CYSHCN Access to Needed Services in Oregon

Chapter 5

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Introduction

Children and youth with special health care needs (CYSHCN) and their families, as a population, have needs that require involvement in nearly every child and family-serving system, including child welfare, developmental disabilities, education, health care, and social services. Title V legislation seeks to assure that CYSHCN and their families have access to necessary services (U.S. Social Security Administration, n.d.). "Access to services" means that mental, behavioral, and physical health care; developmental services; care coordination; and home and community-based supports are easy-to-navigate, high-quality, and integrated (McLellan et al., 2022). Ensuring access requires innovative interventions and programming that attend to these multiple systems (Kuo et al, 2022). Therefore, OCCYSHN describes access to health care, developmental services, early learning and education, early intervention and special education, and social services in this chapter of our five-year needs assessment. Appendix A describes the data sources, methods, and analyses used for this chapter.

Findings

We organize our findings based on service type: health services, developmental disability services, and early childhood education. Within each section, we present individual-level needs, availability, and accessibility of services. We integrate individual-level findings and systemic barriers to service access within each of these sections, as data is available.

We used the National Survey of Children's Health (NSCH) as a primary source of data. Sample sizes for some communities of interest (such as CYSHCN who are Asian or Black/African American, who live in rural Oregon, who experience poverty, or who are uninsured) were too small (<30) to calculate reliable estimates. In these cases, findings cannot be generalized to the community of interest. We included placeholders for these communities in exhibits when sample sizes were too small, and we describe contextually meaningful differences where appropriate.

Access to Health Services

We begin our discussion of access to health services with findings about unmet health care needs for CYSHCN. Because mental health care access continues to be a substantial unmet need, we discuss mental health following our broad discussion of unmet needs. Next, we present needs assessment findings related to medical care, including primary care medical home, other preventive health care services, non-preventive health care services, transition from pediatric to adult health care, and facilitators of health care access.

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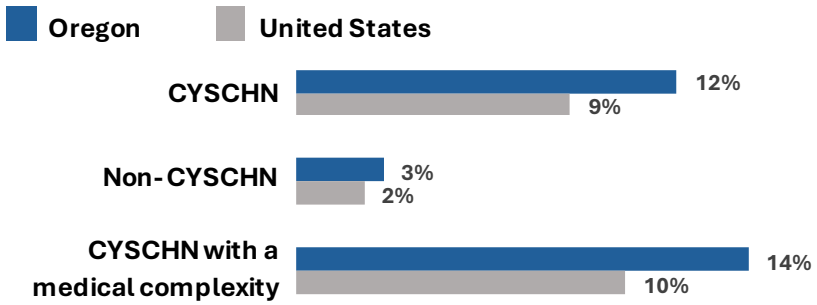
Unmet Health Care Needs

In Oregon and nationally, CYSHCN were about 4 times more likely than children and youth without special health care needs (non-CYSHCN) to go without needed health care services (Exhibit 1). Medically complex CYSHCN reported unmet health care needs at even higher rates, with 14% of Oregon CYSHCN with complex medical needs forgoing care (Exhibit 1).

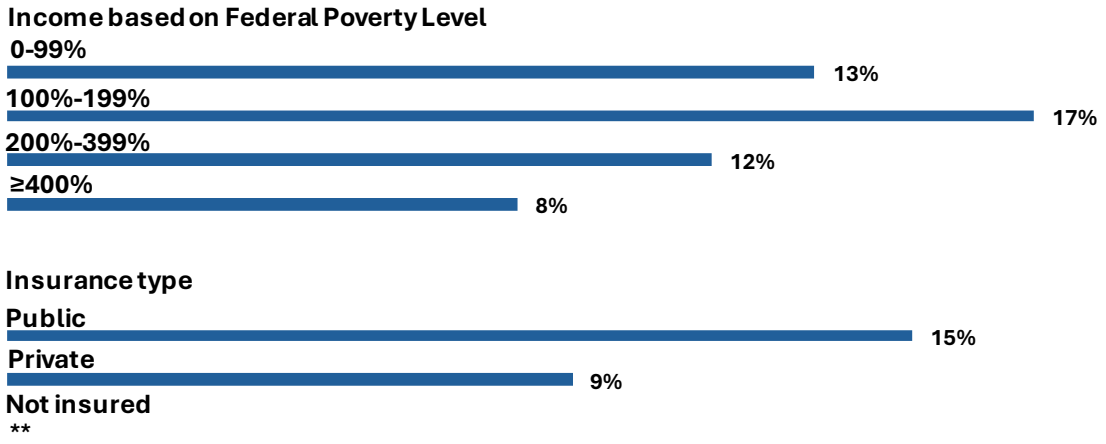
Exhibit 1. Percent of CYSHCN, Non-CYSHCN, and CYSHCN with a Medical Complexity Who Had Unmet Health Care Needs, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022

Health care needs were met less often for CYSHCN whose families have a higher income and who are privately insured (Exhibit 2). We do not have a sufficient sample size to report the percentages of CYSHCN with unmet health care needs across racial/ethnic groups or geographic location (i.e., inside and outside of a metropolitan statistical area). Although sample sizes of YSHCN from ethnic and racial communities other than white and from rural communities are too small to produce reliable estimates, patterns of responses from families in these communities tended to be similar to those found in broader YSHCN population. As described later in this chapter, however, there were substantial differences in access to *specific* health care services for these communities of interest.

Exhibit 2. Percent of CYSHCN and Non-CYSHCN Who Had Unmet Health Care Needs by Income and Insurance Type, 2021-2022



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

Data Source: OCCYSHN Analysis of NSCH 2021-2022

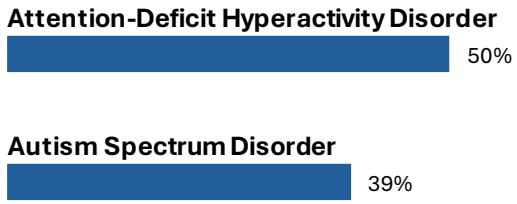
Mental and Behavioral Health Care

NSCH results indicated that the majority (81%) of Oregon CYSHCN with a mental or behavioral health condition received treatment or counseling (Exhibit 3). However, CYSHCN with particular health conditions reported unmet needs. For example, more than one-third of autistic CYSHCN or who have been diagnosed with Autism Spectrum Disorder (ASD) went without needed behavioral treatment services, and half (50%) of CYSHCN with ADD or ADHD went without behavioral treatment (Exhibit 4). Additionally, Oregon high schoolers with special health care needs reported unmet mental health care needs at even higher rates; although one in ten (10.1%) 11th graders with a disabilities had unmet *physical* health needs, over one in five (22.9%) 11th graders with a special health need had unmet *emotional or mental health* needs (Oregon Student Health Survey, 2022).

Exhibit 3. Percent of CYSHCN and Non-CYSHCN with a Mental or Behavioral Health Condition Who Received Treatment or Counseling

Data Source: OCCYSHN Analysis of NSCH 2021-2022

Exhibit 4. Percent of CYSHCN with ADD/ADHD and Autism/ASD Who Did Not Receive Needed Behavioral Treatment Services



Data Source: OCCYSHN Analysis of NSCH 2021-2022

Subpopulations of Oregon CYSHCN and their families also experienced more difficulty accessing mental and behavioral health services, including CYSHCN with more complex health needs, living in rural communities, and who come from Asian, American Indian or Alaska Native, and African American or Black communities (Exhibit 5).

Exhibit 5. Access to Mental and Behavioral Health Services for Communities of Interest

Group	***Access to Mental and Behavioral Health Services Findings***
≥ 5 years	• The need for mental and behavioral health services was the second highest service need of parents of CSHCN,[1] with over half of parents of CSHCN (54.7%) reporting a need for mental or behavioral health services for their child 5 years of age or younger (Pears et al., 2022a). • Of the families who needed mental and behavioral health services for their CSHCN, two-fifths (41.6%) reported difficulty accessing these services (Pears et al., 2022a).
Intellectual and Developmental Disabilities (IDD) Service Recipients	• On average, families of CYSHCN who received intellectual or development disability (I/DD) services reported counseling as their third highest priority need (National Core Indicators, 2022). • Nearly one in five (19%) families of children or youth who receive I/DD services reported that they can only sometimes or seldom/never get needed mental or behavioral health services (National Core Indicators, 2022).
Complex health care needs	• Mental health services were reported as an unmet health need for nearly one in ten (8.8%) Oregon CYSHCN younger than 18 years.
Rural and remote Oregonians	• CYSHCN living in rural areas of Oregon had more difficulty accessing mental or behavioral health services. According to

[1] We use CSHCN when referencing data specific to populations of CYSHCN under the age of 6.

Group	***Access to Mental and Behavioral Health Services Findings***
	the Oregon Office of Rural Health, urban areas have 1.6 full-time mental health care providers for every 1,000 people. Rural and remote areas have over 40 hours of mental health service *less* per week, with only about one half-time mental health provider per 1,000 people (ORH, 2024).
Race and ethnicity	• In a survey of parents of young children (ages 0-5) across Oregon, over half of parents of CSHCN from Latino[2] (52.4%), Asian, American Indian or Alaska Native, and African American or Black (60.6%) backgrounds said that they were not able to access needed mental or behavioral health services for their child.[3] In contrast, substantially fewer White parents of CSHCN (40.2%) reported difficulty accessing mental or behavioral health care services for their child (Pears et al., 2022a). • A report from the Oregon Health Plan Ombuds program found differences in services received in the Emergency Department (ED) and following an ED visit for mental health services. African American or Black youth in mental health crisis stayed significantly longer in the ED, and American Indian or Alaska Native youth waited the longest for a follow-up appointment after an ED visit for mental health services (OHA Ombuds Program, 2023b).
Foster Care	• We have little information about the mental and behavioral health needs of CYSHCN in foster care. An audit of Oregon's mental and behavioral health system found that children and youth in foster care and who have high mental and behavioral health needs have very little access to services and often burn out of placement (Garber et al., 2020b). The report cited lack of services and foster family inexperience with children and youth with high needs as responsible for this outcome (Garber et al., 2020b).

