing services for CYSHCN (Oregon Secretary of State Audits Division, 2020). From 2018-19, only one in three Oregon children who was eligible for special education through EI/ECSE programs received an adequate level of services (Oregon Secretary of State Audits Division, 2020). These results vary by need. Although 62% of children with low needs received adequate levels of services, only 6.2% of those with moderate needs, and 0.7% of children with high needs, received adequate services (Oregon Secretary of State Audits Division, 2020). Funding is a barrier for special education programs; since its inception, funding has never been sufficient to meet the need for services (Oregon Secretary of State Audits Division, 2020).

Medical Home (Oregon Title V National Priority)

Medical home provides care that is family-centered, culturally responsive, comprehensive, coordinated, accessible, continuous, and compassionate (AAP citation). Care coordination is particularly important for CYSHCN; it addresses the interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes (Antonelli et al., 2009). Among the myriad responsibilities of medical homes and care coordination, both are to “provide appropriate resources to match the health literacy, primary language, and culture of CYSHCN and their family” and, in addition, family strengths are respected in the delivery of care, extended family members are included in decision-making according to the family’s wishes, and family driven goals are incorporated in the plan of care” (AMCHP & NASHP, 2017, p. 10).

NSCH 2016-2017 results show that only about 4 in every 10 Oregon CYSHCN under age 18 receive care in a medical home (CAHMI, 2020). The two components of medical home care that CYSHCN are less likely to receive are effective care coordination and needed referrals. CYSHCN experience disparity compared to children without special health care needs in receipt of those medical home components. Results of Oregon’s Consumer Assessment of Health Plans Survey collected from families of children with chronic conditions who are enrolled in Oregon Health Plan (Medicaid) show that about one-quarter of these children do not receive care coordination (Center for the Study of Services, n.d.). When results are disaggregated by Coordinated Care Organization (CCO), findings show that more than one-third of these children with chronic conditions served by a Southwestern Oregon CCO do not receive care coordination (Center for the Study of Services, n.d.). Families of Latino CYSHCN in Central Oregon also reported that their child’s providers did not coordinate with each other (Gallarde-Kim, Bisso-Fetzer, Roy, et al., 2020).

Geography

About one-third of Oregon counties have inadequate access to primary care (Martin & Vega-Juárez, 2020), with provider-resident ratios exceeding 1:1,000 (Oregon Health Authority, 2019), although these results are not specific to the pediatric population. Unmet mental, oral, and physical health care needs are approximately 1.5 times greater in rural and frontier communities than in urban communities (Oregon Office of Rural Health, 2019). Oregonians have an average travel time of 12.4 minutes to the closest Patient-Centered Primary Care

Home (PCPCH) (Oregon Office of Rural Health, 2019). Twenty rural and frontier communities, however, do not have a PCPCH, and their residents experience an average 26 minute drive time (Oregon Office of Rural Health, 2019). In rural and frontier areas: 26 communities have no dentists; nine have no primary care providers, and 71 have less than 0.5 FTE of mental health provider time (Oregon Office of Rural Health, 2019).

Experiences of Racism in Health Care

Families of Black and Latino CYSHCN experience racism in Oregon health care settings. Families described experiencing both personally mediated and institutionalized racism (Jones, 2000). For example, health care providers engage with families of Black CYSHCN in disrespectful, racially stereotypical ways. Providers often lack familiarity with the health conditions and needs specific to Black CYSHCN, which leaves families feeling responsible for searching potential treatment options. Families of immigrant Latino CYSHCN in Central Oregon reported health care providers making blatantly insensitive and racist comments. Some also perceive that they are not allowed access to services because of their ethnicity. Families of both Black and Latino CYSHCN reported that health care providers often failed to address their concerns. For some immigrant Latino families, this experience was caused by poor interpretation services, or a lack of interpretation service altogether. Racism creates conditions such that members of a racial/cultural group distrust the health care system. Until Oregon health care settings address institutional and personally mediated racism, they will not be able to provide the family-centered and culturally-responsive care required of a medical home.

Our findings contrast sharply with NSCH 2017-2018 results for Oregon CYSHCN younger than 18 years. NSCH results show that families of Oregon CYSHCN “always” or “usually” experience family-centered and culturally responsive care: 92% reported the provider showed sensitivity to family values and customs, 91% reported the provider listened carefully to the family, 90% reported the provider gave information specific to parent concerns, and 89% reported that the provider helped parents feel like a partner in their child’s care (CAHMI, 2020). We cannot determine whether the NSCH quantitative findings are representative of the experiences of Black or Latino CYSHCN and their families in Oregon because of the small sample size (fewer than 30). Our qualitative studies did not seek to generalize to all families of Black or Latino CYSHCN in Oregon. However, when juxtaposed with NSCH results, our current study’s findings validate the importance of culturally-specific studies, and suggest a need for improvements to the NSCH sampling methodology.

Families of Black and Latino CYSHCN are often unable to find a provider who understands their culture. State analyses of the health care workforce show gaps between the race/ethnicity of health care providers and those served by the providers (e.g., Oregon Health Authority, 2018b). For example, the proportion of the behavioral/mental health workforce who identify as Latino and the proportion of the population who are Latino do not correspond (Heimeda et al., 2019). Our findings and those of other researchers (e.g., Zuckerman et al., 2014) point to a critical need for more diverse behavioral/mental health providers.

To meet the needs of Oregon CYSHCN, education settings (including early childhood) must also provide culturally responsive care and services. Oregon’s population is becoming increasingly ethnically and racially diverse. One-third of young children served through Oregon’s Early Intervention (EI) services are Latino, which is the largest non-White group of children served. Additionally, one-fourth of the students enrolled in special education services are Latino.

Medical Home Policy

Oregon’s Patient-Centered Primary Care Home Program (PCPCH) is the state’s program to promote patient- and family-centered primary care. The program does not identify pediatric or CYSHCN-specific standards (Martin & Vega-Juárez, 2020). Coordinating care for CYSHCN is one example of how a practice could meet

Standard 5.C, Complex Care Coordination (Martin et al., 2015). Additionally, if a practice chooses to complete Standard 3.A, Preventive Services, they must follow the national Standards of Systems of Care for CYSHCN (Association for Maternal and Child Health Programs, 2014) (Oregon Health Authority, 2018a).

Stakeholder Block Grant Priority Input

Stakeholders agreed with OCCYSHN's proposal to maintain medical home as a national priority for CYSHCN for 2021-2025 (Vega-Juárez & Martin, 2020). Stakeholders emphasized the importance of, and need for, cross-systems care coordination. Stakeholders also identified needs within medical homes for providers to give referrals for services when needed and for providers to possess cultural awareness and sensitivity (Vega-Juárez & Martin, 2020).

Transition from Pediatric to Adult Health Care (Oregon Title V National Priority)

The transition from pediatric to adult health care is a developmental preparation that starts when the youth is 12 years old (Got Transition, 2020). Youth assume increasing responsibility for their health care over time, and youth and their families take steps to prepare for the changes that come with getting care from adult health care providers (Got Transition, 2020). Standards of care for health care settings serving CYSHCN require that these settings have the following transition policies in place: assess youth understanding of self-care and health care use; prepare and transfer appropriate documents to adult health care providers; and confirm establishment with the adult provider (AMCHP & NASHP, 2017; Got Transition, 2020).

NSCH 2016-2017 results show that Oregon youth, particularly young adults with special health care needs (YSHCN), do not receive services necessary to transition to adult health care (CAHMI, 2020). This holds true regardless of whether YSHCN receive care within a medical home, or have adequate and continuous insurance. Four out of five YSHCN who experience behavioral, developmental, or emotional conditions do not receive services necessary to transition (CAHMI, 2020), and families of young adults with medical complexity who OCCYSHN interviewed reported that they had no warning that their child's behavioral health care provider would stop working with their child when the young adult turned 18 (Roy et al., 2020). Two-thirds of young adults with developmental disabilities did not have a transition plan (National Core Indicators, 2018). OCCYSHN program data also showed that we did not achieve a program goal that transition-aged YSHCN would have a shared care plan with at least one transition goal (Oregon Health Authority Public Health Division & Oregon Center for Children and Youth with Special Health Needs, 2020).

Our study shows that families of Black and Latino YSHCN were not prepared for their young adult transition to adult health care. Families from both communities described a lack of preparation and support for this important change. In addition, families of Black YSHCN described the need to stay involved in their young adult's care because their YSHCN was not prepared to manage their own health care, or because the family member did not trust health care providers to ensure that their YSHCN received the necessary care. Privacy regulations were the primary obstacle to families remaining involved in their YSHCN health care when they reached legal adulthood. Other transition-related challenges described by families of Latino CYSHCN concerned loss of insurance, managing their YSHCN's physical size, and "starting over from scratch" with a new set of providers.

Young adults with medical complexity (YAMC) – a subpopulation of CYSHCN – and their families are not adequately prepared or supported for the transition from pediatric to adult health care. Families of YAMC described an absence of guidance for their child's transition to adult health care. They got little to no notice that such a change was necessary and impending, and little to no communication about the steps involved (Roy et al., 2020). Families reported limitations in provider options because of insurance provider networks, few providers who were equipped to manage their YAMC's complex health conditions, and lack of openings in adult practices (Roy et al., 2020). Families experienced challenges working with their YAMC's adult providers because providers lacked experience with caring for YAMC, working with families, and guardianship issues (Roy et al., 2020). Families described consequences of poor transition for YAMC that included gaps in care, declines in health status, and being forced to use costly alternatives to ambulatory care, such as emergency department care (Roy et al., 2020).

An analysis of root causes for the lack of support for YAMC identified impediments to successful health care transition for YAMC (Martin et al., 2019). For example, Providers (both pediatric and adult) are not always knowledgeable about health care transition. Pediatric and adult providers may not have established professional relationships with one another. Fee-for-service payment models disincentivize the more time-intensive care and coordination that YAMC require from providers. Also, electronic health records tend not to have transition components that support incorporating the issue into clinical care (Martin et al., 2019).

Stakeholder Block Grant Priority Input

Stakeholders agreed with OCCYSHN's proposal to maintain transition to adult health care as a national priority for CYSHCN for 2021-2025 (Vega-Juárez & Martin, 2020). Stakeholders emphasized the importance of medical home for CYSHCN, and cross-systems care coordination. Concerns expressed by stakeholders included lacking adequate bandwidth to provide services to transition-aged CYSHCN, and not being well prepared to care for young adults with medical complexity (Vega-Juárez & Martin, 2020).

Adequate and Continuous Insurance

Adequate and continuous insurance is defined as insurance coverage that meets the child's needs, allows the child to see necessary providers, has reasonable out-of-pocket expenses, and provides consistent insurance throughout the past 12 months (CAHMI, 2020). Oregon has made great strides in ensuring that children are insured. However, about one-third of Oregon's children experience insurance that is not *adequate and continuous* (for the last 12 months). Adequacy appears to be a greater challenge than continuity.

Privately insured Oregon CYSHCN report inadequate insurance more often than those who are publicly insured. Additionally, nearly one in five CYSHCN has health insurance that "sometimes or never" offers behavioral/mental health benefits. Families of Black CYSHCN reported insurance challenges obtaining reauthorization for services, having certain services covered, and finding an in-network provider. Specific to behavioral/mental health care: families reported that it was not regularly covered, or they had trouble finding an in-network provider. Immigrant families of Latino CYSHCN reported adequacy and continuity challenges. They cited inconsistent service coverage and high out-of-pocket costs, despite being insured.

Conclusion

The needs assessment identified persistent challenges for Oregon CYSHCN, specifically: accessing behavioral/mental health care, especially culturally-specific providers; receiving care coordination within a family-centered medical home; and gaps in provider knowledge and system of care policies that inhibit preparation for transition to adult health care. Our needs assessment also identified that families of Black and Latino CYSHCN experience racism within health care settings. OCCYSHN is Oregon's public health agency for CYSHCN. We are situated within an academic institution that, like most (if not all) US academic institutions, is grounded in white privilege,[9] and as such, we have a responsibility to acknowledge this privilege and identify

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[9] "White privilege is built upon whiteness and is a legacy of racism and bias that created unearned benefits and advantages for white people. White privilege does not imply that white people have not endured their own personal

our role in dismantling racism in the system of care for CYSHCN. Initially, OCCYSHN will engage in three broad types of activities, which are listed below.[10] OCCYSHN will seek to partner with culturally-specific service organizations to put these plans into action.

I. OCCYSHN will share findings on experiences of racism with professional groups, beginning with health care professionals. Additionally, although our findings are specific to health care, CYSHCN of Color and their families likely experience racism in other settings that would benefit from the information (e.g., education, Developmental Disabilities). OCCYSHN is working with LCA and SCAFO to disseminate these findings.
II. OCCYSHN will work with culturally-specific community-based organizations to ensure that our Title V Block Grant strategies and policies are anti-racist and culturally-responsive.
III. OCCYSHN will seek partnerships with culturally-specific service organizations representing other non-dominant communities (in addition to Black and Latino) to advocate for Oregon CYSHCN and their families.

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struggles, but instead acknowledges the systemic benefits they enjoy because of our social structure. White privilege allows white individuals to walk through the world with the assumption that their needs will be readily met and that they will be given the benefit of the doubt" (Autry, 2020).

[10] We made specific recommendations in Chapters 3 and 4 (Gallarde-Kim, Bisso-Fetzer, Roy, et al., 2020 and Gallarde-Kim, Smith, Roy, et al., 2020, respectively).

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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 atleast 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 atleast 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 8th and 11th 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).[2] 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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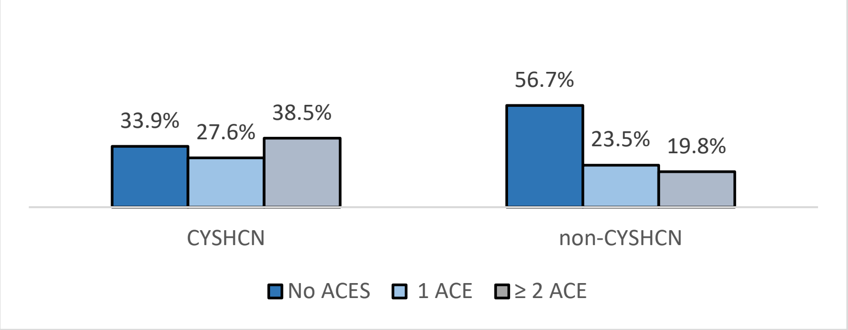
[2] The National Survey of Children's Health uses "Hispanic" on its questionnaire. When talking about NSCH findings, we use their term. When talking about findings from our collaboration with the Latino Community Association, we use their term, "Latino," to describe families from whom they collected data.

mother and 8% live in family with an other structure type (CAHMI, 2020).[3] 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).[4]

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

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[3] 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).

[4] 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[5] through team-based shared care planning, 65% of whom experienced social complexity.[6]

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.[7] 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 anuual 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[8] 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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[5] Eighty-two percent of these children and families also were served through the CaCoon program.

[6] 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).

[7] 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.

[8] 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).[9]

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 8th and 11th Graders Who Considered and Attempted Suicide

	2015		2017		2019	
	8th	11th	8th	11th	8th	11th
Seriously considered attempting suicide	16.2	16.3	16.9	18.2	19.9	18.6
Actually attempted suide	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 11th 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).

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[9] 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 dentail 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).[10] 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).[10]

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[10] 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).[11]

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[11] 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 accomodations 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 CYSCHN 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 centerered 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

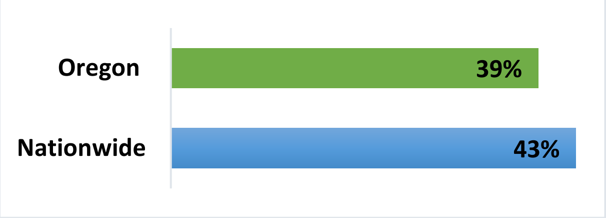
The Maternal and Child Health Bureau (MCHB) requires that each state select at least one national priority area per population served through the Title V Block Grant from its list of predetermined priority areas. MCHB has created measures for each of these priority areas using data available through 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 Inititiative [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).[12]

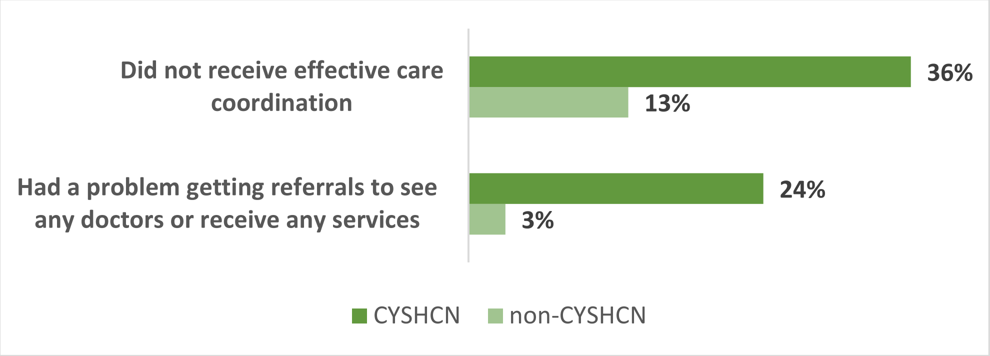
Exhibit 3.3. Percentage of CYSHCN, Birth Through 17 Years, Who Receive Care In A Medical Home



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

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[12] 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.[13]

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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[13] 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 gains 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.[14] 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.[15] 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.[16]

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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[14] 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)

[15] 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)

[16] 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).[17]

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 specifc health goals and needs compared to 18% nationwide.[18] 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).[17]
- 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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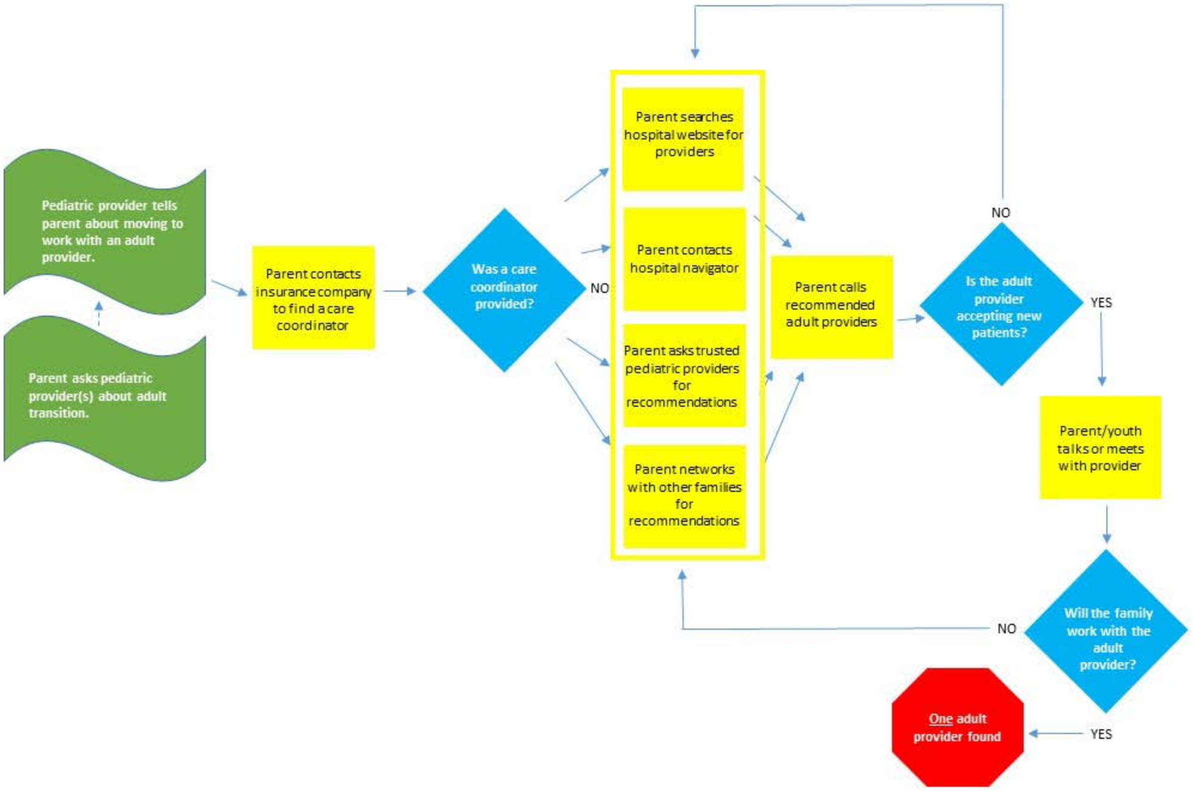
[17] The Data Resource Center advises that consumers use caution when interpreting this estimate due to low sample size (https://www.childhealthdata.org/browse/survey/results?q=5491&r=39&r2=1&g=664).

