Introduction to Oregon's 2025 Statewide Needs Assessment for Children and Youth with Special Health Care Needs.

Chapter 1

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The Title V Maternal and Child Health Services Block Grant program "*aims to support and improve the health and well-being of mothers, children, and families, particularly those with low income or with limited access to health care services*" (Mickler, 2024, p. 1). The block grant is a Federal-grantee (state or jurisdiction) partner to "…*enable each state/jurisdiction to address the health service needs of its mothers, infants, and children, which includes children with special health care needs and their families.*" (Health Resources and Services Administration cited in Mickler, 2024, p. 4). The block grant specifically seeks to *"enable each state to*

- *ensure access to quality health care services for mothers and children, particularly to those with low income or limited availability of care;*
- *reduce the number of infant deaths, preventable disease, and children with disabilities;*
- *reduce the incidence of still birth;*
- *reduce the need for inpatient and long-term care services;*
- *increase the number of children receiving immunizations, health assessments, and follow-up diagnostic and treatment services;*
- *provide prenatal, delivery, and postpartum care for low-income, at risk-women;*
- *provide preventive and primary care services for low-income children;*
- *provide rehabilitation services for blind and disabled individuals are the age of 16 receiving benefits under Social Security Insurance (SSI)(Title XVI of the SSA), if the services are not provided under Medicaid (SSA Title XIX);*
- *promote and provide family-centered, community-based coordinated care services for CYSHCNs; and*
- *facilitate the development of community-based systems of services for CYSHCNs and their families"* (Mickler, 2024, p. 4-5).

Title V grantees are guided by the following key principles to support the delivery of public health services and systems to address MCH populations, including CYSHCN, needs:

1. *"Delivery of MCH services within a public health service model.*
2. *Data-driven programming and performance accountability.*

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3. *Partnerships with individuals, families, and family-led organizations to ensure systems and services that support the interests of all MCH populations.*
4. *Health equity and assurance that all MCH populations achieve their full health potential"* (Mickler, 2024, p. 5).

The Oregon Health Authority (OHA) Public Health Division (PHD) Maternal and Child Health Section contracts with the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) to implement the block grant's requirements to support children and youth with special health care needs (CYSHCN). Title V legislation requires that Title V grantees conduct a statewide needs assessment every five years (P.L. 101-239). The needs assessment should identify services for children with special health care needs that are *"consistent with the health status goals and national health objectives referred to in section 501(a)"* (P.L. 101-239). The results of the needs assessment should guide Title V grantees in their plans to serve the maternal and child health (MCH) populations. Therefore, OCCYSHN's needs assessment sought to understand the needs of Oregon's children, youth, and young adults with special health care needs for:

(1) access to quality health services, and
(2) family-centered, community-based coordinated care.

Methods

Children and Youth with Special Health Care Needs (CYSHCN) are children

> *"…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).*

This definition of CYSHCN was developed in 1998 by the Health Resources and Services Administration (HRSA) to guide the development of systems to address children who require complex and long-term services, have high health care costs, are vulnerable to weaknesses of the health care system, and experience disparities (McPherson et al., 1998). We used this definition to determine the multiple data sources and data collection methods to include in our assessment. A brief description of both sources and methods follows (see Appendix A for a detailed explanation).

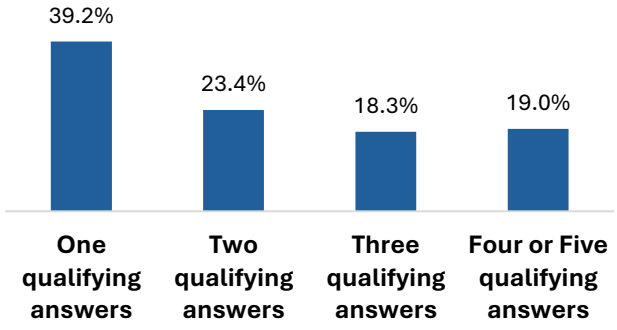
- National Survey of Children's Health. The NSCH is developed and administered by the U.S. Maternal and Child Health Bureau (MCHB), in partnership with the U.S. Census Bureau. The NSCH collects data annually, using a sampling approach that allows results to be generalized to the national and state populations of children and youth. Data collected through survey administration are the primary source that describes Oregon's CYSHCN *population*. We analyzed the 2021-2022 NSCH dataset obtained from the Child and Adolescent Health Measurement Initiative.