Challenges accessing mental and behavioral health (M/BH) services has shown up as an unmet need of CYSHCN in this needs assessment and in previous needs assessments (Aiello et al., 2020; Martin et al., 2015), reflecting the national and statewide mental health crisis (Yang et al., 2023). Oregon has put in place some changes to improve the state's mental and behavioral health system for children. For example, the Oregon Health Plan Ombuds program noted that two new services, Mobile Response and Stabilization Services (MRSS) and

[2] We recognize and respect all individuals who identify as Latiné, Latin@, Latinx. However, the majority of people within the communities with which we work identify as Latino, and we use the term throughout this chapter.
[3] We excluded percentages for families of CSHCN from Asian and American Indian or Alaska Native backgrounds due to small sample sizes.

Intensive In-Home Behavioral Health Treatment (IIHBT), offer important, developmentally appropriate, and community-based services for children and youth (OHA Ombuds Program, 2023b).

Unfair Barriers to Access

Despite some improvements, concerns about mental and behavioral health service access brought to the Ombuds program by members of the Oregon Health Plan under the age of 26 more than doubled – from 19 to 40 reports – since 2020 (OHA Ombuds Program, 2023b). Barriers to accessing these services include the following.

- Long wait times, inconvenient locations and appointment times, and limited capacity;
- Fragmentation of the system;
- Flawed policies and statutes; and
- Incomplete and inconsistent implementation.

Long Wait Times, Inconvenient Locations and Appointment Times, and Limited Capacity

Long wait times for mental health services delay critical supports for children and youth in crisis and limit the ability of some mental health services, like MRSS, to connect children and youth to community-based services (OHA Ombuds Program, 2023a). Insurance approval for important mental and behavioral health services can be delayed too. For example, children insured by the Oregon Health Plan had to wait twice as long for approval to receive residential treatment services compared to their privately insured peers (Garber et al., 2020b).

Inconvenience of mental health services can also limit access. Over one quarter of families (28.3%) and one-third of students (33.6%) who receive Medicaid funded mental health services reported that the location and time of services were inconvenient (Comagine Health, 2022).

Network adequacy for mental health providers is limited, with an average provider to Coordinated Care Organization (CCO) member ratio of 1:64, and only two percent of mental health providers specifically serving pediatric CCO members (OHA, 2025b). No pediatric-focused mental health providers were reported in 2024 for five CCOs serving large rural areas (Cascade Health Alliance, and all four PacificSource Community Solutions CCOs – Central Oregon, Columbia Gorge, Lane, and Marion/Polk; OHA, 2025b).

Limited systems capacity to support CYSHCN who need inpatient and residential mental and behavioral health treatment also continues to be a barrier to accessing care (Ombuds Ombuds Program, 2023b; Garber et al., 2020b). A minority (25%) of children and youth insured by the Oregon Health Plan who were referred for residential treatment services were admitted, and children in foster care were even less likely to receive residential treatment services (Garber et al., 2020b). An audit conducted by the Oregon Secretary of State found

that, because of limited capacity, children and youth in foster care who need residential treatment services

> *"…may be placed with foster families or relatives that have no experience in providing the appropriate level of care and have little training and inadequate guidance and support from the agency. In these cases, children tend to burn out of placements, often repeatedly, and may never achieve permanency with a family or stability in a foster home placement"* (OSS, 2018, pp. 27).

Fragmented Mental Health Systems

Fragmented systems can cause service gaps, resulting in CYSHCN's needs going unmet. Issues with the fragmentation of the mental health system have long been identified by systems leaders as problematic (Garber et al., 2020b). Complaints against the system include lack of accountability to a single entity at the state level, lack of consistent leadership with a consistent vision, and lack of role clarity between agencies and organizations at different levels of the system (Garber et al., 2020b). Additionally, multiple, fragmented funding streams have contributed to the lack of mental health services, especially mental health respite care for children and youth (OHA Ombuds Program, 2023a).

The fragmentation within the mental health system presents a major challenge for children and families attempting to navigate obtaining mental health care. As a result, CYSHCN are left without the adequate services to treat their health. CYSHCN from Black and Native American communities disproportionately experience this barrier in addition to poorer quality of mental health care (Garber et al., 2020b).

Flawed Policies and Statutes in the Mental Health System

Oregon's mental health system also is plagued by flawed policies and statutes. An audit of the system by Oregon's Secretary of State found that there is little consistency and coordination in the implementation of statutory guidelines dispersed in different sections of code (Garber et al., 2020b). One of the primary concerns outlined in the audit was that many of the statutes include vague language that provides a "loophole to deprioritize" programs (Garber et al., 2020b, p. 25). The report cited that use of the phrase, "availability of funds," is particularly problematic because it is too vague and has allowed some agencies to allocate funds elsewhere (Garber et al., 2020b). This phrase also was used in the mandate to develop performance measures and their monitoring and reporting for state level mental health services (Garber et al., 2020b). Despite reporting and monitoring progress, the vague language and inconsistencies have contributed to too few mental health services paid for and implemented across the state, which means that some CYSHCN go without these needed services.

Incomplete and Inconsistent Implementation of Mental Health Services

Incomplete and inconsistent implementation of mental health services statewide, specifically IIHBT and MRSS, have been identified as problems. Ombuds working within Oregon's mental health sector found variability in implementation of IIHBT, where some

programs are in early stages and others are incomplete (OHA Ombuds Program, 2023a). They also report that some counties have not implemented a critical component of the MRSS model, face-to-face intervention, and instead rely on call centers to address urgent mental health needs (OHA Ombuds Program, 2023a). Respite care for mental health services was also inconsistently prioritized across counties, CCOs, and regions of the state (OHA Ombuds Program, 2023a). Inconsistencies in implementation create inequities in available services for children, youth, and young adults with mental health needs across the state (OHA Ombuds Program, 2023a).

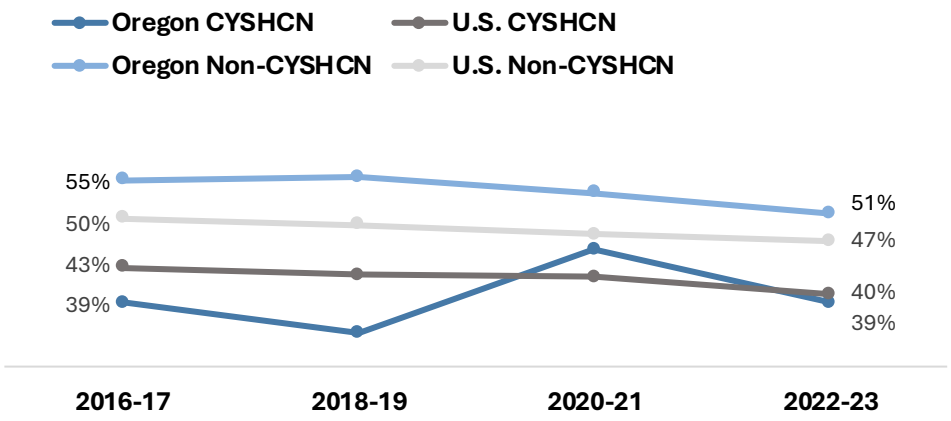
Primary Care Medical Home

The American Academy of Pediatrics (AAP) defines medical home as accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective primary care delivered by well-trained physicians (AAP, 2002). Medical homes are team-based models of care for all children and youth and require collaboration between the people whose expertise, including family members, is needed for care. The concept of medical home has existed since the 1960s, when pediatricians advocated for primary care as a central location for information about CYSHCN (Sia et al., 2004). Since then, there is recognition that all children and youth benefit from access to a medical home; however, access is crucial for CYSHCN. Benefits for CYSHCN associated with receipt of care in a medical home include positive health outcomes, receipt of higher quality of care (McAllister et al., 2009), and increased family satisfaction (Edelsten et al., 2017; Le et al., 2019).

The Maternal Child Health Bureau measures access to a medical home using the National Survey of Children's Health (NSCH) , which operationalizes medical home as a composite of five components: 1) has a usual source of sick care, 2) has a personal doctor or nurse, 3) received family-centered care, 4) experienced problems getting needed referrals, and 5) received effective care coordination when needed. CYSHCN and their families have access to medical home when all five of these aspects of care are received.

Access to a medical home has changed very little in recent years (Exhibit 6). About half (50.5% in Oregon and 46.8% nationally) of all children *without* special health care needs reported receiving care in a medical home in 2022-2023. However, only about two in five CYSHCN (38.5% in Oregon and 39.7% nationally) reported receiving care in a medical home. Although access increased during the COVID-19 pandemic in Oregon, it has since returned to pre-pandemic rates (CAHMI, 2024).

Exhibit 6. Percent of CYSHCN who Had Access to a Medical Home in Oregon and Nationally, 2016-2023



Data Source: CAMHI Interactive Data Website, 2016-2023

The importance of the medical home is underscored by differences in health outcomes and health care service receipt for CYSHCN who have and do not have a medical home. Results of analysis of NSCH data show that 85.5% of CYSHCN with a medical home had very good to excellent overall health compared to 72.7% of CYSHCN without a medical home. Five percent of CYSHCN who have a medical home were *unable* to obtain needed health care services compared to nearly 17% of CYSHCN without.