[18] 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.[19] 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

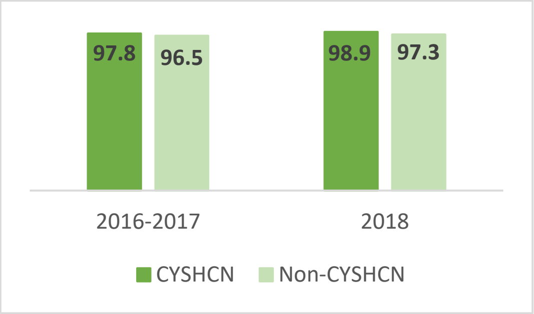
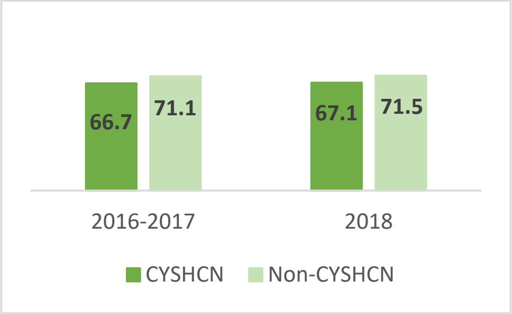


Exhibit 3.7. Percent of Oregon CYSHCN Whose Insurance is Consistent and Adequate



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,[20] and 2% were uninsured.[21]

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[19] 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

[20] 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.

[21] 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, reorted that the reason was issues related to cost.[22]
- 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 priorty 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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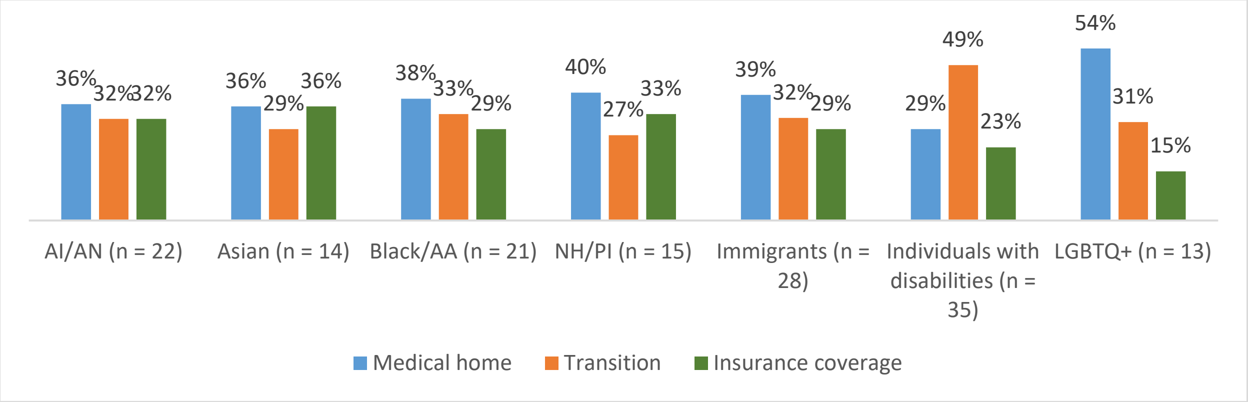
https://www.childhealthdata.org/browse/survey/results?q=5400&r=39&g=664

[22] 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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Oregon Center for Children and Youth with Special Health Care Needs
Title V Needs Assessment
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CHAPTER THREE

Health Care Needs, Access to Care, and Experiences of Racism for Black Children and Youth with Special Health Care Needs and Their Families

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Executive Summary

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) and the Sickle Cell Anemia Foundation of Oregon (SCAFO) collaborated to collect data about the needs and experiences of families of Black children and youth with special health care needs (CYSHCN). Specifically, we sought to describe the following: health and other support needs; access to needed care and support; availability of culturally and linguistically appropriate care and support; and support for the transition from pediatric to adult health care. To collect these descriptive data, SCAFO conducted 11 focus groups around the state with 45 adults who are parents or guardians of Black CYSHCN. Of those, 37 were parents or guardians of children younger than 18 years old and eight were parents or guardians of young adults age 18 through 25 years old.

In 10 of the 11 focus groups, family members described experiences of racism. They reported feeling disrespected and judged by their child's providers, and described health care providers lacking the cultural context to understand health care conditions that primarily affect Black children. Race played a key role in determining the quality of care that Black CYSHCN received. Additionally, in almost all focus groups, at least one family member indicated that they had personally experienced one or more traumatic events when receiving health care. These collective experiences contributed to families' distrust in the healthcare system. They also had low expectations of finding a Black health care provider.

When asked about their CYSHCN's needs, family members in nearly all groups reported that their child needs or uses behavioral or mental health care. Family members reported that it was easy to access primary care and emergency department services, and difficult to access behavioral/mental health care and medical specialists. They described a provider shortage and difficulty in getting appointments. They said they had to advocate persistently to access services. Family members discussed needing to stay involved in their young adult's health care after they turned age 18, and reported a lack of health care system support for the transition to adult health care. Family members in more than one-third of the focus groups described that their child experienced at least one type of adverse childhood experience (ACE), most frequently abuse and neglect.

Although our report findings cannot generalize to all families of Black CYSHCN in Oregon, our needs assessment found that these families experience racism in Oregon's health care systems. To ensure that all CYSHCN in Oregon receive care in a patient-centered medical home, it is imperative to ensure that Black CYHSCN and other CYSHCN of Color have access to family-centered and culturally responsive care. Our report concludes with a set of recommendations that identify opportunities for Oregon Title V CYSHCN to collaborate with culturally-specific service organizations to promote culturally responsive care in Title V Block Grant strategies.

Acknowledgements

The Sickle Cell Anemia Foundation of Oregon (SCAFO) and the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) thank the families who participated in the focus groups; we are grateful for their candor, emotion, energy, information and time. We thank the community partner organization staff members and leaders who supported us in identifying and reaching out to families within their networks, and providing community space to host the focus groups. Finally, we thank Gillian Freney for her essential editing and Brittany Tagliaferro-Lucas and Nicole Cox for their administrative and contract support.

About Sickle Cell Anemia Foundation of Oregon

The Sickle Cell Anemia Foundation of Oregon (SCAFO), formerly the Portland Sickle Cell Anemia Foundation, was established in 1981 by Pastor Marcia L. Taylor, BA, CEO and Executive Director. Its mission is to improve the quality of life of those suffering with sickle cell disorders and to inform and educate the general population. The goal is to promote awareness of the genetic causes and health effects of sickle cell anemia and related conditions; to promote improved access to care through raising the number of sickle cell educated clinicians; to remove the stigma that sickle cell clients are drug seekers which impede the ability to provide sensitive and quality care. It has culturally specific and multi-cultural staff who implement programs and outreach to low-income individuals with sickle cell disease living in Alaska, Idaho, Washington and Montana in addition to Oregon. SCAFO programs include a wide variety of services ranging from patient advocacy, support groups, parent workshops, ongoing education and treatment to assist with physical needs (e.g., heating during winter months, free diagnostic testing through our partnership with Legacy Emanuel Medical Center, food, new coats and toys, and often first and last month's rent through community partnerships), and to keep the sickle cell community informed of new medical treatments and clinical trials. Because of the work of Pastor Taylor and the SCAFO Board, the state of Oregon began testing for sickle cell trait and disease. Her current staff is Michael Aiello, BA, Data Manager, Charles Smith, MA, Program Manager, and Lisa McConnell, BA, Social Worker.

About Oregon Center for Children and Youth with Special Health Needs

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) is Oregon's public health agency for children and youth with special health care needs. OCCYSHN partners with the Oregon Health Authority Public Health Division to implement Oregon's Title V Maternal and Child Health Services Block Grant. OCCYSHN's mission is to improve the health, development and well-being of all Oregon's child and youth with special health care needs.

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Foundational Terminology

Our team provides the following definitions and expanded discussion to facilitate reader understanding and interpretation of our findings.

Racism: We use the following definitions.

- "A system of structuring opportunity and assigning value based on race that unfairly disadvantages some individuals and communities, unfairly advantages other individuals and communities, and undermines realization of the full potential of the whole society through the waste of human resources" (Jones, 2003, p.10).
- "A variety of practices, beliefs, social relations, and phenomena that work to reproduce a racial hierarchy and social structure that yield superiority, power, and privilege for some, and discrimination and oppression for others. Racism exists when ideas and assumptions about racial categories are used to justify and reproduce a racial hierarchy and racially structured society that unjustly limits access to resources, rights, and privileges on the basis of race. Racism also occurs when this kind of unjust social structure is produced by the failure to account for race and its historical and contemporary roles in society" (Cole, 2020).

Institutionalized or institutional racism: Racism that is structured into political and social institutions and directly or indirectly limits the rights of groups of people – and their access to societal goods, opportunities, and services – based on their race (Jones, 2000). Examples of limitations in access include access to safe, quality education, employment, environments, and health care, in addition to limiting access to information, resources, and voice (Jones, 2000). Institutionalized racism also identifies the cultural assumptions and practices of the dominant group as the norm to which all other cultural practices should conform. The individuals who lead and manage our institutions may not be racist individuals, but in carrying out their jobs they may perpetuate discrimination without the awareness that their institution is contributing to a discriminatory outcome.

> *"We live in a society where race is one of the biggest indicators of your success in life…We cannot look at a society where racial inequity is so universal and longstanding and say, 'This is all the doing of a few individuals with hate in their hearts.' It just doesn't make sense… if our systems aren't acknowledged and changed, it will bring negligible benefit to the lives of people of color…" (Oluo, 2019, p.31).*

It is important to understand and identify institutionalized racism because it has resulted in racial stratification and disparities in education, employment, government, health care, and housing. Although many laws were passed in the mid-20th century to make discrimination illegal, the impact of the original policies and practices continues to affect non-dominant racial communities (e.g., mortgage loan redlining, alumni legacy preference in university admissions criteria).

Personally mediated racism: "Prejudice and discrimination, where prejudice means differential assumptions about the abilities, motives, and intentions of others according to their race, and discrimination means differential actions toward others according to their race" (Jones, 2000, pp. 1212-1213). In considering personally mediated racism, it is important to understand implicit (or unconscious) bias. Implicit Bias, also known as implicit social cognition, refers to the attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner. These biases, which encompass both favorable and unfavorable assessments, are activated involuntarily and without an individual's awareness or intentional control. Residing in the subconscious, these biases are different from known biases that individuals may choose to conceal for the purposes of social and/or political correctness.

The implicit associations we harbor in our subconscious cause us to have feelings and attitudes about other people based on characteristics such as race, ethnicity, age, and appearance. These associations develop over the course of a lifetime beginning at an early age through exposure to direct and indirect messages. In addition to early life experiences, the media and news programming are often-cited origins of implicit associations. The experiences of personally mediated racism reported by families participating in this study may have resulted from explicit or implicit biases.

Internalized Racism: "Acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth, and is characterized by their not believing in others who look like them, and not believing in themselves" (Jones, 2000, p. 1213). Internalized racism is detrimental to People of Color because acceptance of negative messages about their ethnicity or race may result in individuals feeling shame about this facet of their identity. They may hate their skin color, hair, or other physical characteristics and may result in low self-esteem and discomfort with themselves because they believe that their race makes them inferior.

The stories and experiences conveyed by the family participants provide illustrations of how parents experience racism when dealing with the health care system; particularly in how power is exerted, privilege is misused, and superiority is conveyed in their dealings with different people within the health care system.

Introduction

The National Survey of Children's Health (NSCH), administered by the U.S. Maternal and Child Health and the U.S. Census Bureaus, and OCCYSHN's five-year needs assessments are the primary sources of data describing the population of Oregon children and youth with special health care needs (CYSHCN).[1] NSCH results provide a wealth of information, yet results that generalize to CYSHCN – particularly Black CYSHCN – often do not exist due to inadequate sample size. OCCYSHN routinely collects input from families when conducting its legislatively-required Title V five-year needs assessments; however, these results do not adequately describe the experiences of families of Black CYSHCN, again because of small sample sizes. Therefore, the Sickle Cell Anemia Foundation of Oregon (SCAFO) partnered with OCCYSHN to inform Oregon's 2020 Title V needs assessment with answers to the following questions:

1. What health care (behavioral, oral, and physical) and other services do families of Black CYSHCN need for their child?
2. What has been the experience of families of Black CYSHCN attempting to access needed care?
3. What has been the experience of families of Black CYSHCN in accessing culturally responsive care?
4. What has been the experience of families of Black CYSHCN in transitioning their child from pediatric to adult health care?

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[1] Children and youth with special health care needs "have or are at an increased risk for a chronic physical, developmental, behavioral, or emotional condition, and… require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138).

Methods

The SCAFO-OCCYSHN team (we) developed a focus groups data collection method to gather data to answer these questions. SCAFO team members recruited, screened for study eligibility, organized, and conducted the focus groups. SCAFO worked with partner organizations (see Exhibit 3.1) to recruit potential families to participate. Families were eligible to participate in the focus groups if (a) their child met the population definition of CYSHCN (McPherson et al., 1998) using a modified version of the accepted population identification method (Bethell et al, 2002), (b) their child's race/ethnicity was African American, African [Black], Caribbean [Black], or Other Black,[2] and (c) their child's age was younger than 26 years. Because we sought to learn about the experiences of families of Black CYSHCN with transition from pediatric to adult health care, we organized focus groups according to child age (younger than 18 years, or 18 through 25 years).

Exhibit 3.1. SCAFO Partner Organizations

- African Family Holistic Health Organization (AFHHO)
- Autism Society of Oregon
- Black Community of Portland
- Black Educational Achievement Movement (BEAM)
- Bridging Communities- Medford
- County Developmental Disabilities services departments
- Easter Seals
- Family and Community Together (FACT) Oregon
- Head Start Programs- Klamath Falls, Redmond
- National Association for the Advancement of Colored People (NAACP) Eugene/Springfield Chapter
- N.W. Down Syndrome Association
- Oregon Family Support Network- OFSN
- Pauline Memorial AME Zion Church- Salem
- Portland Parents Union
- United Cerebral Palsy

SCAFO conducted 11 focus groups around the state with 45 adults who were parents or guardians (family members) of Black CYSHCN. Of those, 37 were family members of children younger than 18 years old and eight were family members of young adults ages 18 through 25 years. In five focus groups, the eight family members of young adults discussed their experience transitioning from pediatric to adult health care. Due to recruitment challenges, two scheduled focus groups had just one family member participate. An average of four family members participated in each focus group, with a range of one to 10 family members participating per group. SCAFO conducted focus groups in six cities across the state. Four were in urban areas, and two were in urban clusters in rural counties (Oregon Office of Rural Health, 2018).

SCAFO collected 30 demographic questionnaires, completion of which was optional for family members. Eighty-seven percent of questionnaire respondents were African American/Black (includes African American, African [Black], Caribbean [Black], or Other Black). Sixty percent of respondents reported being the mother or father of the child. Respondents' average age was 49 years old, and 37% completed some college or received a 2-year degree, and 30% completed high school or received a GED. The average number of people in the respondents' household was four, and 50% reported having an annual household income of less than $24,999.

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[2] SCAFO team members approved use of this definition based on Oregon Health Authority's REAL-D project (OHA Office of Equity and Inclusion, 2020).

Results

We used a thematic approach to analyzing the data. Because the data that result from focus groups are the product of interaction among participants, the focus group is the unit of analysis by which we report results (e.g., seven focus groups described theme x). We identified a theme if an idea or experience was reported in at least five of the 11 focus groups. For transition, we identified a theme if an idea or experience was reported in at least three of the five groups. When analyzing the data, we first identified overarching themes, or content that aligned with our four research questions: (1) types of health-related care, (2) access to care, (3) culturally responsive care, and (4) experiences transitioning between pediatric and adult health care. We then identified second tier themes within each of the four overarching themes; in some cases we also identified third tier themes within the second tier. Discussion of these results follows.

Health-related Care Needs

During each focus group, SCAFO asked family participants to describe the health-related care and services their child has needed (see Exhibit 3.2). The care needs identified by family members are not a comprehensive accounting of all care needs; rather, they represent the needs the family chose to discuss in response to the discussion question. Family members in nearly all groups (n=9) reported that their child needs or uses behavioral or mental health care. Family members in more than two-thirds of the groups (n=7) described their child needing or using supports in an educational setting. Family members also frequently discussed their child's need for occupational, physical, or speech therapy (n=5) and medical specialists (n=5). Exhibit 3.2 includes quotations that illustrate the most common care needs.