- Primary data. We partnered with APANO CUF to collect survey data from families of CYSHCN within Oregon's Vietnamese communities. We also used results from existing OCCYSHN assessment and evaluation projects. For example, results describing local public health authorities' (LPHA) implementation of shared care planning for CYSHCN, and results describing needs about which families contacted Oregon's Family-to-Family Health Information Center.
- Secondary data. We also used existing data sources and reports from Oregon agencies and organizations to understand populations within the broader Oregon CYSHCN population. For example, we used National Core Indicators 2021-22 Oregon Child Family Survey State Report results to describe needs of children under 23 years of age with disabilities. We used Oregon Department of Education IDEA Part B and Part C reports to understand access to educational services, which are a critical aspect of coordinated care for CYSHCN. Part B covers CYSHCN between ages 3 and 21, while Part C refers to children under 3 years old. We used reports from the Oregon Health Authority and Oregon Office of Rural Health to understand health care workforce issues that may contribute to health care access barriers.

Findings

The National Survey of Children's Health (NSCH) uses the screener tool developed by the Child and Adolescent Health Measurement Initiative (Bethell & Read, 2022; Bethell et al., 2002; Bethell et al., 2015), which is the accepted method for identifying CYSHCN. The screener consists of five health consequences that a child may experience as a result of an on-going health condition. The health consequences are: elevated service use; experiencing functional limitations; experiencing ongoing emotional, developmental, behavioral conditions; use of prescription medication; and use of specialized therapies (Ghandour et al., 2022).

Exhibit 1. Percent of CYSHCN by Number of Screener Responses



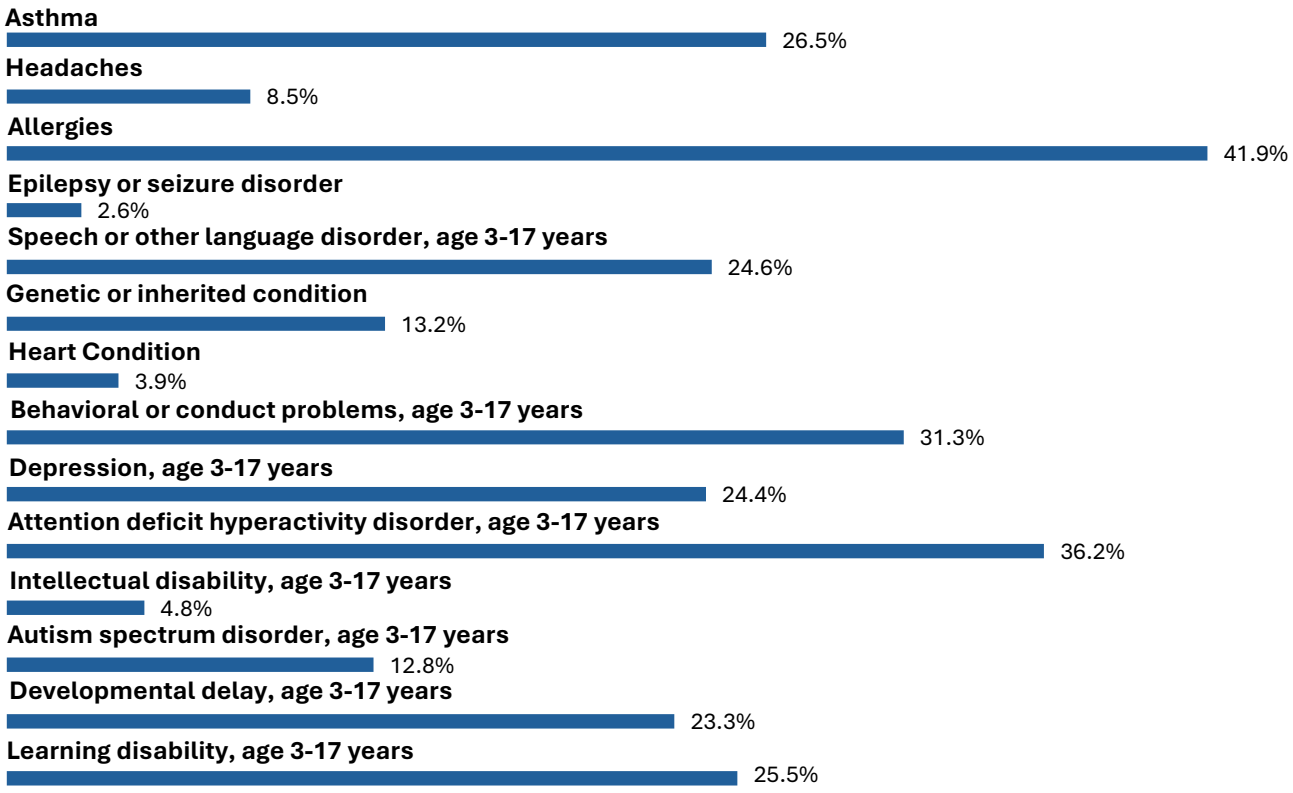
Data Source: OCCYSHN Analysis of NSCH 2021-2022