Receipt of care in a medical home is not experienced equally across groups of Oregon CYSHCN. CYSHCN with less complex health needs were nearly 2 times more likely to have a medical home than CYSHCN with more complex health needs (Exhibit 7). Additionally, CYSHCN in the following groups were less likely to have received care in a medical home (Exhibit 8):

- Aged 12 through 17 years.
- Reside outside of a metropolitan statistical area.
- Are female.
- Are insured through public insurance.
- Are members of Asian, Latino, or other/multi-racial communities.
- Reside in a household with lower household income.

Exhibit 7. Percent of CYSHCN Who Had Access to a Medical Home by Medical Complexity, 2021-2022

Data Source: OCCYSHN Analysis of NSCH 2021-2022

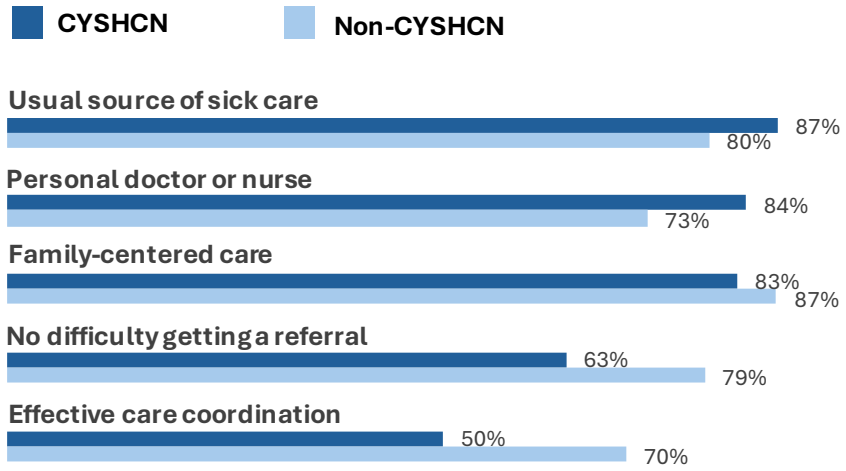
Exhibit 8. Percent of CYSHCN Who Had and Did not Had Access to a Medical Home by Demographic Characteristic, 2021-2022

	Medical Home Access			Medical Home Access	
	Yes	**No**		**Yes**	**No**
Age Group (years)			**Metropolitan statistical area status**		
0-5	45.8%	54.2%	Metropolitan Statistical Area	42.3%	57.5%
6-11	43.2%	53.6%	Not Metropolitan Statistical Area	37.3%	62.7%
12-17	39.5%	60.5%	**Insurance Type**		
Biological Sex			Public health insurance only	34.8%	65.2%
Male	45.1%	54.9%	Private health insurance only	48.0%	52.0%
Female	37.9%	61.7%	Public and private insurance	32.4%	67.6%
Race and ethnicity			Not insured	**	**
Asian NH	41.8%	58.2%	**Income based on federal poverty level status**		
Black NH	**	**	0-99%	31.1%	68.9%
Latino, Hispanic	38.1%	61.0%	100-199%	32.1%	67.9%
White NH	44.0%	56.0%	200-399%	46.1%	53.9%
Other/Multi-racial NH	37.6%	62.4%	≥400%	48.6%	50.9%
Complexity of health care needs					
Less complex	58.0%	42.0%			
More complex	37.3%	62.7%			

*** There is an insufficient sample size to produce a reliable estimate*
Data Source: OCCYSHN Analysis of NSCH 2021-2022

As previously mentioned, five components compose MCHB's medical home measure. More than three-quarters of Oregon CYSHCN had a usual source of sick care, personal doctor or nurse, and family-centered care in 2021-2022 (Exhibit 9). A larger percentage of Oregon CYSHCN reported access to a usual source of sick care and a personal doctor or nurse than non-CYSHCN. The percentage of CYSHCN with access to referrals and effective care coordination – critical services for CYSHCN – was particularly low. Next, we summarize findings specific to four of these five components.[4]

Exhibit 9. Percent of Oregon CYSHCN Who Had Access to Each Component of a Medical Home, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022

Usual Source of Sick Care

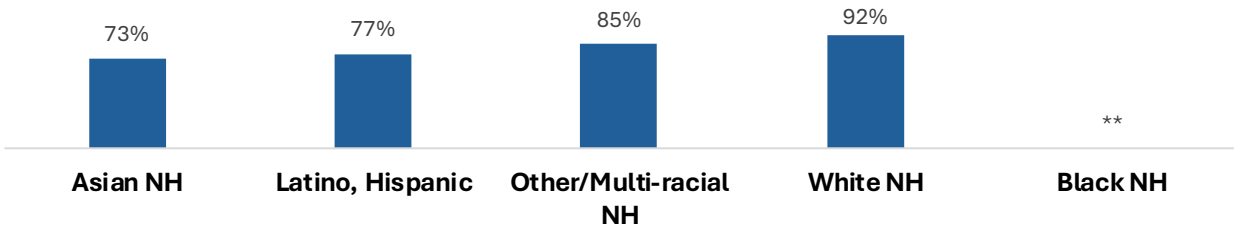
Among all five components of a medical home, the greatest percentage of Oregon CYSHCN reported having a usual source of sick care (Exhibit 9). A usual source of sick care may be provided through primary care. In Oregon, some sub-populations of CYSHCN reported good access to primary care. For example, 95% percent of families whose child receives services for intellectual and developmental disabilities reported that they were always or usually able to see a primary care provider (PCP) when needed (National Core Indicators, 2022), and 93% of youth who receive Medicaid funded mental health services reported having a PCP (Comagine Health, 2022). However, primary care was the fourth most common concern brought to Oregon Health Plan's Ombuds program, suggesting that access to primary care is a challenge for some Oregon communities (OHA Ombuds Program, 2023b).

Results from analysis of 2021-2022 NSCH data showed that a smaller proportion of Oregon CYSHCN from Asian, Latino, and other/multi-racial backgrounds had a usual source of sick care compared to White CYSHCN and their families. While over 90% of White CYSHCN had a usual source of sick care, only about three-quarters of Asian and Latino CYSHCN had the

[4] Findings related to family-centered care are summarized in Chapter 3 (Vega-Juárez et al., 2025).

same access (Exhibit 10). The sample size for Black CYSHCN is too small to produce a reliable estimate.

Exhibit 10. Percent of Oregon CYSHCN Who Had a Usual Source of Sick Care by Race/Ethnicity, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022

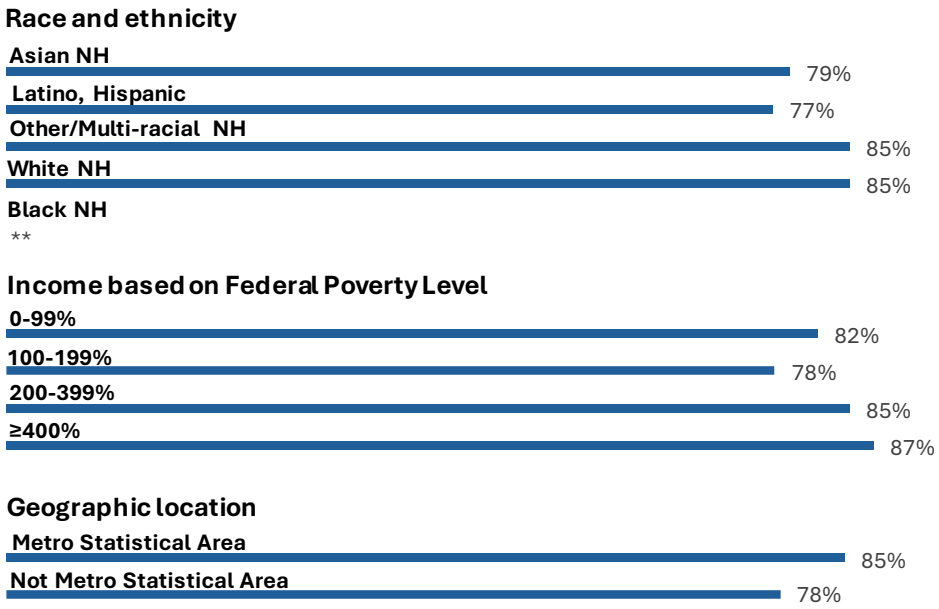
Access to a usual source of sick care also varies slightly by family income and geography. About 81% of families with household incomes below 99% FPL or between 100-199% FPL reported a usual source of sick care, compared to nearly 90% or more families of CYSHCN with incomes higher than 200% of the FPL. There were only slight differences between Oregon CYSHCN living in metropolitan areas (87.8%) and those living outside of metro areas (83.4%).

Personal Doctor or Nurse

Over two-fifths of Oregon CYSHCN had a personal doctor or nurse (Exhibit 9). However, some CYSHCN were less likely to have a personal doctor or nurse, including CYSHCN from Asian and Latino backgrounds, those with fewer economic resources, and those living outside of a metropolitan statistical area (Exhibit 11). The sample size for Black CYSHCN is too small to report.

In Oregon, Coordinated Care Organizations (CCOs) are responsible for ensuring, among other things, that children, who are insured through the Oregon Health Plan (Medicaid), have a personal doctor who knows them. Over the last four years, on average, nearly 90% of child Oregon Health Plan members with chronic conditions – a population of Oregon CYSHCN – had access to a personal doctor who knows them (Center for the Study of Services, 2020; 2021; 2022; 2023). Three CCOs consistently outperformed the state average: Eastern Oregon, PacificSource – Marion Polk, and Yamhill Community Care. Over the last four years, however, fewer children with chronic conditions who received services through Cascade Health Alliance (82% in 2023), Trillium Community Health Plan – South (82% in 2023), and Umpqua Health Alliance (86% in 2023) had a personal doctor who knows them compared to children with chronic conditions receiving services through other CCOs.