Exhibit 3.2. Health-related Care Need Types By Number of Focus Groups

Number of Focus Groups	Health-related Care Need Sub-themes
9	Behavioral/Mental Health Care: Counseling, therapy, behavior therapy, "someone to talk to" *"My decision to have the Black psychologist and why I had him going was he just needs a place to be able to talk because he knows he's different. I've been teaching him that since he was little. It's okay, we all learn different, we're all different, but that didn't stop the bullying, the teasing, the kids that noticed his work was different than theirs even though I made sure he stayed in the classroom and was not pulled out so that he is singled out."* (Focus Group 11)
7	Educational Supports: Early Intervention (EI) or Early Childhood Special Education (ECSE), preschool supports, IEP, 504, classroom support, or school staff trained to support special conditions *"My daughter has two trained support staff at her school for her diabetes who have been trained by the nurse, and everybody in the school has been trained to be able to properly… support her. Like if she was somewhere and something happened, they would know...everybody had to be trained to know what diabetes looks like."* (Focus Group 3)
5	Allied Therapies: Occupational, physical, or speech therapy *"... as a baby and as a toddler it was physical therapy, occupational therapy, speech therapy, and then when she got into school, she has a neurologist because of the seizures, and endocrinologist because she has precocious puberty... she has a medication to stop*

Number of Focus Groups	Health-related Care Need Sub-themes
	that. She has the vision services for the classes, the hearing aid. We see the services for that, and also braces for her feet. It's been a lot of doctors." (Focus Group 2)
5	Medical Specialists: Pediatric specialty or subspecialty care (e.g., cardiologist, endocrinologist, neurologist, ophthalmologist, etc.) *"When he was born... I didn't know if it was a birthmark or a dirt patch... it wouldn't go away.... I was concerned and I took it to his doctor. And he wasn't too concerned about it at first... it didn't really show up till he was a year and a half. And then when I brought him in for his checkup [the doctor is] like, 'this is getting more pronounced. I want him to go see a specialist...' [The specialists] checked him out and they said it was pigmentary mosaicism and it is seen a lot in mixed children."* (Focus Group 8)
4	Care Coordination: Communication and coordination among providers or team-based care.
4	Primary or General Health Care
4	Vision Supports: Eye doctor, optometrist, eye exams, and eyeglasses or other devices to support vision.
3	Durable Medical Equipment (DME): Braces for feet or legs, nebulizers, wheelchairs, hospital beds, traction equipment, canes, crutches, walkers, kidney machines, ventilators, monitors, etc.
3	Emergency Department, emergency room, hospital
3	Prescription Medication
2	Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD) Supports
2	Developmental or Intellectual Disability Care or Supports: Someone to help with daily living activities (e.g., personal support worker), vocational and job supports
2	Oral Health Care: Preventive, orthodontic, or other specialty dental care, surgery, or treatment
1	Augmentative Communication: Devices to supplement or replace speech or writing
1	Clothing or Food Needs
1	Feeding Therapy or Specialized Nutrition Care.
1	Hearing Supports: Hearing aids, audiologists, sign language interpreter, etc.
1	Ambulance Transport
1	Phlebotomist able to draw blood from children with Autism Spectrum Disorder

Access to Care

We asked family members to describe the ease of accessing health-related care for their child. We summarize the types of care that family members needed, and how hard it was for them to access it. The challenges that emerged across most focus groups were health insurance authorization and coverage, the need to persistently advocate to get their child's care, difficulty in getting appointments, and provider shortages in their communities.

Health-related care services that are easy to access

Family members in most focus groups reported that primary care (n=8) and emergency department services (n=6) were easy to access. They described using the emergency department because they could not access non-emergency services in a timely manner. Family members in seven focus groups reported that their child was covered by health insurance. Quotations illustrating these experiences follow. Appendix A lists services discussed in all focus groups.

> *"… primary care is easy, accessible. But you get a new doctor every time you go take them."* (Focus Group 8)
>
> *"When he go to the hospital for the treatment, he's covered [by insurance]. Emergency through the ambulance has been covered. The dentist been covered. He just had a tooth pulled that was covered. I was there for that. Follow-up appointments, it was covered… [The coverage has been pretty good]."* (Focus Group 9)
>
> *"The ER is the only person that's gonna be in there and check everything. They're gonna check everything before they let you go. You're only in there a few hours, but at least you're fitting to get the utmost primary care. Don't matter if you got insurance or not… when you got health care and go to a regular hospital for a checkup or whatever, they look at you like, 'I'll see you later. Come back six months later.'"* (Focus Group 11)
>
> *"Take [your child] to emergency, they don't mind. They just do it. You know? Don't try to take 'em to the doctor. Go to emergency. You get help. I think you get help quicker. You might be there all night but you can get some help."* (Focus Group 6)

Health-related care services that are difficult to access

Behavioral/mental health care (n=6) and medical specialists (n=5) were the types of care that family members in most focus groups described as difficult to access. The following quotations illustrate family members' experiences. Appendix A contains the expanded list of health-related care services that family members in fewer than five focus groups identified as difficult to access.

> *"And I just want someone to come maybe help him out. Behavioral therapy. That way he would be able to... maybe use other coping skills that he can use. 'Til now it's been like four months, no behavioral therapy. You'll call this place, leave a voicemail... You can't find someone. And I don't know if it [is] because [of] OHP? They will automatically say, 'We aren't available.'"* (Focus Group 1)
>
> *"Specialty care is difficult. There is ways to get on lists and stuff with the pediatrician, but we would've had to change from [Hospital 1] to [Hospital 2] doctors. And then there's only certain days of the month that you'd be able to get this specialty person. And there's usually long wait-lists."* (Focus Group 7)

Health-related care services experienced as both easy and difficult to access

Family members' experiences accessing care varied. For example, family members described both positive and negative experiences getting (a) pharmacy services, and (b) educational supports for their child. Family members in four focus groups discussed experiences with pharmacy services. Two groups reported positive experiences, and the other two reported negative experiences. Those that reported negative experiences accessing pharmacy services had trouble refilling medications and getting insurance re-authorizations. The following quotes illustrate families' pharmacy experiences.

"We have a great pharmacy staff here that go to bat for us all the time as far as fighting the insurance for everything..." (Focus Group 3)

"…Pharmacy. We do mail-order pharmacy for the most part… Pharmacy is not a big deal." (Focus Group 7)

"The only issues I've had with the insurance is – because my child is a twin – [the insurer gets] them confused… [OHP] kept merging them into one person… It was …a battle doing the prescriptions... And I guess 'cause they have the same birth date it's confusing when you're trying to do the prescription and stuff at the pharmacy. That's the only hiccup I've always had with them. And it's still happening today. Like they can't figure it out. And I don't know why… But other than that, the OHP, the insurance people, are pretty good. It's just the pharmaceutical side that I'm having issues with." (Focus Group 8)

Family members in seven focus groups discussed their ability to access educational services. Three focus groups described ease of access, and four described challenges. Some families reported that they had easy access to Early Intervention, Individual Education Plans (IEP), and other school supports. Other family members in four focus groups reported delays getting Individualized Education Plans (IEPs) and school supports appropriate for their child's needs. The following quotes illustrate family experiences.

"Why does it take our kids so long to get an IEP when they're in school? …with my ten-year-old, I asked for one last year and he was supposed to get it. They needed to wait for something-or-other and he didn't [get an IEP]. I asked at the beginning of this year, 'Can we get this done now?' Like I called our counsel group so we can come up with a full five plan for him to help him in school. No IEP yet. Why does it take so long?" (Focus Group 2)

"My daughter has two trained support staff at her school for her diabetes who have been trained by the nurse, and everybody in the school has been trained to be able to properly … support her. [They are] more aware if something was to happen [to my daughter]." (Focus Group 3)

Access to care challenges

Family members described challenges they encounter getting the care their child needs. Exhibit 3.3 presents the number of focus groups in which the challenge theme emerged.

Exhibit 3.3. Access Challenge Type by Number of Focus Groups

Number	Type of Challenge
10	Health care insurance challenges
7	Difficulty in getting appointments
7	Persistent family advocacy to access needed services
4	Provider shortage

Challenges with health insurance

Although most family members reported that their child had health insurance, in ten focus groups they described experiencing insurance challenges. They reported issues with service re-authorization, some services not being covered, and difficulty finding a provider within their child's insurance network. The following quotations illustrate family experiences.

"And the counseling was very hard for me… to get him in because of the fact that he has Medicaid. He's not OHP. So I had to go through a whole other list of doctors to try and find him the proper counseling." (Focus Group 5)

"My kids get state insurance because of their disabilities, and they need sedatives a lot… We have a fast metabolizing enzyme that runs in our family, so if you give them one [sedative] for bloodwork, they're gonna be sitting there screaming…I have to pay for that 'cause their insurance doesn't cover it... Sometimes if it doesn't work that time then we gotta wait a couple weeks, pay for a whole other prescription, go in again. It's not only time-consuming, but it should be covered by insurance. I shouldn't have to pay for something that they need in order for them to get their shots that are mandatory by the state just to go to school." (Focus Group 11)

Difficulty in getting appointments

Family members in seven focus groups described difficulties in getting appointments for their child. In all seven focus groups, family members reported experiencing long waits between calling for an appointment and the date of the scheduled appointment. Family members experienced long waits for services, such as developmental assessments and allied therapies. Families also experienced long waits due to overbooked providers, which resulted in having to schedule an appointment months in advance. Having to schedule an appointment so far in advance can result in missing the appointment due to unforeseen circumstances or attempting to balance health care with other quality of life priorities. Family members in four focus groups also described additional types of difficulties getting appointments. Examples of these difficulties included providers scheduling an appointment without confirming the date with the family and not giving a reminder call, finding an appointment time that aligned with the family member's work schedule, and experiencing getting appointments quicker when the child was privately insured compared to when the child was publicly insured. The following quotations illustrate family experiences.

"But it took them at least three to six months to find the speech therapy… You'll call this place, leave a voicemail…You can't find someone. And I don't know if it [is] because [of] OHP? They will automatically say, 'We aren't available.'" (Focus Group 1)

"… you still have to call sometimes before you take your child or you have to get a referral and be like, 'I don't need a referral. I need to get him in right now'… that can get frustrating, and then having to take time off for appointments, because for a while it was like every week…" (Focus Group 2)

"…when you're considered for appointments… they're gonna see people with commercial insurance first because I've been there and I've been able to get into an appointment so quick. But now that the OHP is in play it's a completely different ballgame... They're not allowed to do that, but they do it." (Focus Group 3)

"The dentist – our past experience with the dentist has been a challenge. [The appointment] was way far out. But myself – I had missed an appointment. And so then that brings more challenges 'cause they are so booked out and they have so many people and then they kick you out and stuff like that. So with my own fault of, appointments was a challenge. But even if I hadn't missed an appointment, I felt like the dentists I took him to were poor, poor, poor." (Focus Group 8)

Persistent family advocacy to access needed services

Family members in seven focus groups reported needing to advocate persistently to get the services their child needed. They used various strategies to get their child's needs met. Family members described waiting in a provider's office to get the referral they needed, researching information on their own, and repeatedly contacting a provider's office to try to schedule an appointment. The following quotations illustrate family experiences.

"I ended up calling and calling trying to get into the doctor, and they kept telling me to wait. One day I decided I'm gonna pack a lunch, I'm gonna go down, I'm gonna sit in this doctor's office, and I have all day until they give me a referral to go get the services. We ended up getting that referral…" (Focus Group 3)

"The services are out there, but you gotta do a lot of advocating and asking a lot of questions and the resources. You better do the homework if your child has special needs. Do the homework. It's a lot." (Focus Group 10)

Provider shortage

Related to long waits for appointments, family members in four focus groups described an overall shortage of providers and services in their local community. The following quotations illustrate family experiences.

"...Maybe it's because the type of provider he needs… [is] so backed up… The demand for it is great, but there's not enough suppliers to meet it, so that there [are] backs up and that's another issue." (Focus Group 2)

"…I just think they need more health care providers in this town. Maybe hiring more people. Because as far as making and scheduling appointments, [there are] a lot of people that need to be seen but not enough providers… they need more health care providers in town so it won't be far booked out. That's the stressor." (Focus Group 8)

Culturally Responsive Health Care

During each focus group, we asked family participants to describe their experiences accessing culturally responsive care for their child. Three second-tier themes, which illustrate a lack of culturally responsive care for Black CYSHCN, emerged from the data (see Exhibit 3.4). A description of each of the themes follows.

Exhibit 3.4. Culturally Responsive Health Care Second Tier Themes, by Number of Focus Groups

Number	Second Tier Themes
7	Lack of Black health care providers
10	Experiences of racism
9	Experience-based perceptions about the health care system

Lack of Black health care providers

In seven of the 11 focus groups, family members described challenges finding a Black health care provider, because there are so few of them. For example, one family member stated *"They're rare. So, that answer that you heard was our laugh. Now you know"* (Focus Group 2). Another family member responded, *"I just know there's nobody in [town]. It's our fault for where we live pretty much. But even my daughter now lives in the western part of the state, and sometimes you can find people of color but not necessarily African American"* (Focus Group 7).

In addition to a shortage of mental health providers (see Exhibit 3.2), family members said it was especially hard to access Black (culturally specific) mental health providers. Although families reported preferring that their children see a Black mental health provider, they had trouble finding them. For example, one family member stated, *"I just recently got my son into therapy through [health system]. It took a long time because I wanted an African American counselor"* (Focus Group 10).

Experiences of racism

Family members described experiencing racism in 10 of 11 focus groups. Three third tier themes emerged in the experiences of racism category: lack of cultural understanding, lack of respect, and assumptions made about Black people. Descriptions of these themes follow.

Lack of Cultural Understanding

In nine of 11 focus groups, family members described how health care providers did not have the cultural context to understand the health care needs of Black children and their families. One family member expressed feeling frustration when a health care provider commented on her child's strength and size. She felt like these comments minimized her child's legitimate need for care and treatment. In other examples, family members expressed their dissatisfaction with health care providers not knowing enough about health conditions that are prevalent among Black people. Because of this, health care providers misdiagnosed conditions, or failed to appropriately treat them.

> *"They are 12 years old – they're 5'7" tall and strong. When they go to the doctor, 'You're bigger than me. You're strong.' And I say, 'It doesn't matter. They're sick. They need help. They need medicine. Give them medicine. Don't look their height. Don't look their body. That's none of your business. I came here to treat them. Treat them.'"* (Focus Group 1)

> *"I just remember going to take my son to one of his checkups when he was a baby… but them not knowing that the Mongolian mark, and the nurse and them… making it seem like [it] was a bruise instead of what it was. I'm like, 'No, he's had that since he was born.' I remember my actual primary doctor apologized to me later and him being like, 'I'm gonna make sure there's a note in your chart this time so that doesn't happen again.' But just having that experience, being like, 'This is something he was born with. If you knew anything about biracial or people of color then you would know this is natural.' Just the experience; it was not a cool experience. It was really negative."* (Focus Group 3)

> *"That's one of the major problems that we have. We go to the doctor, which is usually somebody white who has no idea… about African American culture or values, morals, anything like that, and they just kind of give you a rough version of what they think you need or should do."* (Focus Group 11)

Lack of respect

In eight of 11 focus groups, family members described health care experiences where they felt disrespected or discriminated against. They reported that health care providers discounted or ignored family member input, and did not respond to family members' specific requests for services or resources. The following quotations illustrate these dynamics.

> *"I really don't like going to the doctor's. Even if it's for me or even taking my kids. That's one thing I dread doing is going to the doctor's office. I'm so serious. I just don't even like going to appointments because of the disrespect. I just don't. And the discrimination."* (Focus Group 8)

> *"For me what happened was he was complaining about having abdominal pain. So, I felt on him, his stomach, his abdomen. I'm like, okay, something doesn't feel right. So I did this, that, and the other, and I'm like, 'No, there's something there that needs to be addressed.' They would say, 'Oh no, he's just backed up. He just needs to do this.' No, he doesn't need to do that. He's been doing this the whole time. That's not the problem. He needs to be seen by a specialist. Can you please hook that up?"* (Focus Group 11)

This theme also included examples of advocacy by family members. They reported gathering information about their child's health conditions, so they could advocate for services or treatments. They did this because they anticipated their requests would be denied (e.g., see the following quotation). Findings related to advocacy are consistent with the second tier theme under Access to Care: Persistent Family Advocacy to Access Needed Services.

> *"I felt if they push me to doses that I know they're too high and all, I ask the pharmacist: 'Is it the right dose for a little kid?' I go online. I do my own research before I give the medicine to my child. What is the side effect? 'Cause some of the time I ask the doctors, 'What are the side effect of this medicine that I'm giving to my child? Is it gonna bring any negative impact on him? What will be the outcome?' They won't give you an answer. And I was like, 'If you don't tell me then you're hiding something from me that I need to know. He's not taking the medicine. I will find other ways, other resources.' And they were like, 'Okay.'"* (Focus Group 1)

Assumptions made about Black people

In six of 11 focus groups, family members described feeling judged about their marital status, parenting style, or ability to care for their child. Family members felt their health care providers treated them in ways that implied racial stereotyping, like implying that their child was miserable because the parent was unmarried and young, or that money was a primary motivation for them because they were Black. The following quotations illustrate families' experiences.

> *"I wanna say he was in second or third grade and I did have him tested and they wanted me to sign off on him [having intellectual disability], and I would not. I just said, 'No.' This was at a charter school, and I remember the lady saying, 'If you sign off on [intellectual disability], you'll get a check. You'll get money.' And I was offended by that because it made me feel like all Black people want a check and that's what it's about, and that's not what I was about."* (Focus Group 10)

> *"That's why the parent don't already wanna access your services: because they feel like they already know that they got something going on and you coming in judging… I don't need you to come in and beat me more."* (Focus Group 4)

> *"I got my son's medical records one time and I was reading it, and the comments that the doctor made – 'You can tell that she's a young, single, unwed mother.' … – it has absolutely nothing to do with my son, the fact that he has a tumor... He's miserable. He has seizures. He's on medication, so yeah, he's gonna cry for hours. The comment about my parenting …'She doesn't have control of her kid.' Those kind of comments; that wouldn't have been written in there for a wed white mom."* (Focus Group 3)

Family members also reported that health care providers were hypervigilant with Black families. The examples below illustrate instances when family members sought care for their children and were subsequently reported to child protective services.

> *"When we arrived to the emergency room and I'm like, 'Hey, my daughter got into the medical cabinet' the doctor came in and was like, 'How many did you feed your children? What were you trying to do to your kids? You were trying to kill your kids? You were trying to feed your kids pill bottles?' And I was clearly devastated, hysterical…. Child Protective Services comes in and is like, 'I'm really sorry that I have to do this, but I have a lot of questions for you. I can tell that you seem like a totally normal parent, but the doctor is requesting.'…. For me, it's hard to go into an emergency room 'cause you never know who you're gonna get and what kind of judgment you're gonna get, and especially in urgent situations you're not thinking as clear as you probably could be in a normal visit type of thing."* (Focus Group 3)

> *"In order for him to get a bed he had to wait almost two weeks at the hospital. One of the doctors got tired of it and decided he wanted to discharge him. My husband was told by the counselors if they did that to say, 'No, we can't keep him safe.' 'Cause we were afraid he was gonna kill himself. And so then that doctor…..reported us to DHS. So I was down figuring out the plan for him and they said, "Oh, by the way, we need to let you know that you've been reported to DHS'…."* (Focus Group 7)

Experience-based perceptions about the health care system

Our findings indicate that experiences of racism create conditions such that members of a racial or cultural group distrust the health care system and have low expectations of finding health care providers that represent their race or culture. These perceptions were described by family members in nine of 11 focus groups.

Distrust in health care system

In six of 11 focus groups, family members' responses reflected a distrust of the health care system. For example, one family member described struggling with overcoming the perception in the Black community that if she asked health care providers to help her child, the system will separate her from her child. This family member appealed to the health care system to assure Black families that asking for help will not disadvantage her or her family.