Analysis of the 2021-22 NSCH showed that an estimated 174,286 (20.3%) of children under 18 years old in Oregon have special health care needs (Child and Adolescent Health Measurement Initiative. More than half of CYSHCN have an elevated use of services (54.0%), have mental and/or behavioral health conditions (54.6%), and need or use prescription medications (58.2%). About one in five CYSHCN experience four or five of these health consequences (Exhibit 1).

Health Conditions and Functional Difficulties

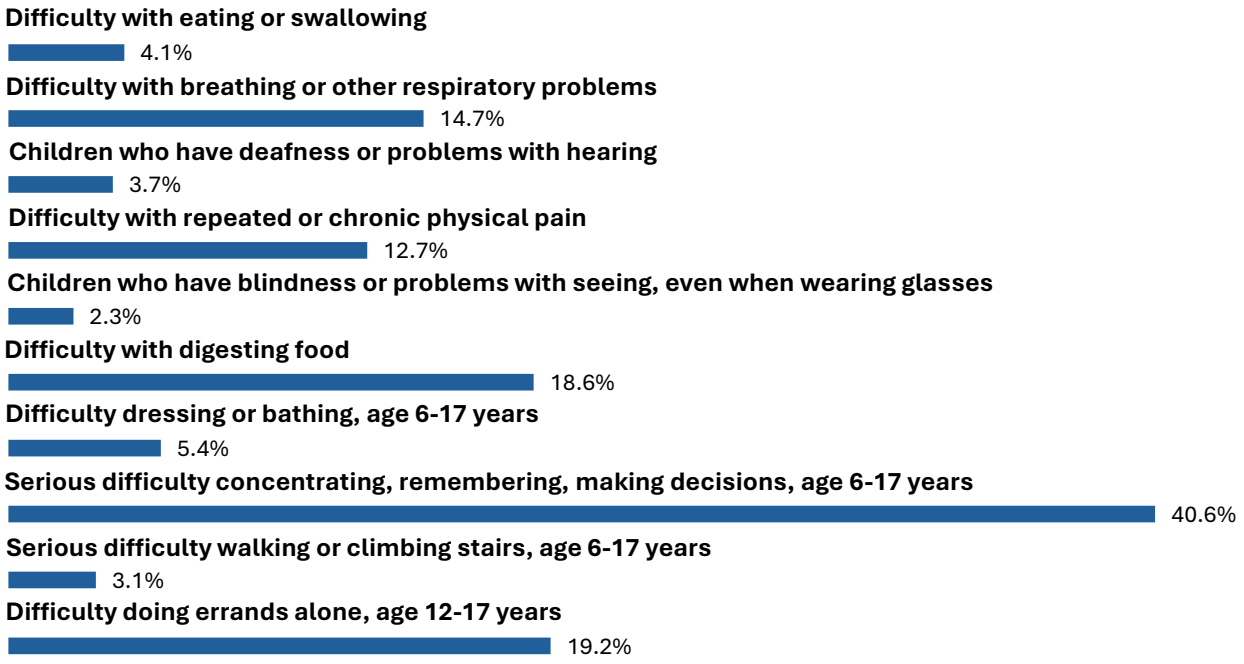
Thousands of diverse health conditions affect CYSHCN. The NSCH provides valuable data for over 20 health conditions and functional difficulties that affect children from birth on. The most frequently reported health conditions among Oregon CYSHCN during 2021-2022 were allergies, attention deficit hyperactivity disorder (ADD/ADHD), and behavioral/conduct problems (Exhibit 2). Additionally, one quarter of CYSHCN had a learning disability, and one in five CYSHCN have a developmental delay, asthma or depression. The most common functional difficulty among Oregon CYSHCN is serious difficulty concentrating, remembering, or making decisions. Around one in four CYSHCN also have difficulty doing errands alone and digesting food (Exhibit 3).