Exhibit 11. Percent of Oregon CYSHCN Who Had a Personal Doctor or Nurse by Race/Ethnicity, Income, and Geographic Location, 2021-2022



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

Data Source: OCCYSHN Analysis of NSCH 2021-2022

Access to preventive medical services is one aspect of having a personal doctor or nurse. More than four out of five (84%) Oregon CYSHCN younger than 18 years old received at least one preventive medical visit per year. This was higher than the percentage of non-CYSHCN (74.4%). Despite better access to a personal doctor and preventative medical care, CYSHCN were 5.5 times more likely to go without needed medical care compared to their peers without special health care needs. This finding may result from CYSHCN having a personal doctor or nurse that is not affiliated with a medical home that includes care coordination.

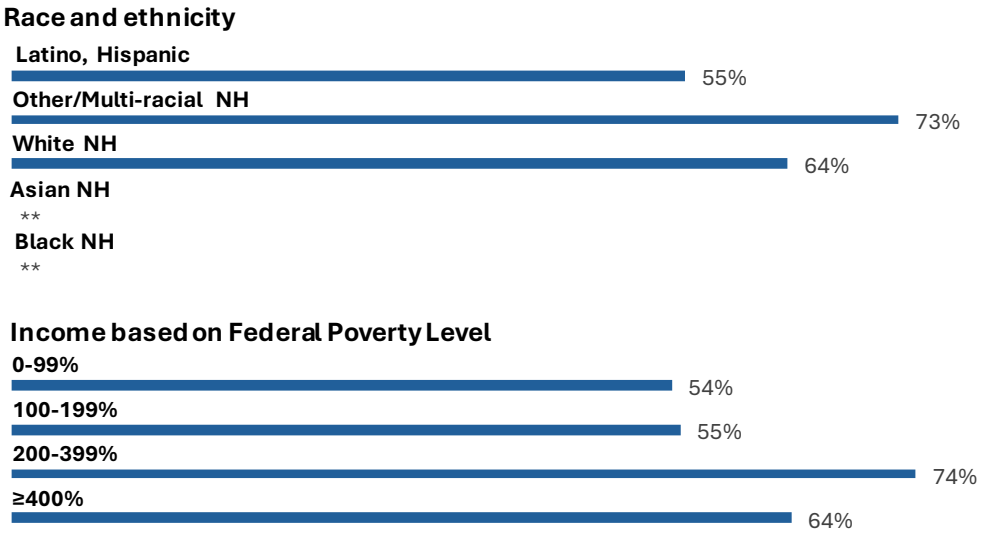
Getting a Referral

CYSHCN often rely on referrals to receive care from different specialties given the diversity and complexity of health conditions they experience. Just under two-thirds (63.4%) of Oregon CYSHCN had no difficulty getting a referral for care. Nearly one-third (35.7%) of Oregon CYSHCN who needed referrals found it somewhat to very difficult to get them, and about 1% were not able to get a referral at all.

Results of our analysis of 2021-2022 NSCH data showed that getting a referral was particularly difficult for CYSHCN from Latino communities and families living at or below 200% of the federal poverty level (Exhibit 12). We are unable to report data for CYSHCN who identify as Asian and Black/African American and who live in non-Metropolitan areas because small sample sizes are too small to produce reliable estimates. Response counts from the sample of surveys collected, however, indicated that respondents from Black families and

families living outside of a metropolitan statistical area tended to report at least some difficulty in getting needed referrals.

Exhibit 12. Percent of Oregon CYSHCN Who Had No Difficulty Getting Needed Referrals, 2021-2022



** *There is an insufficient sample size to produce a reliable estimate*
Data Source: OCCYSHN Analysis of NSCH 2021-2022

Effective Care Coordination

Effective care coordination is a critical service under the medical home model. Given its importance and strategic efforts OCCYSHN makes to support and expand access to care coordination, we dedicated a chapter to findings related to care coordination (see Patterson et al., 2025).

Unfair Barriers to Access

Oregon, like many other U.S. states, experiences greater demand for primary care than its supply of providers (Oregon Office of Rural Health [OORH], 2024). Across all CCOs, for example, the PCP to CCO member ratio is 1:277, with only 18% of PCPs serving children only (OHA, 2025b). In rural and remote communities of Oregon, access to primary care services is more challenging. The average ratio of primary care visits available to visits needed in rural and remote areas is 0.69, whereas in urban areas it is 1.16 (OORH, 2024). Of the 103 primary care service areas in rural and remote areas of Oregon, 9 do not have any PCPs (OORH, 2024). Therefore, it is likely that CYSHCN living in rural communities experience greater difficulty accessing a primary care medical home. Four of seven Community Health Workers we spoke with in rural counties in Oregon reported that Latino families of CYSHCN need primary care services (e.g., prescriptions, immunizations; Patterson et al., 2025).

Consequently, families of CYSHCN living in rural and remote communities in Oregon often must travel to get to primary health care. Travel time to the nearest patient centered primary care home (PCPCH) is, on average, 10 minutes in urban communities, 13 minutes in rural communities, and 22 minutes in remote communities (OORH, 2024). For three rural/remote Oregon communities, travel time to the nearest PCPCH is over an hour (North Lake at 67 minutes, Halfway at 68 minutes, and Jordan Valley at 75 minutes; OORH, 2024). Additionally, the time and distance standard for all CCOs is 30 miles or 30 minutes for members living in urban settings and 60 miles or 60 minutes for those living in rural settings. All CCOs met this standard in 2023; however, as discussed later, some CCOs do not meet these standards for other services (OHA, 2025b).

Other Preventive Health Care

In addition to medical care, we present findings related to other preventive health care services using the NSCH and other data sources. Preventive health care services are, among other reasons, important to reducing the number of preventable hospitalizations. Particularly in rural areas of Oregon, preventive services are limited, and the number of preventable hospitalizations is high. There 5.5 preventable hospitalizations for every 1,000 in urban settings whereas in rural and remote communities, the average number of preventable hospitalizations for every 1,000 people is 7.2 (OORH, 2024). All five communities with the highest rates of preventable hospitalizations are in rural and remote areas of the state: Warm Springs, 21.3; Clatskanie, 14.0; North Lake, 14.0; Reedsport, 13.9; and Shady Cove, 12.1 (OORH, 2024).

Dental Care

Most Oregon children and youth have access to preventive dental care services. Results from our analysis of 2021-2022 NSCH data indicate that more than four in five (85.5%) Oregon CYSHCN had a preventive dental care visit in the preceding 12 months. In comparison, only about three-quarters (77.5%) of non-CYSHCN had a preventive dental care visit. Reports from families of Oregon children who receive intellectual and developmental disabilities services reflect these findings: 84% of children and youth with intellectual or developmental disability reported being able to go to the dentist when needed (National Core Indicators, 2021-22).

Access to dental care for some CYSHCN is more challenging than these figures suggest. For example, the primary care dentist to CCO member ratio in Oregon is 1:1,493 and only 13% of primary care dentists focused on the pediatric population (OHA, 2025b). Additionally, dental services were the third most common concern brought to the Ombuds program among those insured by the Oregon Health Plan in 2023 (OHA Ombuds Program, 2023b). CYSHCN living in rural communities are much less likely to have access to dental services. Dental providers in rural and remote areas offered, on average, 10 fewer hours of services per week, averaging 0.3 FTE per 1,000 people, compared to dental providers in urban areas where there was just over one half-time dentist (0.55 FTE) per 1,000 people (OORH, 2024). Additionally, there were no dentists in nearly one-quarter (23.3%) of Oregon's primary care service areas in rural and remote areas. Findings from interviews with parents of CYSHCN and Community Health Workers in a rural region of Oregon align with these reports as dental services were noted as a

service severely lacking in the area. There was only one pediatric dental clinic in the region, and it was not accepting new patients at the time of data collection in 2023 (Patterson et al., 2025).

> *"Right now, the biggest [service] that I think is [needed is] dental and mental health services. It seems like it's scarce around here. A lot of the families have been trying to get their kiddos into dental services, and there's only one pediatric clinic here, [but it] isn't taking any new clients."*
>
> – CHW in rural Oregon

As a result, families either drive long distances to visit pediatric dental clinics, see a dental provider who typically serves adults, or go without dental care (Patterson et al., 2025).

Vision and Hearing Services

The only data on vision and hearing services available comes from the NSCH. Results of our analyses of 2021-2022 data showed that CYSHCN were more likely to report receiving a vision screening from a provider other than an eye doctor (61.6%) compared to non-CYSHCN (52.7%). There were no substantive differences in vision screenings between CYSHCN with more and less medical complexity (61.6% and 61.8%, respectively). CYSHCN typically received hearing care as needed, with nearly all (99.5%) of Oregon CYSHCN receiving care. A similar proportion of Oregon children without special health care needs reported receiving care (99.4%).

Emergency Services and Planning

Results of our analysis of 2021-2022 NSCH showed that more than twice as many CYSHCN visited the emergency department (ED) at least once annually compared to non-CYSHCN (16% versus 7% respectively). Nearly half of families (43%) of children who receive I/DD services reported that their child did not receive crisis or emergency services when needed (National Core Indicators, 2022).

Given their unique needs and supports, it is important for families of CYSHCN to be able to prepare for emergency situations. The only data we have available on emergency preparedness comes from the National Core Indicators, a survey of families whose child(ren) receive I/DD services. Among these families, more than half (55%) had not discussed how to handle an emergency situation with their child's I/DD service coordinator, suggesting that the burden of emergency planning and preparedness may be on families (National Core Indicators, 2022). However, the majority (83%) of families whose child(ren) receive I/DD services felt prepared to handle their child's needs in an emergency.