> *"That's something very much…that I see in the…African American community, …like I said: don't talk. Let people know it's okay: 'You're not gonna get in trouble. DHS ain't coming after your kid because of you asking for help.'….And that would be something for me because that's the struggle; it's real."* (Focus Group 6)

Another family member described how it took her a lot of time and research to overcome the stigma associated with Individualized Education Plans (IEP). The stigma led to the perception that IEPs will prevent her child from succeeding in school. These examples suggest that the distrust results from past instances in which institutions acted unjustly towards members of the Black community.

> *"I think there's a stigma with IEPs. I think people of color automatically think of pulling them – they're in a class with kids that are really severely disabled, and it took me to do some research to understand that IEP actually is a safety net for your child that helps them. It's not a bad thing. It's not gonna follow them… But it took a while for me to get to that place."* (Focus Group 10)

Low expectations of finding Black health care providers

In seven of 11 focus groups, family members described that it was not realistic to envision having a Black health care provider for their child. Responses from family members reflected low expectations for finding a Black health care provider. These low expectations arose from family experiences. Family members faced barriers when they requested a Black health care provider, and they rarely encountered Black providers in the health care system. The following quotations illustrate this theme.

> *"…if I were to even ask for a black doctor, I would have to fill out a paper. I would have to sign it and say why and how come I want to switch the provider, and why in this and that. It's like it's not worth it."* (Focus Group 5)

> *"…I know living in [city], growing up in [city], we're not gonna see very many African American doctors, 'cause it's not important and that's just not the profession, unfortunately."* (Focus Group 11)

Some family members described that medicine was not a traditional profession for Black people, in part because of lack of funding, and in part because there are few Black role models in health care. In one example, a family member revealed doubts in the competence of Black providers they had encountered. These responses reflect both institutionalized and internalized levels of racism (Jones, 2000). The following quotations illustrate this theme.

> *"There are not very many scholarships for black people unless you go to a historically black university, which are all in the South… and that has to have a lot to do with the lack of providers, you know? As far as doctors and all of that. Like the feedback loop. So if I can't find a doctor for my kids who's black and there's no scholarships… So, yeah, I think that's part of the problem. If people aren't able to get funding to go to college and if they're already having difficulty – all the institutionalized racism. And I think from the kids that I've met that my daughter hangs around with at school….they don't wanna be in that system that is – if all your professors are white……It's a domino effect."* (Focus Group 7)

> *"I'd rather base my information and how I'm choosing off of what is right in front of me, and as much as I'd love to have a Black doctor at some point sometimes, I'm kinda torn 'cause I've heard plenty of bad experiences about it. It's not even the doctor. It's just like you say, they miss something and we kind of get mad at them and just don't want to go back to them."* (Focus Group 11)

Family-centered care experiences

Family members in nine of 11 focus groups described positive, family-centered experiences with specific providers (health and education) or hospitals. Family members felt supported when health care providers heard their concerns regarding their child's health, shared treatment decision-making with families, made referrals, helped them coordinate care, and considered the entire family in their CYSHCN's care. Families who experienced family-centered care often wished such care was the normative standard of care.

"He's a [specialist]. Asian. And I didn't mean to pick him but out of the blue they assigned him, and I sit with him and I say, 'If you gonna rush into surgery and other stuff, give me options. Let me know what the problem is. Don't say, oh, he has this; I have to rush him to surgery.' And he say, 'No, you have the choice.' And I was able to sit with him and work with him." (Focus Group 1)

"I guess just listen. I'm the mom and I'm with my kid all the time. So, if they're behaving differently and I think they have something wrong, I know what I'm talking about. My son's doctor…, he actually says that to me. He's like, 'You know better than I. I'm new to his file. His chart is admittedly too thick to read, so what do you need [from] me?'" (Focus Group 3)

"I think up at [Hospital 1], [Hospital 2], and then also [Hospital 3], it's a different world of pediatrics up there. I feel like the population that they serve is much different than the population that pediatric serves here. They're more experienced with disabilities. When you're in an inpatient environment, they look at the whole family. They care that you're okay. They care that you get to sleep for an hour. They'll send a nurse in to do the hands-on stuff, because for me, everything I've experienced with my daughter I've been alone, so I'm coordinating for my other child here and making sure her routine is staying in place as well as doing everything I need to do there. Inpatient experiences at [Hospital 2] have been amazing. I couldn't ask for better. And then here, early intervention services, they pretty much will help advocate for me and they will do and support whatever I need. Those are some positives. Typically, with primary care too they're really good now at dishing out referrals..." (Focus Group 3)

Transition from Pediatric to Adult Health Care

This overarching theme describes the experiences of families transitioning their young adult from pediatric to adult health care providers. SCAFO held five focus groups with family members of young adults with special health care needs (YSCHN) aged 18 through 25 years. Two second tier themes emerged: (1) Family experiences staying involved in their young adult's health care after age 18, which was described in all focus groups; and (2) A lack of support from the health care system during the transition process, which was reported in four of five focus groups. A description of each theme and examples follow.

Family experiences staying involved in young adult's health care after age 18

In all five focus groups, family members described staying involved in their young adult's health care after age 18. Family members explained their reasons for why they stayed involved, and what helped or hindered them.

Reasons family members stayed involved in young adult's health care

In four of five focus groups, family members described their reasons for staying involved in their young adult's health care, even after their child reached legal adulthood. Family members indicated that their young adult was not prepared to manage their own health care. Additionally, some family members said they did not trust health care providers to provide proper care without family member involvement. Family members stayed involved in their young adult's care by researching ways to manage conditions, finding health care providers in the young adult's new residence, making appointments, ordering medications, managing insurance-related issues, and accompanying their young adult to medical appointments.

"…With my daughter… when she was seeing the doctor from 16….we found that she was prediabetic…..But there was never a follow up. So I was trying to find out what do you normally do for teenagers who's prediabetic… other than eat right and exercise. I already know [that], so I knew then that the doctor wasn't worth a hoot. Okay, so once she turned 18 they moved her upstairs to this other doctor who was a female. She seemed more concerned, because she was telling [my daughter] about her weight. Because she lost a lot of weight. They was telling her about her weight and then she was not prediabetic… See what I'm saying? They don't always check. They just call things out because they don't want to check." (Focus Group 4)

"Like I pretty much still order all her insulin…I order all of her pump supplies and her Dexcom and then I deal with all the – there's just unbelievable nightmares of insurance. So I deal with all of that. And trying to teach her a little bit of it. But it's just a lot for her to handle as a college student." (Focus Group 7)

Barriers to family members staying involved in young adult's health care

In three out of five focus groups, family members described that they felt the need to stay involved in their young adult's health care, but were prevented from doing so by patient privacy rules. Some family members said this was a problem because their young adult relied on their support with health care. Family members in two of the five transition-aged focus groups described that a medical power of attorney or a release of information helped them participate in their young adult's health care. One family member said they were fortunate to be told about power of attorney when their young adult was 17. Examples follow.

"So since the girls get certain age, you can't get no information about them. But guess what? If they get pregnant, guess who they gotta come to? They mom. If they wanna get abortion, they gotta come to the mom. But we don't know [whether they have those issues]. Why? Like the boys – my son turned 12. Well, they took his MyChart off my thing because he turned 12. Yeah. So then I tried to get it put back on my thing. They didn't know how to do it. They still haven't called me about that yet. So I gotta get their permission… And that's how I kept up – it tells you what's going on." (Focus Group 6)

"Well, I have to lie sometimes and say I'm them [laughs]….To call and get their refills or this or that. So that's been a little bit uncomfortable. But as I can I've tried to get the permissions signed from them. But my daughter's in California. So if they're putting up a barrier – but when she turned 15, they wouldn't let us see stuff. They said, "Oh, you can't." At the diabetic place. And that upset me 'cause I said, "I understand if it's related to her sexual health and I'm fine with that. But if it's related to her diabetes, I'm helping her. I'm the one doing the 2:00 AM checks. I'm the one paying for the medical bill." So that was really upsetting, the laws and stuff related to that. But we just worked around it. But, yeah, it's been hard." (Focus Group 7)

"My son has actually had some pretty significant crises, and luckily, we were told when he was 17 that there was this medical power of attorney packet to have him fill out, so we filled that out. We were given some good advice prior to him being an adult about how I can stay connected and involved, so I know he fills it out and he tells all the doctors, 'Ask my mom.' He doesn't know the answers to most of his medical care. It's gone surprisingly smooth having that one little piece of paper with the power of attorney thing saying that I can help him and stuff..." (Focus Group 3)

"He [advocates with the medical provider] but only with my consent. He sees another doctor, but even when I set it up for him to see the Black psychiatrist they said, 'Well, he's over 18, so you can't make the appointment for him.' What I do is I get [my child], I put him on speaker… Even with him getting social security or disability, I had to sign something to say that I can speak to him, that they can release that information to me." (Focus Group 10)

Lack of health care system support during the transition process

Family members in four of the five focus groups described not receiving support from the health care system for the transition process. For example, one family member said that their child's health care provider did not provide requested help to meet their child's needs. Another family member encountered problems maintaining the young adult's health insurance, which interfered with getting a referral to an adult provider. Yet another family member described challenges working with their young adult's specialists.

> *"….Because she had reached 18… and they are supposed to send you to another doctor, which is no longer a pediatrician doctor, but she didn't get to that level. My insurance was gone before she could get to there."* (Focus Group 4)

> *"If I asked a health care provider, when I would ask for help, things on the outside, what can I do to help support him, if they did know, they didn't tell me. It was more or less like, "Well, you can Google this and you can see this" but it was never, "Go to this person. I know this doctor is good. I know this program is good." Anything that I put him in, like I said, has been…me doing homework."* (Focus Group 10)

Family Traumatic Health Care Experience

At least one family member in nine of 11 focus groups described having traumatic or disturbing health care experiences of their own. Family members described feeling uneasy because they had personally experienced intimidation or coercion from health care providers or staff. Additionally, family members recounted experiences of feeling pressured by health care providers or staff to use unwanted services or medications. In some focus groups, family members recounted harmful or painful health care experiences. The following quotations illustrate family traumatic health care experiences.

> *"I had an African American doctor and all he wanted to do was keep me medicated. And I was like I'm done with that… I said 'Something is wrong here. Something is definitely wrong. You telling me this but you're giving me this. I don't buy this. I don't buy this.'"* (Focus Group 4)

> *"… what made me upset with the doctors, with the whole pregnancy, [is that] they kept using scare tactics on me. They kept doing it. They said, 'You're gonna lose her. She can die. She's not gonna make it. She's gonna have this. She's gonna have that. We need to give you a C-section.'"* (Focus Group 8)

> *"Six weeks later… my placenta came out at home, and it put my body through toxic shock. It affected my eyes, my skin. Now I have lupus and sarcoidosis so that I have these flares. I have to take all these medications just for my eyes, my joints, and my body to be okay. It's the same doctors that just put us behind, because if they took the initiative to hear me in the first six weeks I was calling, then maybe this all could've been prevented."* (Focus Group 11)

Adverse Childhood Experiences

Adverse Childhood Experiences (ACEs) are potentially traumatic events that occur during childhood (birth through 17 years of age). According to the Centers for Disease Control and Prevention (n.d.), ACEs include experiencing abuse and neglect, growing up in a household with mental health concerns, growing up with parental substance abuse, living in an unsafe environment, experiencing parental separation and/or divorce, and experiencing the death of a parent. Discussion of ACEs occurred in four of the 11 focus groups. Although that did not rise to our threshold of five focus groups for identifying a theme, we present focus groups data on ACEs because CYSHCN are twice as likely as children without special health care needs to experience two or more ACEs, and Black children are almost twice as likely as White children to experience ACEs (CAHMI, 2020).

The adverse childhood experiences discussed in most focus groups were abuse and neglect. For example, one grandparent described how their daughter's drug abuse led her to neglect her children, who had to care for themselves at a young age. Exhibit 3.5 presents types of ACEs, the number of focus groups that discussed each, and quotations that illustrate these traumatic events.

Exhibit 3.5. Type of Adverse Childhood Experience (ACE) By Number of Focus Groups

Number	ACE	Quotation
3	Abuse and neglect (includes physical, emotional, and sexual abuse)	*"…the child that I'm dealing with is a grandchild. And the mother is on drugs, been on drugs for five years.... She neglects the kids. She started abusing the kids, having the oldest child do the things that the mother should be doing… a nine or ten-year-old going to the store, buying food for all the other younger kids, and then coming home and either cooking it or giving them chips…"* (Focus group 6) *"[My grandson] has lashes where his mom did to him and he wakes screaming, 'No, Mom, no' and I have to tear up out of the bed. It's kind of hard because I can't land on my knees because I have blood clots, and he's screaming and scared…and I don't know what's going on."* (Focus group 10)
2	Household member with mental health concern	*"I have chronic depression. And so there was also times when I cried or didn't feel good. And I also developed RA, severe RA, when my 20-year-old was about 1 [year old]. So a lot of their growing up I was sick."* (Focus group 7)
2	Parental substance abuse	*"[My grandson's] mom has had some major drug issues… [and] my son [isn't] capable to be the... custodial parent…"* (Focus group 5)
2	Unsafe Environment	*"[My nephew] grew up [outside the US] where there's a lot of violence and gunshots and racial/ethnic warfare..."* (Focus group 7)
1	Parental separation and/or divorce	*"… the reason I focus on [my grandson] is because it's a mom and dad situation [who are] not together…"* (Focus group 5)
1	Parent death	*"… [My nephew's] dad passed. So basically [there is] trauma from that as well."* (Focus group 7)
1	ACEs generally	*"[The] 24-year-old with… ADHD…anxiety…she also had some traumas... So there're some ACEs that are automatic at birth."* (Focus group 7)

Note: The CDC (n.d.) groups ACEs into the six categories outlined in the table.

Discussion

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) collaborated with the Sickle Cell Anemia Foundation of Oregon (SCAFO) to better understand the care needs and experiences of families of Black CYSHCN in Oregon. We sought to answer four research questions: (1) What health-related care (behavioral, oral, physical) services do families of Black CYSHCN need to care for their child, (2) What has been the experience of families of Black CYSHCN attempting to access needed care, (3) What has been the experience of families of Black CYSHCN in accessing culturally responsive care, and (4) What has been the experience of families of Black CYSHCN in transitioning their child from pediatric to adult health care? Discussion of findings for each of these questions follows.

Health-related Care Needs

The types of health-related care needs reported by families is consistent with the types of care needs reported by families of Oregon CYSHCN generally. Families of Black CYSHCN most commonly described need or use of behavioral/mental health care, educational setting supports, allied therapies (i.e., occupational, physical, or speech therapy), and medical specialists. The behavioral/mental health findings align with quantitative data describing the population of Oregon CYSHCN. For example, 45% of Oregon CYSHCN had ongoing emotional, developmental, and behavioral conditions, which is similar to national results (44%)(CAHMI, 2020a). In addition, 40% of CYSHCN received treatment or counseling from a mental health professional (CAHMI, 2020). We lack current quantitative data describing the needs of the population of Oregon CYSHCN for allied therapies and medical specialists. However, OCCYSHN's 2015 needs assessment family results showed that CYSHCN very commonly needed these services: 65% of respondents reported that their child needed occupational therapy, 38% reported physical therapy, and 65% reported speech therapy (Martin, 2014).

Care Access Experiences

Family members discussed easily accessing primary care and emergency department services, and commonly reported difficulty accessing behavioral/mental health care and medical specialists. Although the current study's results cannot describe the extent of this difficulty for all families of Black CYSHCN – or the disparity in access between families of Black versus White CYSHCN – the current study's findings align with those of OCCYSHN's 2015 needs assessment. The 2015 results showed that about one-quarter of family survey respondents identified behavioral/mental health care as one of the top three health care needs their child had but had difficulty obtaining (Martin et al., 2015).

Additionally, families of Black CYSHCN often experienced a range of challenges that make accessing care for their child difficult: health care insurance challenges, difficulty in getting appointments, a provider shortage, and a need to advocate persistently for their child to get appropriate care. Similarly, Ngui and Flores (2006) found that Black parents had significantly greater odds, compared with white parents, of reporting that health care services were not easy to use. Again, the current study's results cannot describe the extent to which these experiences are reflective of all families of Black CYSHCN in Oregon, but they do indicate potential differences with families of CYSHCN generally. 2015 needs assessment results showed that few parents of, and care coordinators who work with, CYSHCN reported families experiencing challenges related to insurance. They did, however, report difficulties getting an appointment that aligned with their work schedule, and getting an appointment as quickly as it was needed (Martin et al., 2015).

Culturally Responsive Care

To the best of our knowledge, this is the first study in the United States that uses a large, statewide sample to explore the experiences of families of Black CYSHCN accessing culturally responsive care. The most prominent theme that emerged from our analyses was family members' experiences of racism. Jones' (2000, 2003) levels of racism framework -- institutionalized, personally mediated, and internalized racism – provides a useful structure for understanding the families' experiences.

The inability to access to power is central to the perpetuation of institutionalized racism. Information is a source of power. In our findings, family members reported that health care providers did not respond to family members' requests for information (i.e., resources and services). Family members described having to independently gather information about their child's health conditions so they could advocate for needed care.

Family members experienced personally mediated racism when health care providers made comments or acted according to racial stereotypes, for example, allegations of child neglect and abuse, references to marital status, and reports to child protective services. They felt disrespected when their child's health care provider did not appear to value their concerns and thoughts about their child's care. These examples also suggest institutionalized racism because a health care system enabled its primary actors to carry out acts of personally-mediated racism. Individuals were enabled due to the differential distribution of power between the patient's family and the healthcare provider.

Institutionalized racism – "Differential access to the goods, services, and opportunities of society by race" (Jones, 2000, p. 1212). Differential access is shown through "material conditions and in access to power" (Jones , 2000, p.1212). The former is seen in access to safe, quality education, employment, environment, housing, and medical care; the latter includes information, resources, and voice (Jones, 2000).

Personally mediated racism – "Prejudice and discrimination, where prejudice means differential assumptions about the abilities, motives, and intentions of others according to their race, and discrimination means differential actions toward others according to their race" (Jones, 2000, pp. 1212-1213).

Internalized Racism – "Acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth, and is characterized by their not believing in others who look like them, and not believing in themselves" (Jones, 2000, p. 1213).

This power differential extended to the lack of representation of Black people in the healthcare workforce in Oregon.[3] Families reported experiencing difficulties trying to find Black healthcare providers because there were so few of them. This reflects institutionalized racism in the inequities in the access to medical or other allied health education for members of the Black community, particularly Black men (e.g., Charles, 2018; Harley, 2006; Laurencin & Murry, 2017). Furthermore, our findings showed that health care providers exhibited little to no understanding of specific health care needs of Black CYSHCN. This finding suggests that medical and other allied health care, as it currently exists, is not necessarily responsive to the care needs of Black people, and thus suggestive of institutionalized racism. That is, the finding suggests that health care trainees are not taught about health care conditions and needs specific to the Black community. Thus, in our study findings, families of Black CYSHCN described that they had to assume the responsibility for researching treatments, advocating in the health care setting to make sure their

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[3] Although analysis by the Oregon Health Authority (2018) shows that the gap between Oregon's Black population and the number of Black providers is relatively small, Black providers may not work in geographic areas that the Black population is able to access. Further, there is an overrepresentation of White providers for the size of Oregon's White population.