Exhibit 2. Health Conditions Among Oregon CYSHCN



Data Source: OCCYSHN Analysis of NSCH 2021-2022

Exhibit 3. Functional Difficulties Among Oregon CYSHCN



Data Source: OCCYSHN Analysis of NSCH 2021-2022

Findings from OCCYSHN's 2010, 2015, and 2020 needs assessments indicated that Oregon CYSHCN experience challenges accessing mental health care (Office of Family Health, 2010; Martin et al., 2015; Oregon Center for Children and Youth with Special Health Needs, 2020). Currently, findings show that mental health issues are rising (Oregon Health Authority [OHA], OCCYSHN, & Oregon State University [OSU], 2025). A larger proportion of adolescents in Oregon require treatment or counseling, yet they receive treatment at lower rates compared to youth nationwide. Additionally, adolescents with a medical home, who have a lower federal poverty level, or who identify as Black, Indigenous, or other youth of color currently less often receive needed mental health care compared to their peers who do not have these characteristics (OHA, OCCYSHN, & OSU, 2025). Analysis of 2021-2022 NSCH data shows that CYSHCN ages 12-17 years are more likely to experience anxiety and depression than same-age youth without special health care needs. Additionally, three times as many CYSHCN, ages 12-17 years, currently have or had depression compared to CYSHCN, ages 6 -11 years (Exhibit 4).

Exhibit 4. Anxiety and Depression Among CYSHCN by Age Groups

Data Source: OCCYSHN Analysis of NSCH 2021-2022

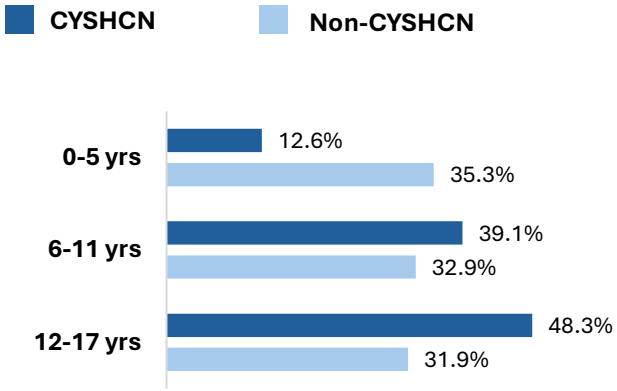
Socioeconomic and Demographic Characteristics

We analyzed 2021-22 NSCH data to describe Oregon's CYSHCN population (< 18 years old) using several sociodemographic characteristics.