Supports for Health Maintenance

We discuss findings related to health care equipment, prescription medication, respite care, specialty care, and specialty services in this section.

Health Care Equipment

Health care equipment may include a range of durable medical equipment, prosthetics, orthotics, and/or medical supplies (DMEPOS). These important supports can be difficult to obtain. For example, over one-quarter (28%) of Oregon children receiving I/DD services had difficulty getting needed special equipment or accommodations (National Core Indicators, 2022). In rural communities, DMEPOS can be especially difficult to access. For example, all CCOs serving members in urban areas met the time and distance standards for durable medical equipment access, which is within 30 minutes or 30 miles (OHA, 2025b). Three CCOs (i.e., Advanced Health, All Care, and Eastern Oregon CCO) did not meet time and distance standards – that durable medical equipment is accessible within 60 minutes or 60 miles – for members living in rural communities (OHA, 2025b).

In 2022, we conducted a root cause analysis of inadequate access to DMEPOS. We found that difficulties in accessing DMEPOS increase when CYSHCN needs and the number of providers involved are high (OCCYSHN, 2023). Barriers to accessing DMEPOS include:

- Difficulty in scheduling a required meeting that includes an allied therapist, DMEPOS vendor, and the family,
- Insurance requirements related to the timing of documentation submission,
- Inadequate knowledge and information sharing about required documentation, and
- Insurance caps on costs covered for DMEPOS; and other approval-related issues (OCCYSHN, 2023).

Prescription Medication

CCOs are responsible for, among other things, ensuring that CYSHCN who receive Medicaid benefits have access to prescription medication. The majority (87%) of Oregon children with chronic conditions insured by Medicaid who use prescription medicine reported receiving prescription medications in 2023, fewer CYSHCN receiving coordinated care through Cascade Health Alliance, Trillium Community Health Plan – North, Umpqua Health Alliance, and Fee for Service reported access to prescription medications in the last four years (Center for the Study of Services, 2020; 2021; 2022; 2023). A greater proportion of CYSHCN whose care is coordinated through the following CCOs received prescription medication: Eastern Oregon CCO, InterCommunity Health Network CCO, Jackson Care Connect, PacficSource – Central Oregon, PacficSource – Columbia Gorge, and PacficSource – Marion Polk (Center for the Study of Services, 2020; 2021; 2022; 2023).

Respite Care

We found that respite care is a considerable need for Oregon families of CYSHCN in previous five-year needs assessments (Martin et al., 2015; Roy et al., 2020), and we continue to see this need. Respite care is the number one need for families of children who receive I/DD services, with 69% of families reporting that they need respite care services (National Core Indicators, 2022). Over half of families who need respite care reported that they sometimes (23%) or seldom/never (35%) get the respite care services they need (National Core Indicators, 2022).

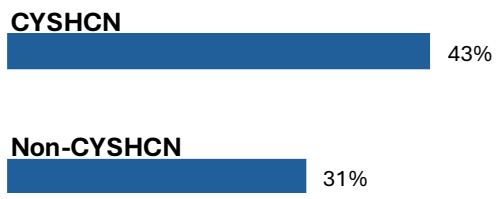
While respite care is difficult to access for many families, some families find respite care to be nearly impossible to find. In a root cause analysis of the challenges to accessing respite care, we found that Black and Latino families of CYSHCN and families living in rural areas of Oregon have more difficulty accessing respite care (Vega-Juárez & Freney, 2022).

Specialty Care from Subspecialists

Specialty care can include services from subspecialty providers, like cardiologists, endocrinologists, gastroenterologists, surgeons, and others. Ombuds for the Oregon Health Plan have cited problems with access to subspecialists. For example, specialty care was the number one concern brought to the Ombuds program for the Oregon Health Plan in 2023 (OHA Ombuds Program, 2023b). They also acknowledged that families who speak languages other than English have more difficulty accessing specialty care services (OHA Ombuds Program, 2023b).

CYSHCN have a greater need for specialty care than non-CYSHCN. Less than one out of 10 (6.7%) non-CYSHCN needed specialty care from subspecialists in 2021-2022 compared to nearly one-third (27.4%) of Oregon CYSHCN. Of those who needed specialty care, CYSHCN were nearly 8 times more likely to have difficulty obtaining specialty care services from subspecialists compared to non-CYSHCN (Exhibit 13).

Exhibit 13. Percent of CYSHCN and Non-CYSHCN Who Reported Difficulty Obtaining Needed Specialty Care, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022

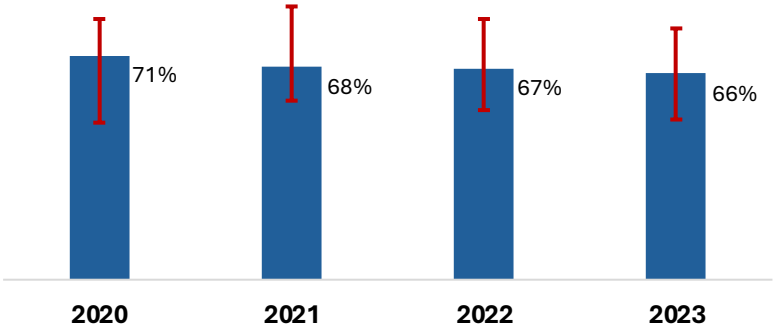
Specialty Therapies and Other Specialty Services

CYSHCN often rely on specialty services such as therapies (e.g., occupational, physical, speech, vision), professional home health care and home visits, hospice care, and others. Most of the available data refer to specialty needs and access to specialty services broadly. Little data describes the needs for and access to specific services like therapies, home health care, etc. We present findings related to the general topic of specialty services first and then present the few findings available related to specific specialty services.

The percent of Oregon CYSHCN on Medicaid who received needed specialty services decreased in recent years (Center for the Study of Services, 2020; 2021; 2022; 2023). Only about two-thirds of CYSHCN on Medicaid received needed specialty services in 2023, which

is down from 71% in 2020 (Exhibit 14). Since 2020, CYSHCN whose care is coordinated by the following CCOs consistently reported having better access to specialty services: AllCare CCO, Cascade Health Alliance, Eastern Oregon CCO, Jackson Care Connect, Pacific Source – Central Oregon, Pacific Source – Columbia Gorge, and Pacific Source – Marion Polk. Fewer CYSHCN served by Health Share of Oregon, Trillium Community Health Plan – North, Trillium Community Health Plan – South, and fee-for-service reported usually or always having access to specialty services (Center for the Study of Services, 2020; 2021; 2022; 2023).

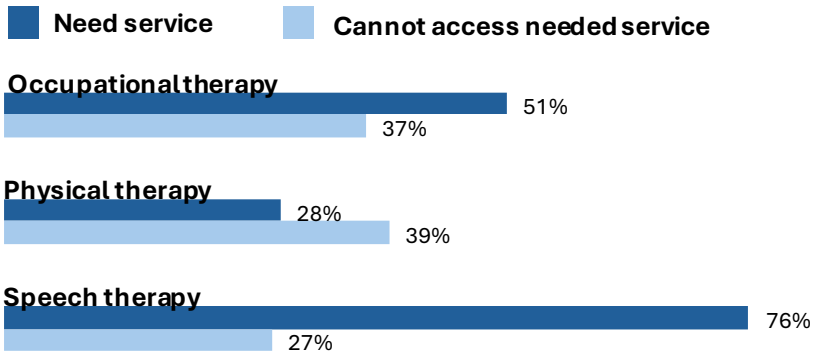
Exhibit 14. Percent of CYSHCN Who Received Medicaid Benefits and Usually or Always Had Access to Specialty Services, 2020-2023



Data Source: Center for the Study of Services, Banner Books 2020-2023

Some of the most needed specialty services are allied therapies including occupational, physical, and speech therapies. In a survey of Oregon parents of young children, speech therapy was reported as the highest need among parents of CSHCN (Exhibit 15; Pears et al., 2022a). Despite substantial need, between one-quarter and two-fifths of these families could not access needed services (Exhibit 15; Pears et al., 2022a). Additionally, Black or African American families of CSHCN reported the most difficulty accessing specialty services compared to families from other racial/ethnic communities (Pears et al., 2022a).

Exhibit 15. Percent of Parents of Young CSHCN Who Needed and Could Not Access Specialty Services, 2022



Data Source: Pears et al., 2022a

In rural Oregon communities, specialty services are lacking. In interviews and facilitated discussions with Community Health Workers and Latino parents of CYSHCN living in a rural region of Oregon, we heard that allied therapies, including occupation, physical, and speech therapies, home health, and ABA therapy, were greatly needed (Patterson et al., 2025).