CYSHCN's needs are met, in addition to defending themselves against unwarranted allegations, and explaining the cultural background for their CYHSCN's health care needs to health care providers.

Families' descriptions of their experiences made clear that race influenced all of their interactions with the health care establishment. Ultimately, these experiences shaped families' distrust of the health care system, and diminished expectations for culturally responsive care, including finding Black health care providers. Some families expressed disbelief when asked about having encountered Black health care providers. Their explanations for their disbelief reflected both institutionalized and internalized levels of racism (Jones, 2000). Other studies showed similar findings. African American mothers of children with Autism Spectrum Disorder experienced covert and overt acts of racial discrimination, which implicated race as the reason for the differential treatment of themselves and their children by medical and educational professionals and required that the mothers be resilient advocates for their children (Lovelace, Tamayo, & Robertson, 2018). Black families of CYSHCN were less likely to report that they: received culturally-sensitive care; felt like a partner in their child's care; or received needed information from their health care provider (as compared to families of White CYSHCN) (Coker, Rodriguez & Flores, 2010). These racial disparities in health care quality and access were unchanged and persisted over time for children with developmental disabilities and autism spectrum disorders (Magana, Parish & Son, 2015).

Findings from our study contrast sharply with NSCH 2017-2018 results for Oregon CYSHCN younger than 18 years. NSCH results show that families of Oregon CYSHCN "always" or "usually" experience family-centered and culturally responsive care: 92% reported the provider showed sensitivity to family values and customs, 91% reported the provider listened carefully to the family, 90% reported the provider gave information specific to parent concerns, and 89% reported that the provider helped parents feel like a partner in their child's care (CAHMI, 2020). We cannot determine whether these NSCH quantitative findings are representative of the experiences of Black CYSHCN and their families in Oregon because of the small sample size (less than 30). Again, the findings from this qualitative study cannot generalize to all families of Black CYSHCN in Oregon. When juxtaposed with NSCH results, however, our current study's findings validate the importance of culturally-specific studies such as this, and suggest the need for improvements to the NSCH sampling methodology.

Transition from Pediatric to Adult Health Care

Prior to this study, little to no data existed to describe the needs and experiences of Oregon families of Black CYSHCN regarding the transition to adult health care. The most prominent theme that emerged from families' description of transition experiences for their YSHCN was that they needed to stay involved in their young adult's health care, even after the young adult turned 18. Some family members felt that their young adults were not prepared to handle the complex tasks involved in self-managing their own health conditions. This points to a lack of transition preparation. Some family members also described that they did not trust their child's health care provider to give the correct diagnosis or medication. This finding reflected their general distrust of the health care system. A fundamental barrier to family members' continued involvement in their young adult's health care is the patient privacy law that goes into effect at age 18. A small number of family members reported overcoming this barrier using a medical power of attorney or a release of information form. Thus, it appeared that the lack of transition preparation extended to a lack of information about supported decision-making and guardianship. Families of Black CYSHCN also reported not receiving transition support from the health care system. They did not get the help they asked for finding adult health care providers for their YSCHN.

These results align with those of the NSCH 2017-2018. Sixteen percent of Black CYSHCN ages 12 through 17 years old in the U.S. received services necessary to make transitions to adult health care compared to 21% of White CYSHCN (CAHMI, 2020b).[4] Although Oregon youth generally, and youth with special health care needs particularly, do not receive services necessary to transition (Roy et al., 2020), it may be that racism experienced by families of Black CYSHCN in health care settings exacerbates the challenges of transition, and the negative outcomes that result when it goes poorly (Gabriel et al., 2017; Schmidt et al., 2020).

Themes Relating to Trauma

Black CYSHCN and their families experienced trauma. Family members described their children's Adverse Childhood Experiences (ACE), and their own traumatic health care experiences. The ACEs most commonly discussed in focus groups were child neglect and abuse. Black children experience a disproportionately greater number of ACEs than White children. Sixty percent of Black children in the U.S. have had ACEs, versus 40% of White children. Black children represent 17.4% of all U.S. children who have had ACEs (Bethell et al., 2017), though they constitute only 13% of the population of U.S. children. ACEs can have lasting, negative effects on health, well-being, and opportunity. They can increase the risks of mental illness, substance misuse in adulthood. They are identified as leading causes of death with chronic illness (e.g., cancer, diabetes, heart disease) and suicide (CDC, n.d.).

Family members of Black CYSHCN recounted traumatic health care experiences. Family members described health care providers using coercive tactics to pressure them into using undesirable medical services (see *Parent Traumatic Health Care Experience* above). They expressed discomfort with and frustration towards health care providers as a result of these events. In some instances, family members who did not get appropriate health care had traumatic adverse outcomes, leading them to require more health care services. Traumas experienced by families of Black CYSHCN may contribute to health care disparities. For example, racism, stigma, and systemic inequities lead to disproportionate health outcomes and sustain health and healthcare inequities (The COVID Racial Data Tracker, 2020). The combined racial health disparities and distrust with the health care system may cause racial minority groups to forego care (The COVID Racial Data Tracker, 2020). If the health care system does not acknowledge Black families' traumatic experiences, there is a risk that Black adults will forego needed health care for themselves or their children.

We analyzed, interpreted, and wrote our findings around the time when awareness of health disparities experienced by Black people in the U.S. were reinforced by their higher COVID-19 mortality rates (The COVID Racial Data Tracker, 2020). The higher mortality rate highlights the fact that Black people suffer disproportionately from underlying medical conditions that exacerbate the disease (C.D.C, 2020). Simultaneously, the Black Lives Matter movement gathered momentum in the wake of Black people being killed at the hands of police in the United States. These events resulted in a nationwide call for reformation of the systems that perpetuate racial discrimination. Individuals of all races and ethnicities, and particularly White people, were asked to engage in anti-racism work at the individual, institutional, and societal level. The findings from our study provide evidence that families of Black CYSHCN experience racism within Oregon health care systems. Black CYSCHN are among our most vulnerable citizens. Acknowledging and addressing racism in the health care system is step towards racial justice.

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[4] These results are not available at an Oregon state level due to small sample size.

Community Reflections

SCAFO team members exclusively wrote the following section. This section describes their observations as they worked to implement the focus groups, and as they participated in the experiences of families sharing their stories and finding connection and support through the process of gathering and engaging in the focus groups.

- **Resilient Parents**- The persistence of parents and grandparents as advocates for their children and families was a powerful theme throughout all the group sessions and individual stories that were shared. The parents' stories provided guidance for others on how to persevere despite multiple barriers, and how to maintain a hopeful spirit when there was little external support for them and their children.
- **Family Stories Illuminated Known Inequities**- The stories of Black families' struggles against racism and bias to get quality health care and support for their children is familiar to those who share the lived experience of being Black in America. The stories shared by the parents were powerful in bringing these inequities to life in a way that makes it possible for those without similar lived experiences "know" and "feel" these inequities more deeply.
- **Sense of Community and Connection among Participants**- The cultural value of shared community and connect was readily observable as the focus groups convened. Focus group participants took the initiative to help one another feel at ease and connected; especially from elders to younger parents. Although parents consistently expressed the challenge of experiencing isolation and not knowing of viable options for finding support, they easily connected with one another in caring and supportive ways; building community even among families who had never met prior to the focus group. Extended family members and other community members also responded to the recruitment efforts. They expressed a shared interest in families from their community who have children with special health needs, and a desire to be supportive and helpful. Many were also personally connected with extended family members or friends who had children with special health needs. Outside of the scope of the formal assessment process, we also convened a community listening session to allow other members of the Black community to share their experiences and perspectives as it relates to focus areas of this study and report. Family and community members clearly conveyed the desire and need for an accessible space and resource to support Black families and children who have special health needs. These views were expressed consistently in every community that we visited throughout the state.
- **Intentional and Persistent Efforts Make A Difference**- In general, families were somewhat reluctant to believe that participating in a focus group would result in their voices being heard in a meaningful way. The combination of history of SCAFO in communities throughout the state, and the relationships and experiences of project team members with a broad cross section of Black families and community-based organizations gave credibility to the overall project in the eyes of Black community members. As outreach continued and more families participated, informal networks of community members began to encourage one another to respond to the focus group opportunities. Focus group participation in the Portland area tripled between the initial session and the final offering one month later.
- **Intergenerational Trauma**- The focus groups ended up also serving as an outlet for parents to voice their personal trauma in dealing with the health care system. People had three stories to tell: the stories of their children, the stories of themselves, and the stories of their parents, ancestors, and community. This study was not designed with an intent to capture these latter two stories, but as

they were being told, we realized the importance and value of allowing them to be voiced and heard by others. This was a healing experience for a number of parents who had not, up to that point, had an opportunity to be fully listened to.

Limitations and Recommendations

Few studies have explored health care access experiences of families of Black CYSHCN. Further, to the best of our knowledge, no studies have examined the experiences of families of Black CYSHCN with culturally responsive care (and certainly not in Oregon). We developed a descriptive study design that aligned with the exploratory nature of our research questions and was responsive to family culture. The primary limitation of our study design is that it does not allow us to generalize findings beyond the families of Black CYSHCN who participated in our study. Secondarily, our study does not reflect health care providers' perspectives. The study design and data collection, however, aligned with our study purpose to understand family experience and perspective.

Despite these limitations, our findings illuminate the need for improved access to family-centered and culturally responsive care for Black CYSHCN and their families. To ensure that all CYSHCN in Oregon receive care in a patient and family-centered medical home, it is imperative to ensure that Black CYSHCN and other CYSHCN of Color have access to family-centered and culturally responsive care. The following recommendations promote this goal.

1. OCCYSHN should work with SCAFO and other partners to disseminate these findings to state agency, health system, and family partners. OCCYSHN and SCAFO should schedule presentations with Oregon health systems to present the findings to clinic managers and providers.[5]
2. OCCYSHN should contract with culturally-specific service organizations to review Title V Block Grant cross-systems care coordination strategies to assess whether they are culturally responsive and sensitive, and to help modify strategies as needed. OCCYSHN also should contract with culturally-specific service organizations to find examples of culturally responsive care being provided within Oregon, and to promote those practices throughout Oregon's health care systems.
3. OCCYSHN should assess the culturally responsive/sensitive training and technical assistance (TTA) needs of LPHAs and their partners. Based on the results of this assessment, OCCYSHN should facilitate high quality TTA to LPHAs.
4. The Oregon Health Authority (OHA) should implement quality measures on health equity for health care providers to improve awareness and practice. Currently, OHA disaggregates Coordinated Care Organization incentive metrics by race and ethnicity to examine how population subgroups fare. The creation and implementation of health care equity quality measures for health care providers may help to improve clinical provider awareness and practice.
5. OCCYSHN should contract with culturally specific service organizations to ensure that transition to adult health care services are provided in culturally appropriate ways. Strategies should encourage health care providers to (a) initiate transition conversations with their patients with special health care needs beginning at least by 14 years of age, (b) help YSHCN learn skills to manage their own health conditions, and (c) work with families to prepare for changes that accompany their YSCHN turning 18, such as the potential need for supported decision-making or guardianship.

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[5] Such presentations should include the Latino Community Association and findings from its study with OCCYSHN. This study similarly found that Latino CYSHCN and their families experienced racism in Oregon health care systems (Gallarde-Kim, Bisso-Fetzer, Roy, et al., 2020).

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Appendix A. Additional Health-related Care Types Families Reported As Easy or Difficult to Access By Number of Focus Groups

Number	Easy to access	Number	Difficult to access
3	Medical specialists	4	General resources and supports
2	Dental Care	3	Black providers
2	Durable medical equipment (DME)	3	Diagnostic testing
1	Allied Therapy	3	Durable medical equipment (DME)
1	Development Disabilities (DD) services	2	Basic needs
1	Health care services in general	2	Culturally-specific supports
1	Recreation	2	Health care services in general
1	Telehealth	2	Medical transportation
		2	Primary care
		1	Allied Therapy
		1	Care coordination services
		1	Dental care
		1	Developmental assessment
		1	Egg-free flu vaccination
		1	Financial supports
		1	Health care insurance
		1	Non-faith based hospital
		1	Personal in-home support provider
		1	Respite care

CHAPTER FOUR

Escúchenos! Immigrant Latino Parents of Children and Youth with Special Health Care Needs in Central Oregon Share their Experiences Accessing Health Care

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Executive Summary

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) and the Latino Community Association (LCA) collaborated to collect data about the needs and experiences of immigrant families of Latino children and youth with special health care needs (CYSHCN). Specifically, we sought to learn about families' health and other support needs and their ability to access them; availability of care and supports that are responsive to the family's culture and language needs; and preparation for and experience with transitioning to adult health care. To meet these objectives, LCA conducted six focus groups with 22 parents or guardians of Latino CYSHCN. Of those, 15 were parents or guardians of children younger than 18 years old, and seven were parents or guardians of young adults ages 18 through 25. All focus groups occurred in the three counties that compose Central Oregon: Crook, Deschutes, and Jefferson. This region is primarily rural, although Deschutes County is home to Bend, Oregon's seventh most populous city (Portland State University Population Research Center, 2020)

In all focus groups, family members described experiences of racism. Family members described culturally-insensitive and discriminatory comments directed to them by health care providers. Family members described challenges they faced interacting with the health system because their primary language is Spanish, or because they belonged to a non-White culture. Family members reported challenges obtaining interpreter services. Requests for interpreters delayed appointments, and families reported frustration with interpretation quality. Race and language played a key role in determining the quality of care that Latino CYSHCN received.

When asked about their CYSHCN's needs, family members in all focus groups reported that their child needs or uses behavioral or mental health care. Family members reported that it was easy to access primary care and obtain health insurance coverage, and difficult to access medical specialists and allied therapy. They described access to care challenges such as a lack of providers and quality care locally, and long wait times for appointments. They said they had to advocate persistently to access services. Family members described a range of experiences with their child's healthcare when their child turned 18; they reported not being given warning that their child would need to transition to an adult provider and they expressed concerns about consistency of health insurance and care for their young adult.

Although our findings do not generalize to all immigrant families of Latino CYSHCN in Central Oregon, our needs assessment found that these families experience racism in Oregon's health care systems. To ensure that all CYSHCN in Oregon receive care in a patient-centered medical home, Latino CYSHCN and other CYSHCN of Color must have access to family-centered and culturally responsive care. Our report concludes with a set of recommendations that identify opportunities for Oregon Title V CYSHCN to collaborate with culturally-specific service organizations to promote culturally responsive care in Title V Block Grant strategies.

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Statement from Latino Community Association

Desde el año 2000, la Asociación de la Comunidad Latina ha sido un punto de encuentro esencial para nuestras familias inmigrantes latinas en Oregón Central. Nuestros programas incluyen: Capacitación laboral, Desarrollo familiar, Familias sanas, Desarrollo juvenil y Enriquecimiento cultural. Nuestra misión es capacitar a nuestras familias Latinas para prosperar creando oportunidades para progresar y construyendo puentes que nos unan y fortalezcan a todos. Tenemos nuestras sucursales en las comunidades de Bend, Redmond, Madras y Prineville en el estado de Oregon.

Since 2000, the Latino Community Association has been an essential connecting point for our immigrant Latino families in Central Oregon. Our mission is to empower our Latino families to thrive, creating opportunities for advancement and building bridges that unite and strengthen us all. Our programs include Workforce Education & Training, Family Empowerment, Healthy Families, Youth Rising and Cultural Enrichment. We have offices in Bend, Redmond, Madras and Prineville, Oregon.

About Oregon Center for Children and Youth with Special Health Needs

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) is Oregon's public health agency for children and youth with special health care needs. OCCYSHN partners with the Oregon Health Authority Public Health Division to implement Oregon's Title V Maternal and Child Health Services Block Grant. OCCYSHN's mission is to improve the health, development and well-being of all Oregon's child and youth with special health care needs.

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Foundational Terminology

The terms used in this report are defined as follows:

Racism – "A system of structuring opportunity and assigning value based on race that unfairly disadvantages some individuals and communities, unfairly advantages other individuals and communities, and undermines realization of the full potential of the whole society through the waste of human sources" (Jones, 2003, p.10).

Institutionalized racism – "Differential access to the goods, services, and opportunities of society by race" (Jones, 2000, p. 1212). Differential access is shown through "material conditions and in access to power" (Jones, 2000, p.1212). The former is seen in access to safe, quality education, employment, environment, housing, and medical care; the latter includes information, resources, and voice (Jones, 2000).

Personally mediated racism – "Prejudice and discrimination, where prejudice means differential assumptions about the abilities, motives, and intentions of others according to their race, and discrimination means differential actions toward others according to their race" (Jones, 2000, pp. 1212-1213).

Internalized Racism – "Acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth, and is characterized by their not believing in others who look like them, and not believing in themselves" (Jones, 2000, p. 1213).

Introduction

The National Survey of Children's Health (NSCH), administered by the U.S. Maternal and Child Health and the U.S. Census Bureaus, and OCCYSHN's five-year needs assessments are the primary sources describing the population of Oregon children and youth with special health care needs (CYSHCN).[1] NSCH results provide a wealth of information, yet results that generalize to CYSHCN often do not exist due to inadequate sample size. Results are further limited for CYSHCN who are Latino.[2] The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) routinely collects input from families when conducting its Title V legislatively-required five-year needs assessments; however, these results do not adequately describe the experiences of families of Latino CYSHCN, again because of small sample sizes. Therefore, to inform Oregon's 2020 Title V needs assessment, the Latino Community Association (LCA) partnered with OCCYSHN to collect data to answer the following questions:

1. What health (behavioral, oral, physical) and other care services do immigrant families of Latino CYSHCN need to care for their child?
2. What has been the experience of immigrant families of Latino CYSHCN attempting to access needed care?
3. What has been the experience of immigrant families of Latino CYSHCN in accessing culturally responsive care?

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[1] Children and youth with special health care needs "have or are at an increased risk for a chronic physical, developmental, behavioral, or emotional condition, and… require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138).

[2] LCA team members determined that we should use the term "Latino" for our project as that is the term that the community uses to describe itself.

4. What has been the experience of immigrant families of Latino CYSHCN in transitioning their child from pediatric to adult health care?

Methods

The LCA-OCCYSHN team (we) developed a focus groups data collection method to gather data to answer these questions. We co-developed the focus group discussion guide, which was translated into Spanish by an LCA team member. LCA team members recruited, screened for study eligibility, and arranged and conducted the focus groups in Spanish. Families were eligible to participate in the focus groups if (a) their child met the population definition of CYSHCN (McPherson et al., 1998) using a modified version of the accepted population identification method (Bethell et al, 2002), (b) their child's ethnicity was Latino, and (c) their child's age was younger than 26 years. Because we sought to learn about the experiences of immigrant families of Latino CYSHCN with transition from pediatric to adult health care, we organized focus groups according to child age (younger than 18 years, or 18 through 25 years). However, recruiting family members of young adults in the older age group proved challenging, so the age groups were combined.