Age and Gender

Nearly half of Oregon CYSHCN are youth between the ages of 12-17, and 39.1% are between 6 and 11 years old (Exhibit 5). There is a small proportion of CYSHCN between 0 and 5 years old. Nearly 54% of CYSHCN are male and 46% are female.

Exhibit 5. Age of Oregon Children by CYSHCN Status



Data Source: OCCYSHN Analysis of NSCH 2021-2022

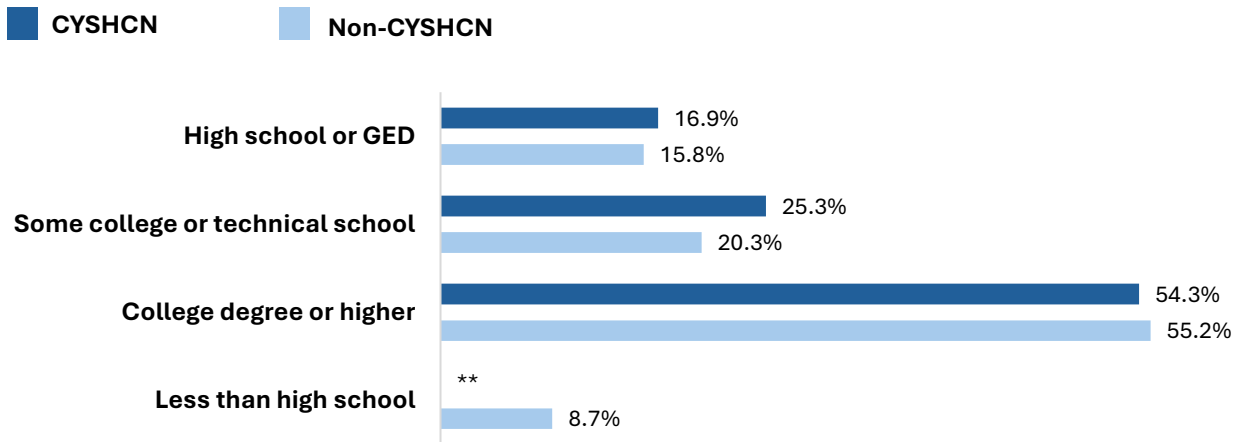
Geographic Location

Geographic location is a significant social determinant of health because it influences access to both care and other important resources affecting health. In the U.S., children living in rural areas face more barriers in accessing care for their needs than children living in urban areas (Crouch et al., 2024). Children living in rural areas are also more likely to be poor and uninsured. This, coupled with barriers to transportation and availability of local providers, can compound the barriers to their access to healthcare (Skinner & Slifkin, 2007). Although urban and rural designations are not available, the NSCH uses Metropolitan Statistical Areas (MSA) to group children by geographic type (i.e., living in or near a metropolitan area and living outside of a metro area). Oregon CYSHCN and their families tend to reside close to metropolitan regions (89.2%) and live in households where the home is owned by the family (71.5%).

Household Education

Results of our analysis of 2021-22 NSCH data show that more than half (54.3%) of Oregon CYSHCN households attained at least a college degree, and about one quarter of CYSHCN households completed some college or technical school (Exhibit 6). About 17% of CYSHCN's families reported that someone in their household completed a high school diploma or General Educational Development (GED) certification. We lack sufficient data to estimate the population of households with CYSHCN who did not complete high school. There are no meaningful differences between the educational credentials held by CYSHCN households and credentials held by non-CYSHCN households (Exhibit 6).