> *"Este, estaba atendiendo a las terapias ocupacional, de habla, y física. Ya casi no porque ya no había terapistas, y de hecho acaban de cerrar el lugar donde lo llevábamos."*
>
> – Latino parent of a CYSHCN in rural Oregon
>
> English Translation: *"Well, he was attending occupational, speech, and physical therapy. Not so much anymore because there weren't therapists, and actually they just closed the place where we were taking him."*
>
> – Latino parent of a CYSHCN in rural Oregon

One family even considered moving to a more populated area of the state so that their child had better access to needed services:

> *"…estábamos pesando a mover a Gresham cuando abran este centro para niños con autismo de ABA. Y le dije a mi esposo, 'nosotros tenemos que ir a donde están los servicios porque siento ahorita no van a venir a nosotros."*
>
> – Latino parent of a CYSHCN in rural Oregon
>
> English Translation: *"…we were thinking about moving to Gresham when they open this ABA center for Autistic kids. And I told my husband, 'we have to go where the services are because I feel like right now they're not going to come to us."*
>
> – Latino parent of a CYSHCN in rural Oregon

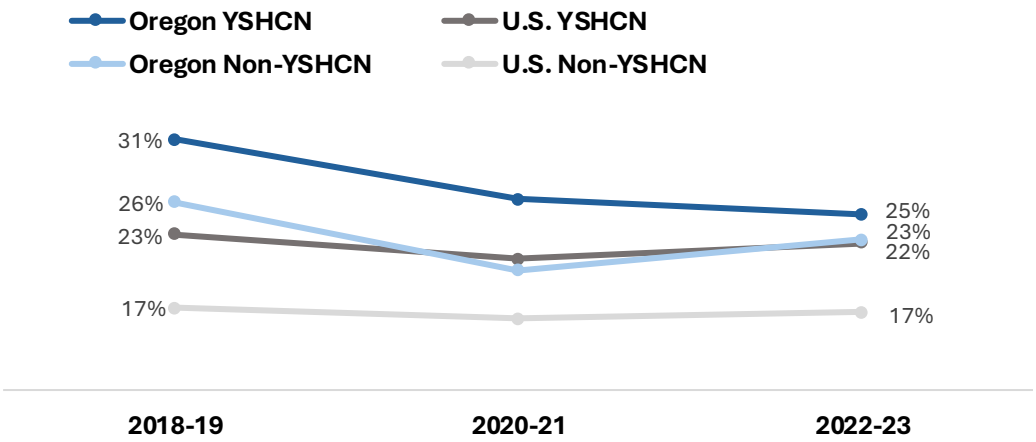
Health Care Transition Preparation

Health care transition is the process of moving from pediatric to an adult model of health care (White & Cooley, 2018). Distinct differences exist between pediatric and adult models of the health care systems; for example, a pediatric model of care engages the family in joint decision-making whereas an adult model of health care expects that a patient can independently make decisions and navigate the health care system (Castillo & Kitsos, 2017). The process of transition has three phases: 1) preparation, 2) transfer between providers, and 3) integration with adult providers. Preparing for this change should begin around 12-14 years of age by helping the patient take a greater role in their health and care management. Transfer to a new provider should occur between the ages of 18 and 21. While health care transition is important for all young adults, it is a critical period for young adults with special health care needs (YSHCN) because YSHCN often rely on the support and care of their family members to coordinate and access health care and make decisions about the course of treatment.

In collaboration with the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians, Got Transition published a set of six standards for the transition to adult health care (Got Transition, 2020). Some of these standards are captured in the Maternal Child Health Bureau's measure of transition to adult health care using NSCH data. The measure consists of three preparation-related components: 1) YSHCN talking with a provider privately during an appointment, 2) provider actively works with the YSHCN to understand the changes that happen at age 18, and 3) provider actively works with the YSHCN to gain skills to manage their care. CYSHCN and their families are identified as having received services necessary to transition when all three of these aspects of care are received.

As previously described, all three components of health care transition preparation need to be met to be considered having received transition services. Although a greater number of transition aged YSHCN in Oregon received transition services than YSHCN nationally, fewer than one-third of Oregon YSHCN received all three components in preparation of the transition to adult care (Exhibit 16). Results of our analysis of 2021-2022 NSCH data showed that about one in ten (9.0%) YSHCN reported receiving *none* of the three.

Exhibit 16. Percent of YSHCN Who Received Services to Transition from Pediatric to Adult Health Care in Oregon and Nationally, 2018-2023



Data Source: CAHMI Interactive Data Website, 2018-2023

Some YSHCN are less likely to receive health care transition services (Exhibit 17), including YSHCN who:

- Identify as male,
- Have public insurance, or
- Live below 200% of the federal poverty level.

Although sample sizes of YSHCN from Asian, Black, and other/multi-racial communities are too small to produce reliable estimates, patterns of responses from families in these communities tended to be similar to those found in broader YSHCN population.

Exhibit 17. Percent of YSHCN Who Received Health Care Transition (HCT) Services by Demographic Characteristic, 2021-2022

	Received Healthcare Transition, age 12-17 yrs			Received Healthcare Transition, age 12-17 yrs	
	Yes	**No**		**Yes**	**No**
Biological sex			**Income based on Federal Poverty Level**		
Male	19.1%	80.9%	0-99%	**	**
Female	34.6%	65.4%	100%-199%	21.2%	78.8%
Race and ethnicity			200%-399%	28.9%	71.1%
Asian NH	**	**	≥400%	28.6%	71.4%
Black NH	**	**	**Metropolitan statistical area status**		
Latino, Hispanic	27.0%	73.0%	Metropolitan Statistical Area	26.5%	73.5%
Other/Multi-racial NH	**	**	Not Metropolitan Statistical Area	**	**
White NH	25.8%	74.2%	**Complexity of health care needs**		
Insurance type			Less complex	28.2%	71.8%
Public health insurance only	21.9%	78.1%	More complex	27.1%	72.9%
Private health insurance only	28.3%	71.7%			
Private and public	**	**			
Not insured	**	**			

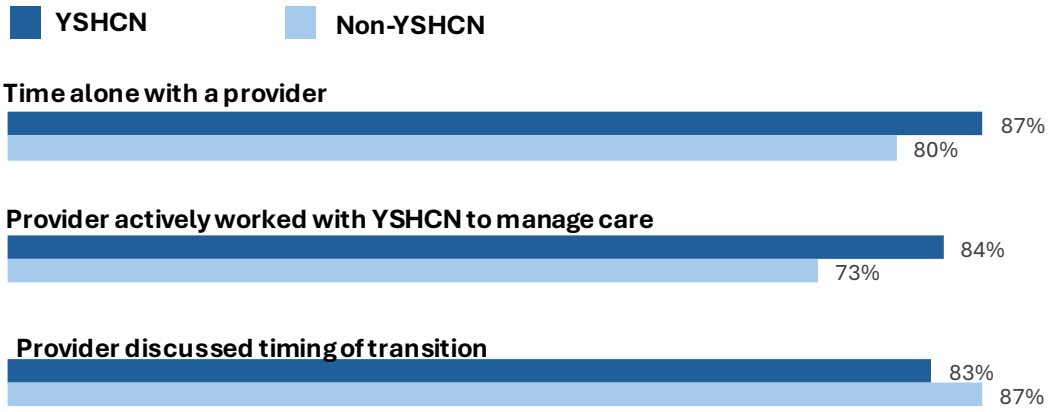
Abbreviations. yrs = years; NH = Non-Hispanic

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

Data Source: OCCYSHN Analysis of NSCH 2021-2022

Although only about one quarter (26%) of YSHCN received *all three* components of transition to adult health care preparation, a high proportion of YSHCN reported receiving at least one aspect of health care transition services (Exhibit 18). This indicates that the majority of YSHCN receive one or two health care transition services, but they do not receive all three services that prepare YSHCN for the transition to adult health care.

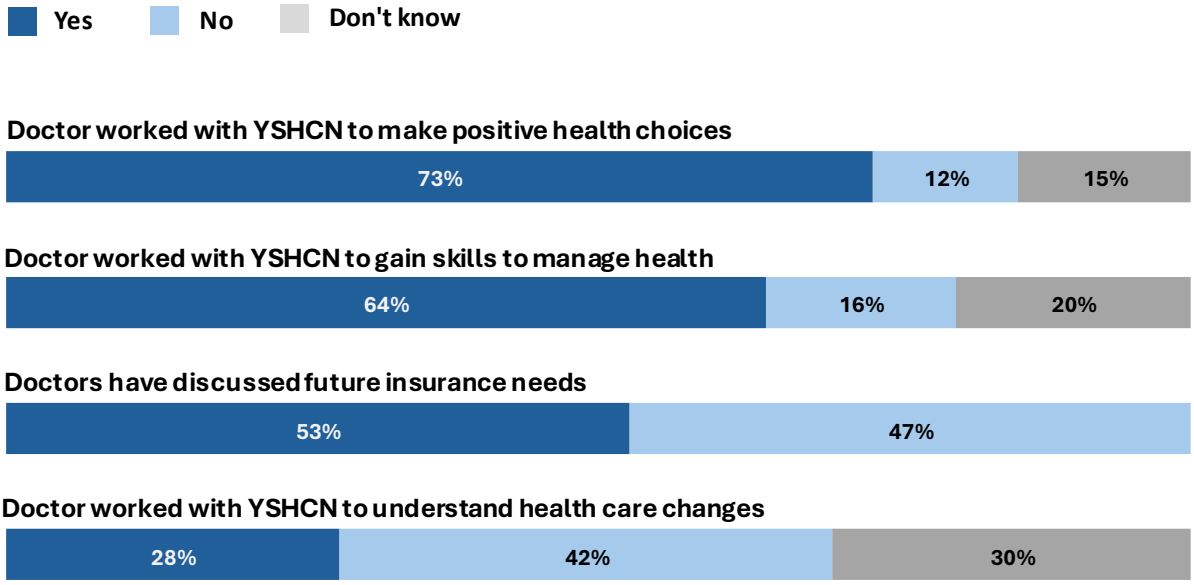
Exhibit 18. Percent of Oregon YSHCN Who Had Access to Each Component of Health Care Transition Services, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022

Additional NSCH items describe health care transition services provided to YSHCN by their doctors (Exhibit 19). The majority (73%) of YSHCN reported working with their provider to make positive health choices and gain skills to manage their health (64%). Nearly half (47%) reported that their provider has *not* discussed future insurance needs. Only about one-quarter (28%) had the opportunity to work directly with their doctors to understand health care changes when transitioning into adult care.

