

Oregon's Children with Special Health Care Needs

Five Year Needs Assessment Findings – October 2, 2020

CHAPTER ONE

How are Oregon Children and Youth with Special Health Care Needs Faring? *Summary of Findings*

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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.

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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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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 services⁵”; 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 occupation⁶ for

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

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 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

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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