Exhibit 6. Household Education of Oregon Families by CYSHCN Status



** *There is an insufficient sample size to produce a reliable estimate*

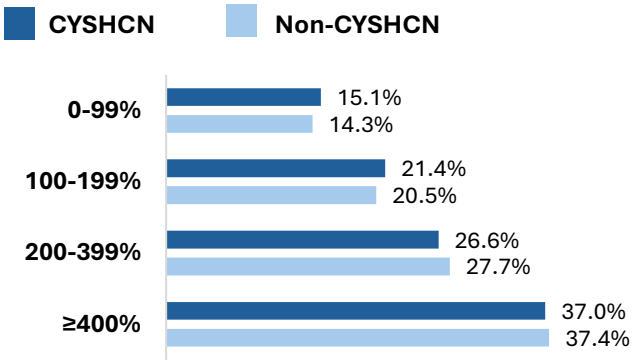
Data Source: OCCYSHN Analysis of NSCH 2021-2022

Income

Income is an important determinant of fair access to health because of its relationship with housing, lived environment, and transportation. Households with lower incomes also have decreased access to resources such as transportation, internet, health insurance and childcare (Krieger et al., 1997; Lykens et al., 2009). Income references in this needs assessment are based on the federal poverty level (FPL) status of households of CYSHCN. FPL is used to determine eligibility for various federal programs and benefits like Medicaid and food assistance programs like the Supplemental Nutrition Assistance Program (SNAP).

Although a large proportion of CYSHCN households are higher income, about 15% of households of CYSHCN are in poverty (Exhibit 7). One in five households are on the verge of poverty and a little over 25% are low-income. Non-CYSHCN households have a similar income distribution compared to households with CYSHCN.

Exhibit 7. Income based on Federal Poverty Level by CYSHCN Status



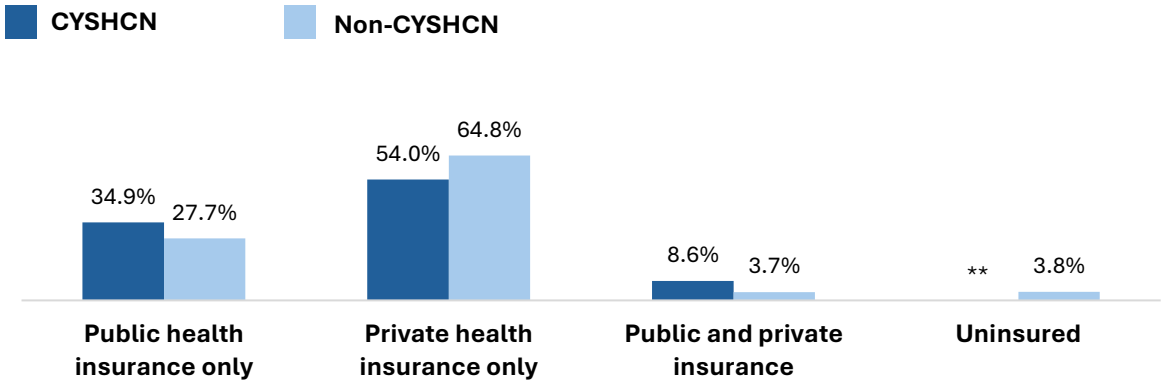
Data Source: OCCYSHN Analysis of NSCH 2021-2022

Insurance

Over 95% of CYSHCN were either currently insured or had continuous insurance coverage with no gaps in the 12 months prior to survey data collection. More than half the population is privately insured, and 1 in 3 CYSHCN are insured solely through public insurance. While both CYSHCN and non-CYSHCN are more likely to have private insurance than public health insurance

alone; children without special health care needs are more likely to have private insurance compared to CYSHCN. Additionally, CYSHCN are more likely to have a mix of public and private insurance (Exhibit 8).