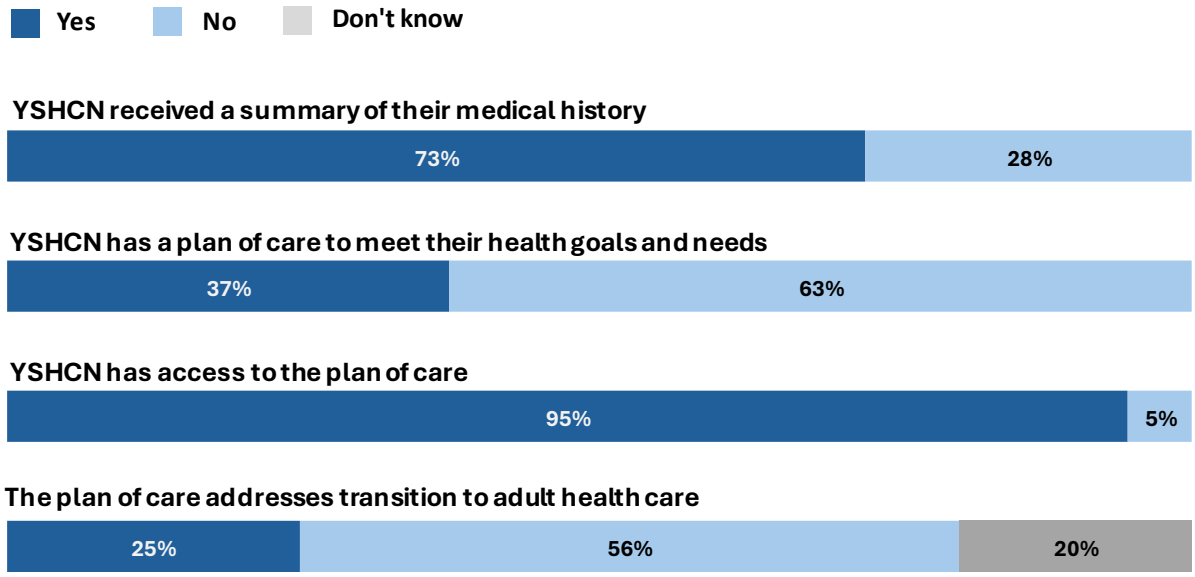
Exhibit 19. Percent of Oregon YSHCN Whose Doctor Provided Health Care Transition Services, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022

Additionally, although YSHCN often received a summary of their medical history, few had a plan of care and even fewer had a plan of care that addresses transition (Exhibit 20).

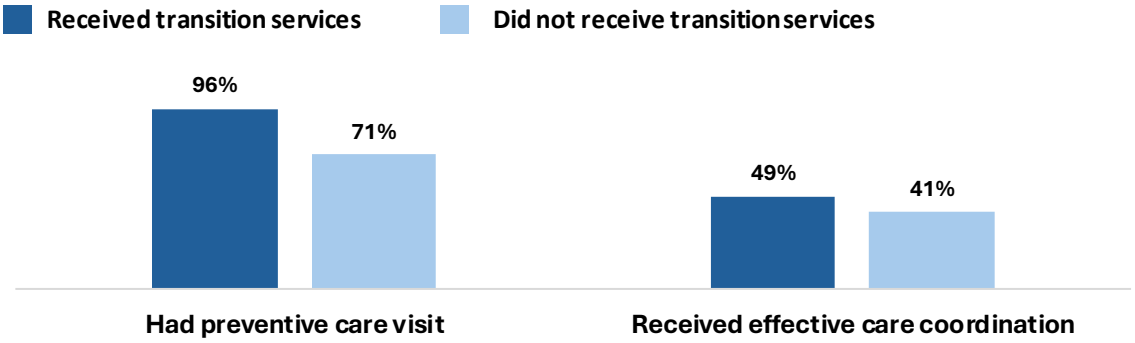
Exhibit 20. Percent of Oregon YSHCN Who Had Access to Different Health Care Transition Services, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022

The importance of health care transition services is underscored by differences in receipt of care for YSHCN with and without health care transition services. YSHCN who received health care transition services were more likely to receive preventive care and effective care coordination compared to YSHCN who did not receive health care transition services (Exhibit 21).

Exhibit 21. Percent of Oregon YSHCN Who Received Preventive Care, and Effective Care Coordination by Receipt of Health Care Transition Services, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022

Access to Services Facilitators

Getting access to critical health care services discussed so far may depend on external factors, such as interpretation, transportation, and telehealth options. Next, we present our findings on these facilitators of service access for CYSHCN.

Interpretation & Other Language Services

Language services such as interpreters and translators are invaluable, and challenges with accessing quality interpretation services is a significant barrier to accessing needed health services. Research shows that language barriers affect multiple aspects of health care, including access, health status, use of services, patient communication with providers, satisfaction with care, and quality of care (Mosquera & Samuels, 2016). Oregon's systems that serve CYSHCN are not consistently meeting families' language service needs, creating barriers to service access and poor service quality for families who speak a language other than English.

Families who speak a language other than English reported experiences with not having an interpreter provided and canceled appointments because they did not bring an interpreter to the appointment, or the clinic did not schedule one (Gallarde-Kim et al., 2025; OCCYSHCN, 2024; OHA Ombuds Program, 2023b; Patterson et al., 2025). Immigrant Latino families of CYSHCN also described challenges accessing interpretation services. For example, family members reported that requests for interpretation services created delays in getting an appointment (Gallarde-Kim et al., 2020a). Additionally, some Vietnamese parents of CYSHCN report challenges with communicating with their child's providers and scheduling interpreters (Gallarde-Kim et al., 2025). Additionally, those who are deaf and hard of hearing had trouble accessing accessible services (OHA Ombuds Program, 2023b). Providers were also unaware of resources and tools available to support language access for patients (OHA Ombuds Program, 2023b).

OHA's Ombuds (2023b) reported that OHP members who prefer a language other than English access the following services at a lower rate than English-speaking members:

- Specialty care
- Dental care
- Primary care
- Education
- Non-emergent medical transportation
- Emergency departments

When interpreters are provided, the quality of interpretation often is inadequate. Latino families of CYSHCN and Community Health Workers (CHW) in rural Oregon reported a lack of high-quality language interpretation services (Patterson et al., 2025). They shared stories about struggling to understand medical providers and educators at appointments either

because there was none, or the interpreter was not qualified. They described negative outcomes that resulted from the poor-quality interpretation. Families missed or misunderstood important information, and there were misunderstandings between families and professionals. Additionally, interpretation in medical and educational settings for CYSHCN relies on complex and high-level language. The interpreter needs to be knowledgeable and certified to interpret specific terminology. A common complaint among Latino families of CYSHCN and CHWs was that the literal translation of complex and high-level language excluded additional context or information.

> *"I do feel like a lot of the times they hire bilingual workers. They are technically bilingual, but can't fully communicate with the family. So for example, my client who was dealing with the person with DDS, she was technically bilingual, but she couldn't communicate fully with the mom, and the mom was like 'I don't understand you; I need you to speak to me in Spanish.' She's like, 'oh, sorry, my Spanish isn't great.' And so she's just kind of like, 'well, then, why are you my bilingual worker?'"*
>
> – CHW in rural Oregon

Immigrant Latino families of CYSHCN in Central Oregon and Vietnamese families of CYSHCN also described similar experiences with the quality of interpretation in health care settings (Gallarde-Kim et al., 2020a; Gallarde-Kim et al., 2025). For example, they described interpreters not accurately interpreting words, leaving out important information, and not conveying nuances correctly. Because of this, Vietnamese families of CYSHCN described needing to advocate for their child by learning medical terms and communicating directly with the provider using a translation app on their phone. Immigrant Latino families of CYSHCN in Central Oregon described how issues with interpretation quality interfered with the development of a productive provider-family relationship.

As a result of these challenges, some families of CYSHCN who speak a language other than English will utilize a family member as their interpreter. For example, a Vietnamese caregiver of CYSHCN reported that their child is the interpreter at health care appointments (Gallarde-Kim et al., 2025). Some immigrant Latino families of CYSHCN in Central Oregon described that their children or other family members who speak English helped them with interpretation (Gallarde-Kim et al., 2020a).

In Oregon, a CCO incentive metric was created to track meaningful language access to culturally responsive health care services (OHA Ombuds program, 2023b). OHA measures this metric in two ways,

> *"1. CCOs must complete a self-assessment of the language services they provide. CCOs verify whether they meet minimum requirements and provide higher quality and more robust language services over time. 2. CCOs report whether people who've said they want interpreter services get them from a qualified or certified interpreter for each visit to health care"* (OHA, 2025a, p. 7).

In 2023, only four CCOs met the second component of the measure. Although there is room for improvement, this measure is a promising strategy to ensure providers are meeting the language needs of their patients.

Transportation

Transportation, whether a personal vehicle or public transport, can facilitate families of CYSHCN accessing needed services. About one in ten (8.2%) families had forgone health care due to problems securing transportation or child care (OCCYSHN Analysis of NSCH 2021-2022, 2024). This is comparable to the percentage of families without a child with a chronic health condition (12.2%) who did not receive needed health care due to transportation or child care issues. Travel distance and cost of transportation are barriers to securing transportation.

Travel time to attend appointments is most problematic for CYSHCN and their families living in Oregon's rural and remote communities (OORH, 2024; Patterson et al., 2025). As previously described, families who live in urban areas drive, on average, 10 minutes to the nearest Patient Centered Primary Care Home (PCPCH). Families in remote areas drive, on average 12 minutes more (or 22 minutes total), to the nearest PCPCH (OORH, 2024). There are 23 service areas in rural and remote areas of Oregon that do not have a PCPCH, and families must drive to the next service area which is, on average, 27 minutes away (OORH, 2024). Families in three service areas must drive over an hour to get to the nearest PCPCH (North Lake at 67 minutes, Halfway at 68, and Jordan Valley at 75 minutes, on average; OORH, 2024). Rural communities often lack specialty services like allied therapies and needed evaluation services, and families either travel long distances to access these services or never enroll (Education Northwest, 2022; Patterson et al., 2025). Long travel times to appointments was a theme in interviews and facilitated discussions with Latino families of CYSHCN living in a rural Oregon community (Patterson et al., 2025).