LCA conducted six focus groups in Central Oregon with 22 adults who were parents or guardians of Latino CYSHCN. Of those, 15 were parents or guardians of children younger than 18 years old and seven were parents or guardians of young adults age 18 up to 26. In five focus groups, the seven parents or guardians of young adults were asked about their young adult's experience transitioning from pediatric to adult health care. An average of four family members participated in the focus groups, with a range of two to seven participants in each group. Three counties compose Central Oregon: Crook, Deschutes, and Jefferson. This region is primarily rural, although Deschutes County is home to Bend, Oregon's seventh most populous city (Portland State University Population Research Center, 2020)

LCA collected demographic questionnaires from all focus group participants. Ninety-five percent of family members were Latino/a (includes Hispanic or Latino Central American; Hispanic or Latino Mexican; Hispanic or Latino South American; Other Hispanic or Latino). The average age was 40 years, and 91% were the mother or father. Seventy-two percent reported having health insurance. On average, respondents completed 11 years of school, with a range of 5 to 17 years. The average number of people in the family member's household was five, and 63% reported having an annual household income of less than $34,999.

Results

We used a thematic approach to analyzing the data. Because the data that result from focus groups are the product of interaction among participants, the focus group is the unit of analysis by which we report results (e.g., seven focus groups described theme x). We identified a theme if an idea or experience was reported in at least half of the focus groups. When analyzing the data, we first identified overarching themes, or content that aligned with our four research questions: (1) types of health-related care needs, (2) access to care, (3) culturally responsive care, and (4) experiences transitioning from pediatric to adult health care. We then identified second tier themes within each of the four overarching themes; in some cases we also identified third tier themes within second tier themes. Discussion of these results follows.

Health-Related Care Needs

During each focus group, LCA asked family participants to describe the types of health-related care needs and supports that their CYSHCN currently or previously used or needed (see Exhibit 4.1). Family members in all groups (n=6) reported that their child needs or uses behavioral or mental health care. Similarly, in all groups (n=6), family members described their child needing or using primary care and specialty care services. In addition, family members frequently discussed need for or use of occupational, physical, sensory, or speech therapy (n=5). Exhibit 4.1 includes quotations that illustrate the most common care needs.

Exhibit 4.1. Health-related Care Need Types By Number of Focus Groups

Number of Focus Groups	Health-related Care Need Sub-themes
6	Behavioral/Mental Health Care: Need or use of behavioral, mental, psychiatric health services, such as behavioral therapy, assessments, psychologist, etc. *"… My daughter, who has all the diseases, is becoming very aggressive and began to develop aggressiveness. I try to talk to her, but she does not reason, she is a special girl so sometimes she does not reason and it is difficult … I am seeing that my daughter is developing aggressiveness. I have to talk to her specialist and tell her and that I do not understand why. Is there anything that uncovers aggressiveness in children? Because I am trying to understand, my daughter was a very sweet girl, she was very kind. The teachers tell me that she was a very sweet girl but lately not anymore, and I would like to know what takes the children to that level?"* (Focus Group 4)
6	Primary Care Providers (General Provider, Gynecology, Pediatrician): Need or use of primary care, including regular check-ups. *"… My one and a half year old boy was diagnosed with autism, but it is not such severe autism, so the services he receives right now is with the doctor, [the PCP] has been a very good doctor for us because he is the one that has put him in speech therapy, sensory therapy, years ago, like 8 years he was very active in these therapies. There were not as many services as we would have liked, because the therapies only lasted about 15 min, but those services that they have given him."* (Focus Group 6)
6	Specialists: Need or use of pediatric specialty or subspecialty care such as burn care specialist, cardiologist, ENT, geneticist, neurologist including seizure assessment and monitoring, specialists who work with Glass syndrome, eye surgeon, sleep apnea center, etc. *"My child is going to be four years old and his condition is a very rare condition, it is Glass Syndrome and his learning level is very slow, very, very low. He also does not eat through his mouth, does not speak, I give him food through a tube in his stomach."* (Focus Group 1)
5	Allied therapy: Need or use of occupational therapy, physical, sensory, or speech. *"I have a daughter who is now 10 years old, she is a burn survivor and she also receives services. She needs surgeries. She had an accident when she was two years old and had many skin graft surgeries and was in the hospital for several weeks. She was in and out of the hospital for several weeks and even now she still has surgeries for that situation. She received physical therapy, occupational therapy, and the services of a burn specialist surgeon"* (Focus Group 3)
4	Developmental specialists: Need or use of pediatric specialists or subspecialists to assess and care for Autism Spectrum Disorders, developmental and intellectual disabilities.

Number of Focus Groups	Health-related Care Need Sub-themes
4	Educational Support: Need or use of educational supports such as Early Intervention (EI) assessments and services or supports in primary or secondary schools.
4	Prescriptions: Need or use of prescription medication or transfusions.
3	Durable Medical Equipment (DME): Need or use of feeding tubes, crutches, machines, wheelchairs, etc.
3	Hospital / Emergency Department Visits: Need or use of hospital or Emergency Department services.
3	Nutrition services: Need or use of nutrition services such as a nutritionist.
2	Audiology and hearing care: Need or use of audiology assessments and hearing supports and services.
2	Family Support: Need or use of supports for the family, including parents/guardians or siblings
2	Vision supports: Need or use of vision supports such as an eye doctor.
1	Care Coordination: Need or use of communication and coordination among providers or team-based care.
1	Other Health Care Support: Need or use of other health care support and staff.

Access to Care

We asked family members to describe the ease or difficulty of getting the health care their child needed. The challenges that emerged across most focus groups were health insurance challenges, lack of local providers, poor care quality, long wait times to get services, and the need to advocate persistently to get care.

Health-related care services that are easy to access

In five focus groups, family members described the types of health-related services that they found easy to access. Family members in almost all of the focus groups (n=5) reported that their child was covered by health care insurance. Family members in nearly all groups (n=4) also reported that primary care was easy to access. Appendix A contains the list of services discussed in three or fewer focus groups.

"My daughter was born in Medford, and the legal guardian processed everything. My daughter in five days already had [health insurance coverage]." (Focus Group 1)

"For me it has been good to apply for OHP without a problem and I have tried to be a little disciplined when I should renew or when I should send the information they are requesting so they can continue to have coverage. So far I have not experienced any difference between my children having OHP coverage from the state than if they had private coverage." (Focus Group 3)

"My [child's] doctor is another pediatrician… she cares about children. She does call me as soon as they refer me to Portland. She takes care of calling them and gives me the references I have to have." (Focus Group 1)

"As they say here, the easiest [to access] is the pediatrician but for others it is very difficult." (Focus Group 4)

Health-related care services that are difficult to access

In all focus groups, family members described the types of health-related care services that they found difficult to access. Family members most often reported difficulty accessing medical specialists (n=6) and allied therapies (n=5). Allied therapies consist of occupational, physical, and speech therapy. Appendix A contains the expanded list of health care and other service types, which were discussed in fewer than three focus groups.

> *"So the other services that are difficult to access are the services for which you have to go to Portland. They are like the most specialized services; for example, because of sleep apnea (which is something very new for parents) we all have to be going to Portland."* (Focus Group 1)

> *"…it has been very difficult despite the fact that the doctor has supported us, because the doctor started helping us about 3 years ago, but from then on it did make it difficult for us to find therapies, because… they lasted very little, they were every 8 days, there were not so many services."* (Focus Group 6)

Access to care challenges

Family members described challenges they encounter getting health-related services for their child. The challenges consist of health insurance challenges, a lack of local providers, lack of quality care, long wait times for services, and the need to advocate to get their child needed care. Some family members described traveling outside of their community to access needed services, because their local community lacked providers and quality care. Exhibit 4.2 presents the number of focus groups in which the challenge theme emerged.

Exhibit 4.2. Access Challenge Type By Number of Focus Groups

Number	Type of Challenge
5	Health insurance challenges
4	Lack of providers locally
3	Lack of quality care locally
3	Long wait times to obtain needed services
3	Persistent family advocacy to access needed services

Health insurance challenges

Although family members frequently reported that their child was covered by health care insurance, they described experiencing challenges in five focus groups. They reported experiencing difficulty finding a provider within their child's insurance network, issues with certain services not covered by insurance, and challenges with health insurance representatives. The following quotations illustrate experiences described by families.

"…The dentist has been a bit complicated because they have a contract with certain dentists and sometimes you can't take them wherever you want because they don't have a contract with the state [insurance]…" (Focus Group 3)

"… Sometimes there are medicines that are expensive. The medical [insurance] cannot cover certain medicines, so they should provide the amount that does not matter what the medicine costs that they give it to all parents, not only for her… There are medicines that cost a lot of money and they don't want to give them to you." (Focus Group 6)

"Sometimes [the health insurance representatives] are mean. I don't think they are motivated to help people like us. There are a few people willing to help from the bottom of their hearts... Because sometimes they think they are superior because they have that job, and they think they have the right to treat us like that, and I get upset..." (Focus Group 7)

Additionally, one parent described experiences with providers preferring private insurance over public insurance, *"… I feel they look at what kind of insurance you have, if you have a good one or private one, the one you pay out of your pocket, then the first appointment available is for you. But since we have the state insurance, I could pay more for my girl to have both, but unfortunately I can't"* (Focus Group 1). This discrimination on the basis of insurance type illustrates how Latino families of CYSHCN can face intersectional discrimination (e.g., ethnicity and socioeconomic status) when accessing care.

Lack of providers locally

Family members in four focus groups discussed the lack of local providers and services. They described traveling outside of their community to access a needed provider. The following quotations illustrate experiences described by families.

"Everyone has to go to Portland, there's nothing here." (Focus Group 1)

"It has not been easy, but we tried to look for help… for her therapies… the doctors told me, 'you have to take her to Portland, are you going to go or not?'… you just tell me where and I'll take them." (Focus Group 7)

"…what they always say is that the state is a small state…there are not many doctors. Here what is needed in the state of Oregon is specialist doctors, who have the capacity to care, no matter where someone comes from, towns or counties… it was difficult for us when we arrived here in 2005… we were in [City, Out of State] and there that state did have enough. We realized that many things are missing here… When we started looking for help as we already knew my son had Autism… we regretted coming here… everything is very limited, and we would like to ask the government…for Oregon to support us. That they give more support, that they give more funds… because we do not know how many more children and more diseases are being found today, so that is what I would like more doctors, more medicine, I would like them to set up a workshop.…" (Focus Group 6)

Lack of quality care locally

In three focus group, family members described a lack of quality care in their community. Family members reported providers not following up after an appointment, providers not coordinating with each other, feeling that providers did not attend to child's needs, and local providers misdiagnosing their child. Additionally, some family members reported traveling outside of their community to access quality care. When family members described traveling outside of their community to access quality care, they most often referenced traveling to Portland. The following quotations illustrate experiences described by families.

“My daughter has down syndrome…as for all her doctors in Portland I am very happy to take her to Portland. I have had small details here with some providers… they are talking a lot about the sleep apnea… They sent her for evaluations here with a provider in Bend, but this provider told me that my daughter supposedly did not hear that she had apnea and that they had to operate and… put tubes because she could not hear. I said: ‘Do you know what? You are wrong, my daughter does hear and they just had her evaluated in Portland. I do not know why you said she can’t hear...’ So I worried a lot, my husband and I decided to take her to Portland. They did the sleep studies again… she has sleep apnea, but my daughter hears well. Then we decided that they would better treat her in Portland not here in Bend.” (Focus Group 1)

"For my son, my experience right now is being the best, because I took action. In Portland they have been helping me a lot, and everything I ask to be done they do everything. And I am happy to take it to Portland, although it is a little difficult to drive there, and more so in this time because of the snow. But the truth is I don't think I would go back to see the doctors here and leave [the doctors in Portland]." (Focus Group 5)

"It has been hard for me to take my daughter to her appointments, she needs a lot of services and some of them are here in Madras. For 2 years I took her 3 days a week to Bend and then to Portland. [Clinic] is in Portland. She needed therapy and I took her to Redmond but [Clinic in Portland] was better, I took her there just once a week. I'm pretty sure she would be more advanced if I would have had something like that here." (Focus Group 7)

Long wait times to obtain services

Family members in three focus groups reported experiencing long wait times for services. They described long wait times for a neurological evaluation, therapies, and specialists. One family member described a delayed diagnosis for their child. The following quotations illustrate experiences described by families.

“Since August, four months ago… the doctor there said that in about three weeks he had to have the [brain] evaluation done. He was going to talk to the pediatrician here and until now they have not called, I have asked, but they have not told us anything.” (Focus Group 1)

“… They take a long time to give you appointments where children need some therapy. Because it is from [the] government (the OHP) then you go and ask for an evaluation and they tell you it takes six months, but instead if you have private insurance they do attend [to] you quickly. But with OHP it takes six months to a year to [get] an appointment…” (Focus Group 4)

“Everything is complicated due to his blood, he suffers from nosebleeds. He just had surgery on his nose last week, we hope it will be the solution to stop bleeding. I already decided to take him to Portland because as I said, I did not like how [the local provider] treated me. If my son needed the quick service, it took three years for him to be diagnosed. When I took him to Portland... the doctor said: ‘Why did it take so long, a little longer and his red and white blood cells would no longer serve him anymore, and if it had taken longer, he could have had leukemia,’ just because I was here looking for the doctors and for them to tell me that they couldn't do anything for what my son doesn't have. And back in Portland they quickly detected the problem he had.” (Focus Group 5)

Persistent family advocacy to access needed services

In three focus groups, family members reported that they had to advocate persistently to get their child needed services. They reported a variety of ways they had to assert themselves within the health care system, including repeatedly calling their child’s school to access Early Intervention, having to “yell” or “be rude” to the provider to get an appointment for their child, or talking to their child’s principal about the lack of school support for her child's special needs. The following quotations illustrate experiences described by families.

"[My daughter] has seizures, and when she lacks of medicine she starts having small episodes and starts to wake up a lot at night. I called the doctor about four times to see if they could give me more medicine or if the doctor wanted to see her or call the pharmacy to give me more medicine to get through the month. They passed me from message to message and person to person. Until one day I called and said 'I want to know if the doctor wants to see her or [if he is going to] give me the medicine' and she said 'yes, I can give you an appointment in May' I said 'no, I already I have an appointment in February why would I need one in May?, I need you to fix this now'… I feel bad because sometimes I have to yell at them and be rude to the people who are working there…it is difficult especially with a child in special needs." (Focus Group 1)

"… I think [my daughter] needs another surgery… and [the doctors] say 'no, that she is fine.' I've been fighting with doctors; I need power because they ignore me..." (Focus Group 4)

"I had to go to 4 appointments, and take letters to the psychologist, psychiatrist, occupational, and speech therapists. They told me it wasn't good for her to take external therapies if at school they wouldn't help her… Early Intervention, the school district, and the state people had a meeting and all of them told me the same. I was alone with a blindfold over my eyes because I didn't know anything about my daughter's condition. I had to do my own research through the internet… I told myself, this is not ok and you have to look for help and assistance. I was with the pediatrician insisting and insisting, letter after letter. Every year when my daughter started [school], they never had anything about her condition, so I had to collect all the information from the psychiatrist and send everything again. For me, dealing with the school has been the worst part of the process. You basically need to be alert and fight for the assistance..." (Focus Group 7)

Culturally Responsive Health Care

During each focus group, LCA asked family participants to describe their experiences accessing culturally responsive care for their child. Two second tier themes emerged from the data: Experiences of Racism (n=6) and Interpretation Issues (n=5). A description of each theme follows.

Experiences of Racism

In all six focus groups, family members reported experiencing racism in the health care system. For example, family members and children were subjected to culturally-insensitive and discriminatory comments. These comments made families feel that the environment was hostile, and that their concerns for their child were not taken seriously. One family member described that they did not receive family-centered care; the provider did not take into consideration that they were members of a non-dominant culture, and may not be familiar with therapies like speech and occupational therapy.

"I have noticed certain things; for example, when I had my daughter in speech therapy, occupational, at first it was something new for me. I had never needed that before nor had it been such an open topic for me because I was not familiar. So sometimes I needed more information because it was different because of my culture and what I was used to… although the language was no problem, I felt that there was something else. They assumed that I already had to know." (Focus Group 3)

"…when my daughter had surgery on the arteries that had clots, the doctor said it 'is that you are Hispanic and Hispanics invent diseases.'[3] *And my daughter was dying because of the clot she had, and they sent her home."* (Focus Group 4)

"…A few years ago when he was at school, he wore diapers… he's chubby, one of the nurses was changing his diaper… told him 'I'm pretty sure you eat just Mexican food, that's why you are the way you are.' I was like 'in what world could she even say that to my son?' She was American, and I think is discrimination." (Focus Group 7)

Experience of family members facing language and cultural barriers with care providers

Family members described facing challenges interacting in health systems because they did not speak English, or because they belonged to a non-dominant culture. Family members described feeling nervous and discouraged that they did not have an opportunity to express themselves in the language they felt most comfortable speaking. Some family members described that their children or other family members who spoke English helped them with interpretation. One family member felt uncomfortable asking for interpreters because they anticipated they would face discrimination as a result of the request. These instances contributed to the racism experienced by immigrant Latino families in Central Oregon.

"For me it's very, very difficult because I don't speak any English. Call to a place where they do not speak Spanish and I do not speak English it has been difficult. As I said, my husband is the one who calls everywhere because he is the one who speaks a little English. I almost always ask my friend Carolina, and she tells me where to call to talk to someone in Spanish." (Focus Group 3)

"It has always been difficult to get help for my children because I always depend on a person to do something. I cannot fight for my daughter because if she is going to be my interpreter she will not translate as if I am angry, and she always tells me that she is going to say how she can but it does not convey that I am angry and frustrated and that they need to listen to me!" (Focus Group 4)

"There have been other occasions, such as when we go to a blood test, and we see that there is no interpreter, and sometimes we get discouraged, we better not ask because we already know that they are going to answer us ugly." (Focus Group 7)

Issues with interpretation

Five of the six focus groups discussed this second-tier theme. Family members talked about challenges getting interpretation services. Requests for interpretation services delayed the availability of appointments. Family members also expressed dissatisfaction about the quality of interpretation. They felt that interpreters left out important information and did not convey nuances such as the tone of the conversation. This interfered with the development of a productive provider-family relationship.

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[3] Latino community members in Central Oregon would not use the term "Hispanic" to describe themselves. In this example, the term "Hispanic" was used by a health care provider and, given the term's origins, contributed to personally mediated racism.