Exhibit 8. Insurance Type of Oregon CYSHCN vs Oregon Non-CYSHCN



*** There is an insufficient sample size to produce a reliable estimate*

Data Source: OCCYSHN Analysis of NSCH 2021-2022

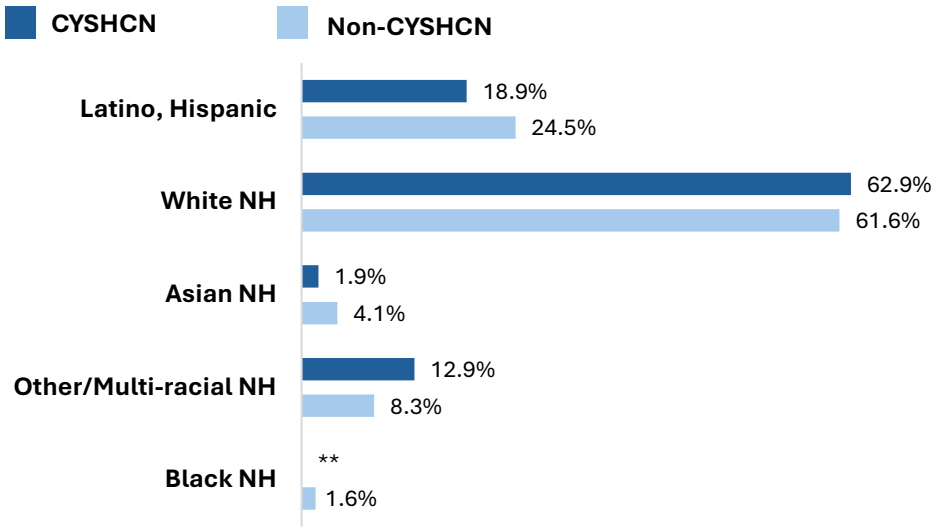
Primary Household Language

Research has shown an association between primary household language not being English and adverse health outcomes for CYSHCN, which often results from barriers when communicating with providers, reading prescription and other relevant instructions, and navigating the healthcare system (e.g., Yu et al., 2015). Results of analysis of 2021-22 NSCH data show that about 5% of Oregon CYSHCN live in households whose primary language is not English. However, households speaking languages other than English may be underrepresented because the survey is primarily available in English and Spanish, with additional steps required for responses in other languages.

Race and Ethnicity

Results of analysis of 2021-2022 NSCH data show that a large proportion (63%) of CYSHCN are White, non-Hispanic (NH). CYSHCN also belong to the following racial and ethnic communities: Latino, Other/Multi-race NH, Asian NH, and Black NH (Exhibit 9). We lack sufficient data to adequately estimate the percent of CYSHCN who are members of the following racial and ethnic communities: American Indian or Alaska Native NH, Black NH, Native Hawaiian and Other Pacific Islander NH, and Pacific Islanders NH. Together, estimates suggest that 5.6% of CYSHCN are members of these communities.

Exhibit 9. Race and Ethnicity of Oregon Children by CYSHCN Status



*** There is an insufficient sample size to produce a reliable estimate*

Data Source: OCCYSHN Analysis of NSCH 2021-2022

Complexities

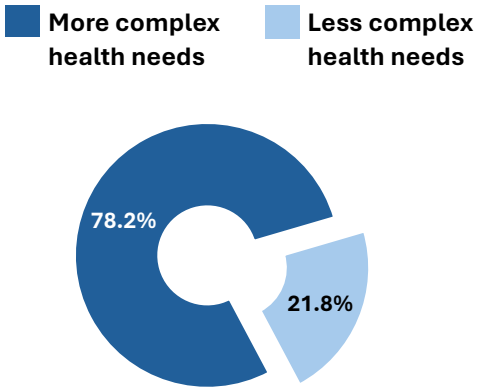
CYSHCN can experience medical complexities, social complexities, or a combination of both. OCCYSHN works to identify the CYSHCN population in Oregon who have these complexities, determine challenges they encounter and areas where they need support, resources and services.

Medical Complexity

Children with Medical Complexity (CMC) are a specific group of CYSHCN who have multiple chronic health problems, functional limitations, and elevated use of resources and/or specialized services (Kuo & Houtrow, 2016). Prevalence estimates range from about one percent of the child population to about six percent depending on how medical complexity is measured (Berry et al., 2014; CAHMI, 2021). CYSHCN with medical complexities depend on one or more services including but not limited to mental health care, developmental disability, special education, and physical or speech therapies (American Academy of Pediatrics [AAP], 2016). This population of CYSHCN has unique needs for coordination of care (Cohen et al., 2011) provided by pediatric and/or adult primary and specialty care providers in addition to educators, DD case managers, insurers, allied therapists, emergency care, home-based health care, pharmacists, and others depending on the child or young adult's particular needs.

CAHMI identifies CYSHCN with more complex health needs as those who meet one or more criteria addressing elevated need or use of specialized services, therapies, or functional limitations. These children may also need prescription medications (CAHMI, 2021). Using this definition, analysis of 2021-22 NSCH data shows that almost 80% of CYSHCN are more medically complex (Exhibit 10). We report results for CYSHCN who are medically complex in subsequent chapters.

Exhibit 10. CYSHCN with Medical Complexity



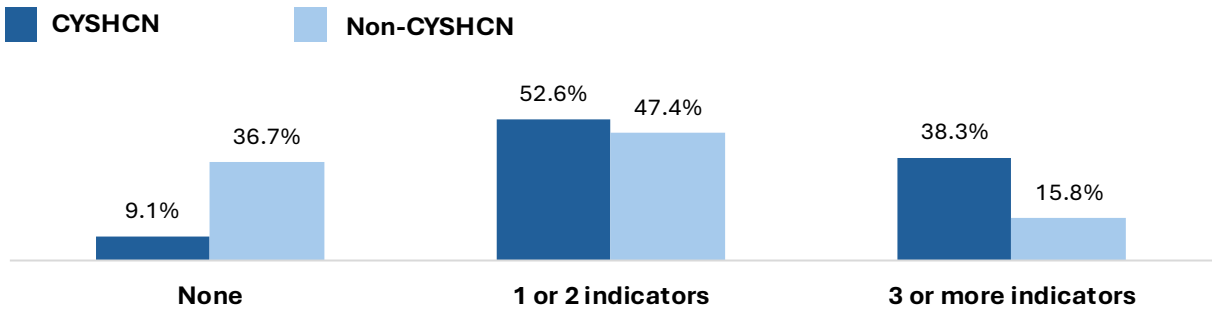
Data Source: OCCYSHN Analysis of NSCH 2021-2022

Social Complexity

Social complexity is defined as a set of co-occurring characteristics related to a child's individual, family, or community (Schrager et al., 2016). These characteristics can affect many aspects of their life but can particularly affect their health and access to care. For example, children with social complexity are more likely to need a comprehensive medical home (Fuentes et al., 2018). The NSCH collects data on 13 of these characteristics (see Appendix A).

Analysis of 2021-2022 NSCH data show that half (53%) of Oregon CYSHCN have experienced one or two of these indicators while nearly 40% have experienced three or more (Exhibit 11). Less than ten percent of CYSHCN have not experienced any of these indicators. There is notable difference in how frequently Oregon CYSHCN experience these indicators of social complexity compared to Oregon non-CYSHCN. CYSHCN have experienced an average of 2.33 of these indicators while non-CYSHCN have experienced an average of 1.22. More about this concept and related characteristics will be discussed in other chapters of this needs assessment.

Exhibit 11. Percent of Oregon Children With Indicators of Social Complexity



Data Source: OCCYSHN Analysis of NSCH 2021-2022

Setting the Foundation for Change

There is an incredible amount of diversity within the Oregon CYSHCN population, encompassing a wide range of health conditions, socioeconomic and demographic characteristics, and social challenges. The following chapters will focus on describing Oregon CYSHCN quality of life, their families' well-being, their access to services and care coordination, and systems barriers that affect their ability to access care.

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