"My neurologist does not have an interpreter either, and if you ask for an interpreter they take longer to [schedule] the appointments. If you don't need an interpreter, they give it to you faster." (Focus Group 1)

"….It has been harder for me because of the language… I do not speak English to understand all my children's illnesses because I am depending on a person who speaks English or translates it and sometimes they do not say what one is saying. They say things that one didn't say or they don't tell you what the doctor says." (Focus Group 4)

"…. I asked a doctor if he could do an evaluation for my son… I told him in Spanish, 'please doctor, would it be possible to do an analysis of the liver for my son, because he says it hurts?' But then the interpreter told [the doctor] as an order, not as something I was asking him for, so the doctor got angry because he said that I couldn't know more than him [and was] sure it wasn't the liver." (Focus Group 6)

Family-centered care

In all six focus groups, family members described positive, family-centered experiences with specific health care and educational providers. However, these experiences of family-centered care were not the typical experiences of immigrant Latino families.

"For me, I have a good relationship with my son's doctor. Dr. [name] is a very good doctor, very patient. Dr. [name] is the psychologist who speaks pure English, but he has also had a lot of patience, he has given us a lot of opportunity to go and talk to him. For me they have been good experiences." (Focus Group 4)

"The teacher she had was a good disability specialist teacher. The teacher paid a lot of attention to her. My daughter was happy even with the assistant, my daughter was very happy. And I know they welcomed her well, and she understood in English." (Focus Group 5)

"He is a very great, good doctor, he supports everything. Sometimes when my son needs an appointment, he says I have many patients but I will do my best, bring him to me in the afternoon I will do my best, no matter." (Focus Group 6)

Transition from Pediatric to Adult Health Care

Of the six focus groups conducted by LCA, five groups included a total of seven family members of young adults with special health care needs ages 18 through 25 years. These family members described a range of experiences with their child's healthcare when their child turned 18, but we did not achieve saturation, or the point where analysts gain no further new insights, to enable us to identify themes in responses (Krueger & Casey, 2009). The results do, however, provide initial understanding of the experience of transition to adult health care for Latino CYSHCN living in Central Oregon.

Family members reported not being given warning that their child would need to transition to an adult provider. Family members expressed concerns about consistency of health insurance and care. Family members also described difficulties engaging with their child as a young adult. Exhibit 4.3 presents a full summary of family concerns and experiences.

Exhibit 4.3. Transition to Adult Health Care Concerns and Experiences by Focus Group

Focus Group	Type of Experience
1	• Parent experienced difficulty answering adolescent questions of why the health condition happened to the adolescent.

Focus Group	Type of Experience
3	• Parent was not given referrals for insurance for their child after public insurance ended when their young adult turned 18. • Parent has concern about young adult losing their health insurance and paying for $5,000/month medications; young adult previously insured through Cover All Kids.
4	• The young adult's physical size combined with their conditions presents threat to parent's physical safety. • Young adult's behavior has resulted in neighbors calling the police; parent has to share information about the young adult's condition with neighbors so that they do not call the police.
5	• Parent found it difficult to accept that their child is an adult. • Parent found it difficult to accept that they would have to "start over from scratch" in identifying and working with new adult providers. • Parent experienced no changes. The same provider who worked with child as a pediatric patient will work with young adult as an adult patient. • Parents were given no, or one month's, notice about pediatric care stopping.
7	• Parents have inconsistent information about whether they can get paid for caring for their over 18 year old young adult and other available supports. • Parent has concern about young adult losing their specialists when turn 21. Parent was given advance notice. • Parent expressed concern about state law that allows 14 year old children to decide that they do not want to work with a psychologist, even if the child needs mental health care. • Parents heard through word of mouth with other parents that they should do all they can to obtain services for their child [before 18], because "when they're older, [health care providers] will forget about them." Young adults will lose support, and providers will not listen to families. • Parents were given no, or one month's, notice about pediatric care stopping.

Discussion

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) collaborated with the Latino Community Association (LCA) to better understand the care needs and experiences of immigrant families of Latino CYSHCN in Central Oregon. We sought to answer four research questions: (1) What health-related care (behavioral, oral, physical) services do immigrant families of Latino CYSHCN need to care for their child, (2) What has been the experience of immigrant families of Latino CYSHCN attempting to access needed care, (3) What has been the experience of immigrant families of Latino CYSHCN in accessing culturally responsive care, and (4) What has been the experience of immigrant families of Latino CYSHCN in transitioning their child from pediatric to adult health care? Discussion of findings for each of these questions follows.

Health-Related Care Needs

The types of health-related care needs reported by immigrant families of Latino CYSHCN is consistent with those reported by families of Oregon CYSHCN generally. Most notably, all six focus groups reported that behavioral/mental health care, primary care, and specialty care and support were needed for their CYSHCN. In addition, allied therapies (i.e., occupational, physical, sensory, or speech therapy) were noted to be an important need among Latino CYSHCN. The behavioral/mental health findings align with quantitative NSCH results describing the population of Oregon CYSHCN. For example, 45% of Oregon CYSHCN had ongoing emotional, developmental, and behavioral conditions, which is similar to national results (44%; CAHMI, 2020). In addition, 40% of CYSHCN received counseling from a mental health professional (CAHMI, 2020). We lack current quantitative data describing the needs of the population of Oregon CYSHCN for allied therapies. However, OCCYSHN's 2015 needs assessment family results showed that CYSHCN very commonly need these services: 65% of respondents reported that their child needed occupational therapy, 38% reported physical therapy, and 65% reported speech therapy (Martin, 2014).

Care Access Experiences

Family members reported that primary care and health insurance coverage were easy to access, although medical specialists and allied therapies were not. Although this study's results do not describe the extent of this difficulty for all families of Latino CYSHCN – or the disparity in access between families of Latino versus White CYSHCN – the current study's findings align with those of OCCYSHN's 2015 needs assessment. The 2015 results showed that 39% of family survey respondents identified specialty medical care as one of the top three health care needs they had difficulty meeting for their child (Martin et al., 2015).

Additionally, we found that immigrant families of Latino CYSHCN often experienced challenges with inadequate health insurance coverage, long wait times for services, lack of local quality care, and a lack of needed providers. Similarly, Zuckerman (2015) found that Latino parents of children with Autism Spectrum Disorder (ASD) described the ASD diagnostic process as complex, slow, and disjointed. They experienced long waits for care, and a lack of communication among providers involved in the child's care. Family members' descriptions of a lack of quality care locally included providers who failed to coordinate with each other. The current study's findings also align with findings from our 2015 needs assessment in that a majority of family survey respondents reported that it is at least sometimes difficult to obtain appointments as quickly as needed, and 47% of family survey respondents reported "rarely" or "never" receiving as much help as they wanted arranging or coordinating their child's care. (Martin et al., 2015).

Culturally Responsive Care

The most prominent theme that emerged from the focus groups discussions with immigrant Latino families of CYSHCN in Central Oregon was experiences of racism in the health care system. This includes experiences of institutionalized and personally mediated racism (Jones, 2000). Immigrant Latino families in Central Oregon faced barriers to accessing care for their CYSHCN, which suggests that the medical setting was not equipped to provide care responsive to Spanish-speakers and patients/families who did not belong to the dominant culture. Family members described needing more information about their child's care than was provided by their health care providers. Information, or knowledge, is a form of power (Jones, 2000; Mondros & Wilson, 1994); inhibiting families from accessing information about their child's health prevents them from accessing power to care for their child and perpetuates *institutionalized* racism. Families also experienced institutionalized racism when inadequate interpretation services gave them unequal access to information. Interpreters

Institutionalized racism – "Differential access to the goods, services, and opportunities of society by race" (Jones, 2000, p. 1212). Differential access is shown through "material conditions and in access to power" (Jones, 2000, p.1212). The former is seen in access to safe, quality education, employment, environment, housing, and medical care; the latter includes information, resources, and voice (Jones, 2000).

Personally mediated racism – "Prejudice and discrimination, where prejudice means differential assumptions about the abilities, motives, and intentions of others according to their race, and discrimination means differential actions toward others according to their race" (Jones, 2000, pp. 1212-1213).

were not always readily accessible. When they were available, interpreters left important details out of conversations between family members and providers. Families reported dissatisfaction and frustration at being unable to express themselves clearly. Lacking information about the child's health and care needs may result in poorer health outcomes for Latino CYSHCN. For example, Mosquera, Samuels, and Flores (2016) found that when bilingual providers or trained interpreters were unavailable, it decreased the quality of care and parental satisfaction of Non-English Primary Language families and led to serious consequences for the health of CYSHCN.

Family members also experienced *personally mediated* racism through blatant culturally insensitive, discriminatory comments and invalidation of their concerns from health care providers. This created an unsafe, hostile space for Latino family members, who described feeling nervous, discouraged, and uncomfortable in medical settings in anticipation of discriminatory actions from health care providers and lack of support in expressing their needs.

In addition to receiving care from health care systems founded in white supremacy, the overall gap in health care providers who identify as Latino further contributes to an inability to access culturally responsive care. The Oregon Health Authority (2018) found that the ethnic and racial diversity of the health care workforce has not kept pace with the changing ethnic and racial diversity of Oregon's population. The greatest gap between the ethnicity and race of Oregon's population and health care providers in the state is for the Latino community: 12.4% of Oregon's population identifies as Latino, in contrast to only 5.2% of the health care workforce identifying as Latino. In addition, professionals who are Latino are more often represented in health care positions that require fewer licenses (OHA, 2018).

Overall, our findings suggest that Latino CYSHCN and their families in Central Oregon do not receive culturally responsive and family-centered care. These are foundational components of a medical home.

Transition from Pediatric to Adult Health Care

Oregon CYSHCN do not receive services necessary to transition to adult health care; only 16% of youth with special health care needs ages 12 through 17 years received *at least one* of the three services needed (Roy, Vega-Juárez, Gallarde-Kim, & Martin, 2020). When national NSCH results are disaggregated by ethnicity, about the same percentage (15%) of Latino youth with special health care needs received services necessary to transition. This percentage, however, is lower than that of White youth with special health care needs (21%) (CAHMI, 2020).[4] Reports from family members who participated in our focus groups indicate that they did not receive warning that their child would need to transition to an adult provider. Family members expressed concerns about consistency of health insurance and care when their child turned 18 years old. They also described difficulties they experience as their child develops into a young adult and increases in physical size. These experiences are similar to those described by families of CYSHCN during Oregon Family-to-Family Health Information Center listening sessions.

Community Reflections

LCA team members exclusively wrote the following section. This section describes their experience conducting the focus groups, emotions observed during the focus groups, and working with immigrant Latino families in their community.

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[4] These results are not available at an Oregon state level due to small sample size.

At the beginning of this collaborative research project with the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), our project team of three at the Latino Community Association (LCA), of course, held a few assumptions. We assumed that our immigrant Latino parents with special needs children would experience many barriers in accessing health care for their kids. We were not surprised that they faced language barriers or that their experiences working with interpreters was mixed – sometimes great and sometimes awful - with their kids or relatives often filling this role. We were not surprised to hear that it was difficult, especially for the parents with children who will never speak and who cannot walk or fend for themselves. And we were not surprised that Central Oregon is void of many of the specialists whose services their children require.

What we did not anticipate was the degree to which parents are exhausted, chronically anxious and oppressed by the isolation they experience and the hopelessness they often feel. We did not expect the parents to shout out for emotional and psychological support, not only for themselves, but for their other kids. We never considered the impact on the siblings, the brothers and sisters, of kids with special needs. Of course they gain invaluable experience that will likely serve them for the rest of their lives, but they inevitably lose the attention the parents have to give to their special needs siblings - and their childhoods, in some cases, are taken from them as they are regularly obligated to fill the roles of caretaker, interpreter and surrogate parent.

We learned that these parents are strong, caring, dedicated and loving people. Their deep love and endurance are legendary. We learned that it is of great benefit to them (and to us) to have opportunities to vent and express their worries, frustrations and dreams. They were grateful for the experience to share and that we care enough to listen. They carry a great burden, and they expressed joy in meeting with other families facing similar challenges and saw hope in the possibility of supporting each other. We learned that our health care providers in Central Oregon, with just a couple extraordinary exceptions, are ill-equipped to serve these families the way they deserve to be served. They are made to feel that they are a burden on the providers who show with their body language, and sometimes their words, that they are not very happy to see them when they arrive.

Some parents spoke of having to be loud and, basically, mean to get the provider's attention. They said it was hard to get the provider to take them seriously – that they often felt ignored and their observations and concerns were not valued. Because of this, they felt doctors often diagnosed their kids much later than they should have, which they believe worsened their child's chances of getting better and living a more normal life. At least half of the parents we spoke with gave the very clear impression that they were made to feel "less than" by the doctor or other medical staff. This was probably the saddest and most unnerving revelation – that not only did they endure the hard work of caring for a special needs child, but they also had to endure a healthcare system that more often than not invalidated their lived experience and their insights about their children. Portland was the exception. Care providers and specialists in Portland were uniformly spoken highly of and with endless gratitude. There they were welcomed with open arms and genuinely friendly gestures.

This community-based research experience has opened our eyes and expanded our awareness. We knew there were immigrant Latino families with special needs children in our region, but we had no idea how many or to what degree they need our community's support. As the focus groups facilitators, we felt privileged to be trusted by the families to hear and to pass on their stories. We felt sadness, joy, pride and anger as they shared the many challenges they face accessing healthcare. We believe that in a region with over 200,000 inhabitants, our health care system ought to be able to provide more of the services these families need locally to save them the time and expense of having to travel to Portland. We need to make sure our health care providers are aware of their experiences and that they recognize the value and importance of providing culturally responsive healthcare. We need to make sure investments are made to improve services for these families closer to the communities where they live. This report is an important first step in the right direction. ¡Escúchenos! Let's listen to their voices and take action.

Limitations and Recommendations

To the best of our knowledge, no studies have examined access to culturally responsive care for families of immigrant Latino CYSHCN. Certainly it has not been studied in Oregon. We developed a descriptive study design that aligned with the exploratory nature of our research questions and was responsive to family culture. The primary limitation of our design study is that it does not allow us to generalize findings beyond the immigrant families of Latino CYSHCN who participated in our study. Due to the current political climate and fears of deportation in the community, we experienced challenges recruiting focus group participants, particularly families of young adults with special health care needs. Finally, this study describes the family experience and perspective well, but it does not represent those of health care providers. Further research is needed to obtain their perspective.

Despite these limitations, our findings illuminate the need for improved access to family-centered and culturally responsive care for immigrant Latino CYSHCN and their families. To ensure that all CYSHCN in Oregon receive care in a patient and family-centered medical home, it is imperative that Latino CYSHCN and other CYSHCN of Color have access to family-centered and culturally responsive care. The following recommendations promote this goal.

1. OCCYSHN should work with LCA and other partners to disseminate these findings to state agency, health system, and family partners. For example, OCCYSHN and LCA should share findings with the Oregon Health Authority (OHA) Office of Equity and Inclusion's Health Care Interpreter Training Program to help improve access to highly qualified professional interpreters. OCCYSHN and LCA should schedule presentations with Oregon health systems to present the findings to clinic managers and providers.[5]
2. OCCYSHN should contract with culturally-specific service organizations to review Title V Block Grant cross-systems care coordination strategies to assess cultural responsiveness and sensitivity, and to help modify strategies as needed. OCCYSHN also should contract with culturally-specific service organizations to find examples of culturally responsive care being provided within Oregon, and to promote those practices throughout Oregon's health care systems.
3. OCCYSHN should assess the needs of its local public health authority partners for cultural responsivity/sensitivity training and technical assistance (TTA). Based on the results of this assessment, OCCYSHN should facilitate high quality TTA to LPHAs.
4. OHA should implement quality measures on health equity for health care providers to improve awareness and practice. Currently, OHA disaggregates Coordinated Care Organization incentive metrics by race and ethnicity to examine how population subgroups fare. The creation and implementation of health care equity quality measures for health care providers may help to improve clinical provider awareness and practice.

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[5] Such presentations should include the Sickle Cell Anemia Foundation of Oregon and findings from its study with OCCYSHN. This study also found that Black CYSHCN and their families experience racism in Oregon health care systems (Gallarde-Kim, Smith, Roy, et al., 2020).

5. OCCYSHN should contract with culturally specific service organizations to ensure that transition to adult health care services are provided in culturally appropriate ways. Strategies should encourage health care providers to (a) initiate transition conversations with their patients with special health care needs beginning at least by 14 years of age, (b) help youth with special health care needs learn skills to manage their own health conditions, and (c) work with families to prepare for changes that accompany their YSCHN turning 18, such as the potential need for supported decision-making or guardianship.

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Appendix A. Ease or Difficulty of Accessing Health-related Care Types Described in Fewer Than Half of the Focus Groups

Number	Easy to access	Number	Difficult to access
2	Allied therapy	2	Behavioral/mental health care
1	Basic needs	2	Condition-specific support
1	Dental care	2	Developmental assessments (learning disability, autism)
1	Durable Medical Equipment (DME)	2	Educational supports
1	Educational supports	2	Specialized evaluations (sleep study, neurological evaluation)
1	Emergency department	1	Basic needs
1	Local community-based network of health clinics	1	Diagnostic testing (MRI)
1	Mental health care	1	Disability services
1	Nutrition services	1	Durable medical equipment (DME)
1	Specialty care after obtaining health insurance coverage	1	General resources and supports for CYSHCN
1	SSI	1	Habilitative care
1	Visiting specialists from Portland	1	Health care insurance
		1	Health care services in general
		1	Medical transportation
		1	Pharmacy
		1	Primary care (Pediatrician, gynecology)
		1	Recreation
		1	SSI
		1	Supports for parents and family

Oregon Center for Children and Youth with Special Health Care Needs
Title V Needs Assessment
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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

Alison J. Martin, PhD, and Raúl Vega-Juarez, BS[1]

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.

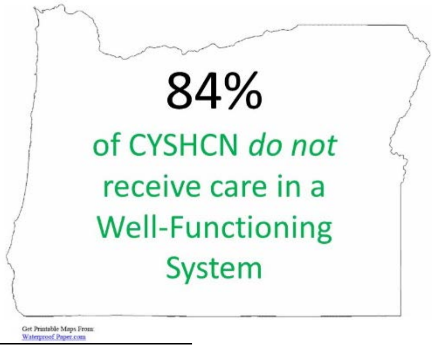

Exhibit 5.1. Elements of A Well-Functioning System for CYSHCN

- 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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[1] Suggested citation: Martin, A.J., & Vega-Juarez, R. (2000). *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.* Portland, OR: Oregon Center for Children and Youth with Special Health Needs.

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.[2]

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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[2] 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.

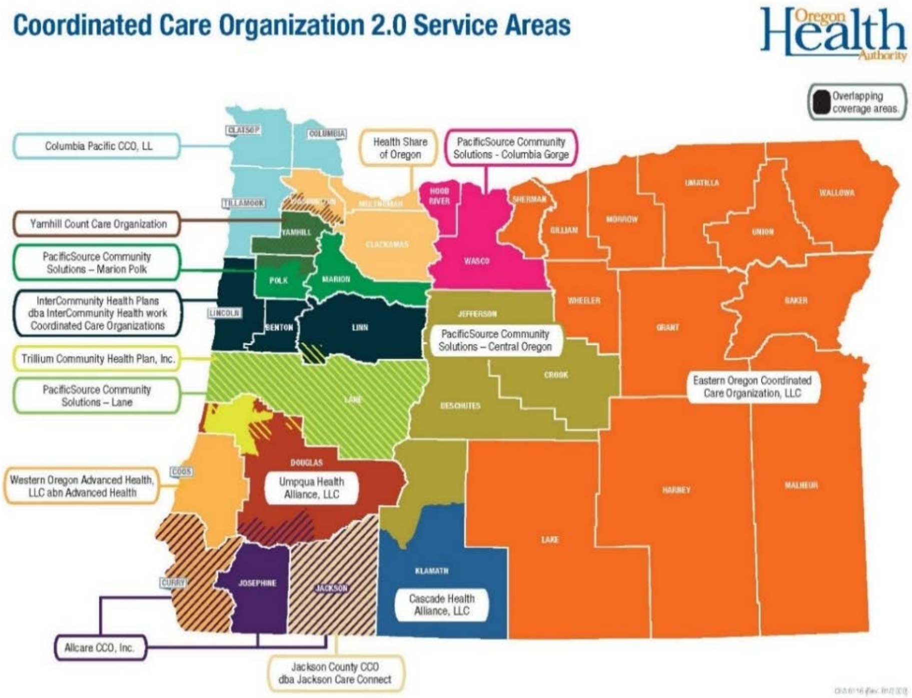
Two CCOs (AllCare Health Plan and Cascade Health Alliance) performed below the state average on *four of the five* CCC areas of care. Two other CCOs (Trillium Community Health Plan and Umpqua Health Alliance) performed below the state average on *three of the five* CCC areas of care. Prior to January 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%	• AllCare Health Plan • Columbia Pacific • Trillium Community Health Plan • Umpqua Health Alliance
Access to Specialized Services	69%	83%	48%	• Cascade Health Alliance • Columbia Pacific • Eastern Oregon CCO • Fee For Service • Jackson Care Connect • Primary Health • Trillium Community Health Plan
Getting Needed Information	91%	96%	87%	• Advance Health • AllCare Health Plan • Cascade Health Alliance • Eastern Oregon CCO • Umpqua Health Alliance
Personal Doctor Who Knows Child	87%	94%	78%	• AllCare Health Plan • Cascade Health Alliance • Health Share • InterCommunity • Jackson Care Connect • Pacific Source – Central Oregon • Trillium Community Health Plan
Coordination of Care	78%	87%	66%	• AllCare Health Plan • Cascade Health Alliance • Fee For Service • Health Share • Pacific Source – Columbia Gorge • Primary Health • Umpqua Health Alliance

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[1]	Unmet Needs Score[2]	County Location[3]	Travel Time to Nearest PCPCH[4]	Primary Care Capacity Ratio[5]	Dentists per 1,000[6]	ED Dental Visits per 1,000[7]	Mental Health Providers per 1.000[8]	ED Mental Health Visits per 1 000[9]	138-200% of FPL[10]	Prev. Hosp. per 1,000[11]	2019 County Child Popn[12]
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).

[1] All of these communities have a “rural” geography designation.

[2] Lower scores indicate greater unmet need. The lowest (worst) score possible is 0; the highest (best) score possible is 90.

[4] 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).

[5] 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.

[6] Comparison of local dentist patient care FTE to the local population.

[7] “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).

[8] 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.

[9] "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).

[10] "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%).

[11] "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).

[12] 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.[3] 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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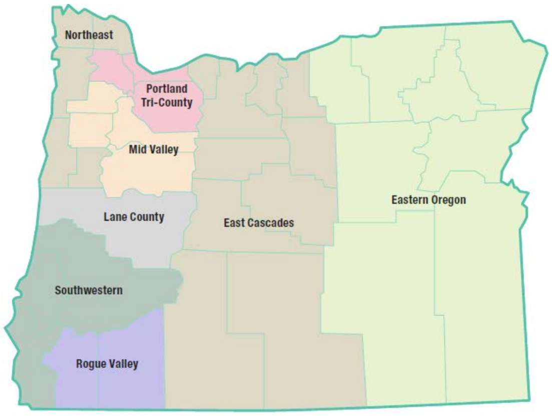
[3] These reports are not specific to pediatric providers.

> *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.[4] 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 psychiatists are the one group of behavioral healthproviders 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 analysies 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%

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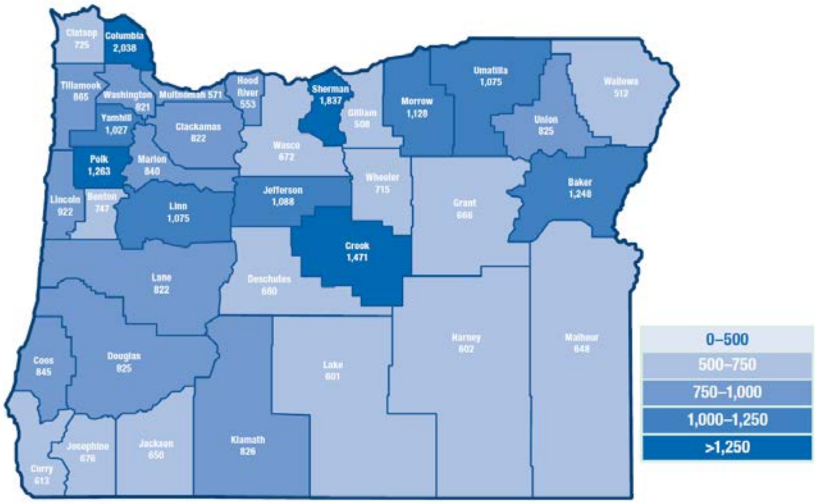
[4] Licensing boards collect data describing demographic characteristics of professionals at the time of license renewal; therefore, the results do not describe all currently active licensed professionals in Oregon (OHA, 2018).

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).

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.

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.

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).[5] 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

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[5] 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 betetween 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[a]	Number of Services Areas Below State Average	Primary Care Capacity Ratio[b]	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).

[a] 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.

[b] 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).*[6]
- *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,*

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[6] 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.[7] 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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[7] 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.[8] The audit found that "only 33.4% of children eligible for [Early Intervention and Early Childhood Special Education] services received the recomneded 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 resistence 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 resistence 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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[8] Based on the Fall enrollment for the 2018-2019 school year (581,730 students kindergarten through 12th 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 inlcuded 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 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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Title V Needs Assessment
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CHAPTER SIX

Stakeholder Feedback on Title V Priorities for Children and Youth with Special Health Care Needs

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Stakeholder Feedback on Title V Priorities for Children and Youth with Special Health Care Needs

Oregon Title V Needs Assessment Chapter 6: Children and Youth with Special Health Care Needs

Raúl Vega-Juárez, B.S. and Alison J. Martin, Ph.D.[1]

OCCYSHN solicited input on Oregon's 2021-2025 national, state, and emerging block grant priorities for CYSHCN from a group of 43 stakeholders. Family members of CYSHCN, culturally-specific service organization staff, and mid-level local public health authority (LPHA) managers from 32 Oregon counties composed the stakeholder group. Thirty of the stakeholders participated (70% of those invited).

Stakeholder Request

OCCYSHN proposed prioritizing medical home and transition to adult healthcare for 2021-2025, as we did from 2016-2020. We asked stakeholders a short set of questions to gauge the extent of their agreement with our proposal. We summarize our rationale for the proposal and the stakeholder responses below.

Medical Home Rationale and Input

The American Academy of Pediatrics described a medical home as a practice that ensures care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective (AAP, 2002). Oregon's Patient-Centered Primary Care Home (PCPCH) Program encourages clinical practices to achieve Oregon's medical home standards. OCCYSHN coordinates with partners to advocate for inclusion of pediatric standards that would benefit CYSHCN. Care coordination is foundational to medical home, and it is essential for CYSHCN and their families (AAP Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee, 2014). In addition, standards of systems of care that serve CYSHCN and their families assert that the team of family and professionals who provide care to CYSHCN ought to provide coordinated care (AMCHP & NASHP, 2017). Cross-systems care coordination addresses interrelated medical, dental, mental and behavioral, social, educational, and financial needs to achieve optimal health and wellness outcomes (MCHB, 2017).

OCCYSHN's 2015 Needs Assessment pointed to a unique opportunity to promote care coordination for CYSHCN through partnerships with LPHAs for the 2016-2020 block grant cycle (Martin, Gallarde, & Hartzell, 2015). OCCYSHN specifically focused medical home strategies on providing CYSHCN with family-centered, cross-systems care coordination; that is, coordinating care among families, health, education, and community service providers. Our strategies align with PCPCH Program Standards, elements of Oregon's Public Health Modernization, and Early Learning Hubs' direction to ensure that care is coordinated for young children.

National Survey of Children's Health (NSCH) 2016-2017 results suggest that Oregon CYSHCN still do not receive effective care coordination and referrals when needed (CAHMI, 2020). Additionally, families of Black and Latino CYSHCN described many challenges getting health care services for their CYSHCN. For example, Black families reported that they had difficulty accessing behavioral and mental health and

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specialty care services (Gallarde-Kim, Smith, Roy, et al., 2020). Some Black families reported that they had to persistently advocate to get services for their CYSCHN (Gallarde-Kim, Smith, Roy, et al., 2020). In some instances, health care providers did not accept their insurance, or the services they needed were not covered by their insurance (Gallarde-Kim, Smith, Roy, et al., 2020). Families of Black CYSHCN also reported encountering racial stigmatization (e.g., stereotyping, labeling, etc.) (Mendible, 2019) in the health care system, which exacerbated the difficulty of getting services for their child (Gallarde-Kim, Smith, Roy, et al., 2020). Families of Latino CYSHCN in Central Oregon described long wait times for appointments, and a lack of local providers and quality care (e.g., misdiagnosis, lack of attention to child's needs, lack of follow up after appointments) were impediments to getting the care their child needed (Gallarde-Kim, Bisso-Fetzer, Roy, et al., 2020). Like families of Black CYSHCN, families of Latino CYSHCN reported that they had to persistently advocate for their child to get services, and that they experienced racial stigmatization in health care settings (Gallarde-Kim, Bisso-Fetzer, Roy, et al., 2020).

Our cross-systems care coordination strategies seek to change the way that the partners in the system of care for CYSHCN communicate and engage with one another. Such changes require time. We have made great strides with our partners since we initiated these strategies in 2016-2017. We would like more time for organizations to test and implement change to improve care coordination for children and families. Therefore, we proposed keeping medical home as a Title V strategy for CYSHCN for the 2021-2025 block grant cycle.

We asked stakeholders to rate the extent to which they agreed with keeping medical home as a national priority using a zero to five rating scale based on the Fist to Five Voting and Consensus (NASCO, n.d.; see Exhibit 6.1). Nearly all respondents (93.3%) supported (three) or rated highly (four, five) OCCYSHN's proposal to keep medical home as a priority. Reasons for supporting the medical home priority, as well as concerns about keeping it, follow. Additionally, respondents provided considerations and recommendations to improve the medical home priority.

Exhibit 6.1. Respondents Ratings of Support to Keep Medical Home Priority in 2021-2025

Response Option	Count
5 = I love selecting medical home; I will champion its selection.	10
4 = I like selecting medical home; it is a good idea.	12
3 = I will support its selection.	6
2 = I have concerns but will go along with its selection.	1
1 = I have serious reservations, but choose to move forward with selecting it.	1
0 = This is a terrible idea that I cannot support.	0
Total	30

Rating of Four and Five

Twenty-two out of 30 stakeholders expressed strong support for keeping medical home as a priority (see Exhibit 6.1). The stakeholders reported that the medical home is essential to families receiving family-centered care, and sets the foundation for optimal health care for CYSCHN and their families. The stakeholders reported that care coordination, increased collaboration, and culturally responsive care are needed for families. These stakeholders also offered suggestions to improve the medical home. These included providing more linguistically responsive services; providing referrals and resources for families; and understanding and addressing families' barriers and challenges.

> *"Effective care coordination, assisting families with service referrals and connecting to a medical home is important work, and we hear similar needs in our community."*

> *"There is still a great need for improvement in this area: people connecting with a medical home in an authentic way, and providers being genuinely responsive the needs of the families and children they serve; including cultural responsiveness and access to services."*

Rating of Three

Six of the 30 stakeholders rated supporting the medical home priority a three (see Exhibit 6.1). Their suggestions for improving the medical home were often consistent with suggestions made by stakeholders who expressed strong support for maintaining medical home as a priority. For example, stakeholders reported the need for more cross-system care coordination, increased cultural awareness, and improved collaboration between health care providers and public health.

> *"I agree [with the medical home priority]; we need more time to develop cross-system care coordination."*

Rating of One and Two

Two of the 30 stakeholders supported maintaining medical home as a priority, but they expressed concerns about it as a priority (see Exhibit 6.1). Although respondents recognized that medical homes improve access to medical care, they pointed to the need for cultural and diversity training among health care providers. In addition, stakeholders reported that LPHAs need help from primary care providers to better facilitate shared plans of care. The stakeholders suggested that primary care provider support will allow LPHAs to focus on supporting the medical home.

> *"If we are referring to medical home I support that but, if we continue to focus on Shared Plans of Care, we at local health departments often cannot get the PCP to the table and really the PCP's office should be convening these."*

Transition to Adult Health Care Rationale and Input

Care coordination is a foundational element of medical home. Preparing for the transition from pediatric to adult health care is a component of high quality care coordination. NSCH 2016-2017 results suggest that Oregon children generally, and CYSHCN specifically, do not receive services necessary to transition to adult health care (CAHMI, 2020). Our participatory needs assessments with the Sickle Cell Anemia Foundation of Oregon and the Latino Community Association identified transition-related challenges. Both groups of families reported experiences in which the health care system failed to prepare them for transition. In some focus groups, families of Black CYSHCN reported difficulty staying involved in their youth's care after they turned 18, because of patient privacy laws (Gallarde-Kim, Smith, Roy, et al., 2020). Family members reported that they needed to stay involved, because their child was not ready to assume responsibility for their own health, and because the family did not trust that necessary care would be provided without their involvement (Gallarde-Kim, Smith, Roy, et al., 2020).

Families of Latino CYSHCN described a range of concerns that included losing insurance and paying for care once their child turned 18 to "having to start over from scratch" with a new set of health providers caring for their child (Gallarde-Kim, Bisso-Fetzer, Roy, et al., 2020). Because OCCYSHN's is the primary voice championing transition at a state level, and because some health systems are beginning to see the value of well-executed transition, we proposed keeping transition as a Title V strategy for CYSHCN for the 2021-2025 block grant cycle.

We asked stakeholders to rate the extent to which they agreed with keeping transition to adult health care as a national priority using the same rating scale as we used for the medical home priority. Nearly all respondents (90%) rated their support as a three or higher for our proposal (see Exhibit 6.2). Reasons for supporting the transition to adult health care priority, as well as concerns about keeping it, follow. Additionally, respondents provided considerations and recommendations to improve the transition to adult health care priority.

Exhibit 6.2. Respondents Ratings of Support to Keep Transition to Adult Health Care in 2021-2025

Response Option	**Count**
5 = I love selecting medical home; I will champion its selection.	9
4 = I like selecting medical home; it is a good idea.	9
3 = I will support its selection.	9
2 = I have concerns but will go along with its selection.	1
1 = I have serious reservations, but choose to move forward with selecting it.	2
0 = This is a terrible idea that I cannot support.	0
Total	30

Rating of Four and Five

Eighteen out of the 30 stakeholders rated highly the proposal to maintain transition to adult health care priority (see Exhibit 6.2). Respondents recognized that there is a general lack of education and training for families and health care providers when a youth needs transition services. This lack of information makes it challenging for youth to navigate the adult health care system, which creates uncertainty and fear for families. Respondents provided many suggestions for improving the transition to adulthood health care priority. For example, respondents recommended finding payment options for health care providers who conduct transition activities. Other respondents advocated for greater cultural sensitivity among health care providers. Finally, some suggested starting transition services early in life and providing better outreach to families.

> *"... Having a road map to help families and providers navigate through this [transition] period is critical towards helping CYSHCN youth ease into adulthood with the skills and supports they need to be successful as adults. Advanced planning on the part of providers (education, health care, employment, etc.), parents, and youth can help make a smoother and more successful transition."*

Rating of Three

Nine out of the 30 stakeholders rated their support for maintaining the transition to adult health care priority as a three (see Exhibit 6.2). Respondents indicated that transition services will help youth understand and develop responsibility for their own health. The stakeholders suggested that providing awareness of services; training and educating families; and improving cultural sensitivity among health care providers are needed to improve transition to adult health care. Additionally, respondents noted that providing these services early on will help alleviate family concerns and anxiety when their youth reaches the legal adult age.

> *"This proposal will reduce high levels of anxiety and fear from parents who do not know what to expect when client reaches legal age and status of client's medical services once in adult health care."*

Rating of One and Two

Three out of the 30 stakeholders expressed concerns or reservations about the transition to adult health care priority (see Exhibit 6.2). Respondents agreed that transition to adult health care needs to be addressed for CYSHCN. LPHA respondents, however, reported that the population of young adults with special health care needs who are transitioning is a small population to serve. LPHAs experience challenges serving this population. In some cases challenges result because they do not receive enough referrals for young adults with special health care needs, and therefore cannot meet OCCYSHN contract goals. In other cases LPHA staff are not well-equipped to provide transition services, with the result that it takes more time than they can afford.

> *"... Our staff are not adequately trained with this age group; their expertise and reason for working here is to support pregnancy and infancy/toddlers populations. We don't have the infrastructure to support this age population (charting templates and knowing partner service agencies) ... We have learned this is a great need in our community, and would like to be a supportive voice for care coordination to be available for this age range..."*

State and Emerging Priorities

As part of Oregon's Title V statewide five-year needs assessment, the Oregon Health Authority Maternal and Child Health Section reviewed existing public health and hospital community health needs assessments (OHA, 2020). This review helped OHA identify seven emerging need areas for Oregon's Maternal, Child, and Adolescent Health populations (OHA, 2020). Considering those seven, plus Oregon's three 2016-2020 state priorities, we asked stakeholders to select one or two areas that would best address the needs of Oregon CYSHCN and their families. The stakeholders most frequently identified (1) Social determinants of health and equity; (2) Toxic stress, trauma, adverse childhood experiences, and resilience; (3) Culturally and linguistically appropriate services; and (4) Social connectedness (see Exhibit 6.3). Oregon Title V leadership selected state priorities using used this stakeholder input, results of the 2020 needs assessment, and knowledge of Title V program capacity. The three areas selected were: (1) Social determinants of health and equity; (2) Toxic stress, trauma, adverse childhood experiences, and resilience; and (3) Culturally and linguistically appropriate services.

Exhibit 6.3. Respondent Ratings of Ten State and Emerging Priority Areas in 2021-2025.

Response Option	Count
Social determinants of health and equity	14
Toxic stress, trauma, adverse childhood experiences, and resilience[a]	10
Culturally and linguistically appropriate services[a]	6
Social connectedness	6
Child care	4
Adolescent mental health	3
Maternal mental health	3
Food insecurity[a]	2
Drug use and misuse: Impact on pregnant women and children	2
Adult alcohol misuse	0
Total	50

[a] Current (2016-2020 Oregon Title V State Priority Area)

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