> *"Y le dije [a la aseguranza de PacificSource] que es que yo necesitaba que me ayudaran, que encontraran a alguien porque le digo que no hay aquí las terapias. Me recomendaron a este lugar a Beaverton y en Bend… Le dije que yo no puedo manejar dos o tres horas casi de aquí para ir a terapia todos los días."*
>
> – Latino parent of CYSHCN in rural Oregon
>
> English Translation: *"And I said [to PacificSource insurance] that I needed them to help me; that they find someone because I told them that there are no therapies [available] here. They recommended that I go to a place in Beaverton and Bend… I told them that I can't drive almost two or three hours from here to go to therapy every day."*
>
> – Latino parent of CYSHCN in rural Oregon

In some rural communities, it is unrealistic for families of CYSHCN to take public transportation to their child's appointments, especially for specialty services that are not available in their community (Patterson et al., 2025).

Cost of transportation was also a concern, particularly for families in households with fewer economic resources. Education Northwest (2022) found that families in households with fewer economic resources were unable to make appointments or were dropped from services because of the cost of transportation to appointments. We also heard from CHWs in a rural area of Oregon that many of the families they serve are low income and rely on public transportation (Patterson et al., 2025). One CHW underscored the issue with public transportation:

> *"One [service need] that is like super common is helping people with transportation because, I mean you have to get to, if you're applying for anything like HUD or energy assistance, like you have to go to those appointments, and if somebody doesn't have transportation, then they're not going to make it to those appointments..."*
>
> – CHW in rural Oregon

Telehealth

Since the COVID-19 pandemic, telehealth services have become more widely available. To take advantage of these services, families must have access to reliable internet and a device like a computer, tablet, or smartphone. A survey of parents whose child(ren) receive I/DD services showed that most (71%) families had reliable internet, but nearly one-third (29%) of families had access to internet that only sometimes, rarely, or never worked (National Core Indicators, 2022). Internet access can be less reliable in rural areas of Oregon. Some early intervention providers and home visitors working in rural regions of Oregon were unable to provide virtual services because of unreliable or non-existent internet access (Education Northwest, 2022). Corroborating these findings, significantly more youth living in urban communities reported attending a virtual mental health session compared to youth in rural communities (Comagine Health, 2022). Although youth survey participants did not report on internet access directly, one plausible explanation to these findings is limited internet access in rural communities.

Access to a connective device is also critical for telehealth. The large majority of families (94%) whose children receive I/DD services reported that they have access to computer, tablet, or smartphone (National Core Indicators, 2022). However, some families, including those experiencing houselessness may lack access to connective devices and the internet (Education Northwest, 2022).

Access to Intellectual and Developmental Disabilities (I/DD) Services

Several services are provided to CYSHCN by Oregon's Office on Developmental Disability Services, including service coordination and case management, family support, children's

intensive in-home services, and others. Most of the data about access to I/DD services available to us is related to service coordination.

We found mixed results related to access to service coordination services. Results of analysis of survey data collected from families whose child(ren) receive I/DD services indicated that most families (89%) were able to contact their child's service coordinator when they want (National Core Indicators, 2022). However, in interviews we conducted with Latina mothers of CYSHCN and CHWs in a rural part of Oregon, we heard that locating consistent, reliable, and helpful service coordination is difficult (Patterson et al., 2025). One mother described her experience getting bounced around between I/DD service coordinators, with very little contact and support:

> *"In less than one year, [service coordinator] called me twice to give me 3 different case workers for [my child]. Out of those three case workers, nobody ever followed up except one around Christmas time, and she was like, 'oh, I'm calling from [organization]. I want to give you a $100 gift card to Fred Meyer so you guys can spend it for your Christmas dinner.' That was the only thing…it caught me off guard because it's like, OK, you guys never call me. You guys never do anything…It's just like so random that [I had] three case workers in less than a year, only one called…"*
>
> – Latina parent of CYSHCN in rural Oregon

Latino parents of CYSHCN and CHWs noted turnover and lack of communication within organizations as barriers in accessing quality service coordination in their region of the state (Patterson et al., 2025). Additionally, the role of the service coordinator may not be clear to all families. An audit of the I/DD system found that the service coordinator's role in working with other systems to support client needs was unclear to families (OSS, 2021).

Finally, some families may have difficult accessing I/DD services broadly. An audit of the system reported that, "*enrolling in services is not easy and clear for many people; people with varying cultural needs and preferences find it hard to find information and to communicate due to language-access issues*" (OSS, 2021, p. 9).

Access to Early Childhood Education

Early childhood education services (i.e., early learning and child care,[5] early intervention, early childhood special education) are crucial to healthy development of CSHCN and the well-being of their family. However, over the last decade, we consistently found that access to early childhood education services is lacking for Oregon CSHCN (Martin et al., 2015; Roy et al., 2020). Challenges in accessing child care and special education services are related but different, and we summarize our findings for each of these service systems separately.

[5] For the purpose of this Needs Assessment, we consider early learning and child care synonymous and use child care throughout the remaining sections.

Child Care

A dearth of child care slots exists across Oregon communities (First Five Years Fund, 2024; The Ford Family Foundation, 2024). Thirty-five of Oregon's 36 counties are considered child care deserts for infants and toddlers, and 18 counties are child care deserts for preschoolers (Pratt & Sektnan, 2023). The effects of the lack of child care, which include impacts on employment and economic productivity (First Five Years Fund, 2024; Pears et al. a, 2022a), are felt across many Oregon families. Families of CSHCN, however, encounter specific and unique barriers to accessing high-quality child care.

In a statewide survey of Oregon families with children ages birth through 5 years, more families of CSHCN[6] (48.6%) reported looking for child care in the past year than families of non-CSHCN (38.6%; Pears et al. a, 2022a). Families of CSHCN typically reported using more combinations of child care settings (e.g., a family sends their child to a center-based program for half-day care, *and* a relative cares for their child the rest of the day) than families of non-CSHCN (Pears et al. a, 2022a). The more child care settings a family uses, the more burden and stress a family may face in coordinating their child's care with their own and their child care providers' schedules. This difficulty is reflected in differences in families' satisfaction with the alignment between their work and child care schedules: over one-quarter (27.8%) of families of CSHCN reported that they do not have enough days of care per week compared to one-fifth (20.3%) of families of non-CSHCN (Pears et al. a, 2022a).

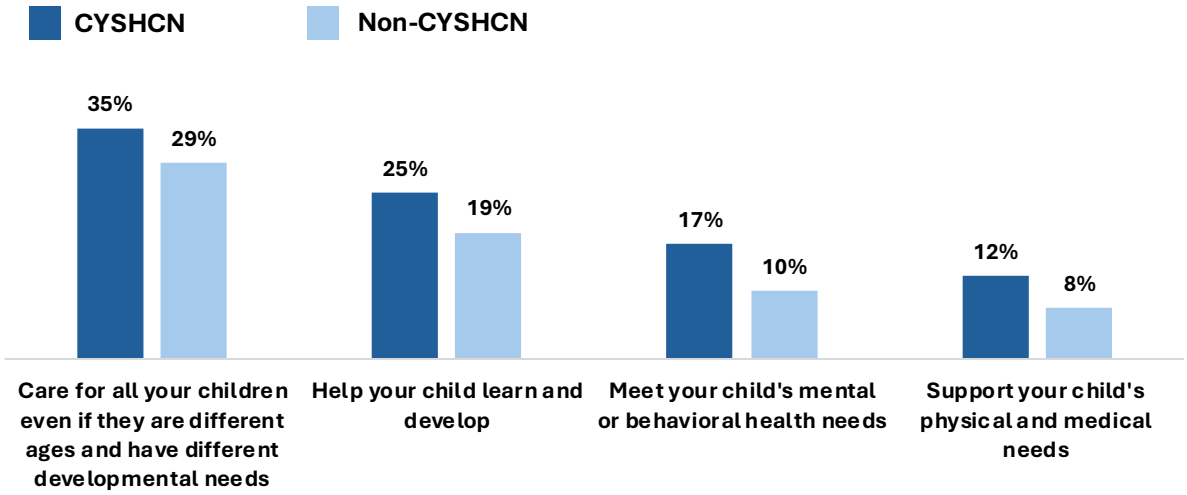
Families of CSHCN reported more difficulties in finding child care providers that meet their child's needs compared to other families (Exhibit 22; Pears et al., 2022a). As described in the quote from an early intervention provider below, medical needs can present unique challenges for some child care providers in supporting young CSHCN.

> *"Speaking about child care, it is nearly impossible for children with mobility disabilities, especially if they require full wheelchair accessibility. Child care providers are unwilling to take children with most health/medical needs, including G tubes, seizures, cathing, etc. Some will take kids who can move themselves around by whatever means, especially home daycares, if they don't require a wheelchair, and some have been amazing at rising to a challenge—getting [ankle foot orthoses] on, using walkers, putting on hearing aids and glasses, etc. However, if the kids can't move much, once they are beyond babyhood, people are much more reluctant. … even when a building is wheelchair accessible, the bathroom is often not, and the only accessible playground I've found… is at Head Start."*
>
> – Early Intervention Provider (Education Northwest, 2022, p. 24)

[6] The report identifies these children as "children with an IFSP, a developmental disability, or chronic medical needs." We shortened this language and refer to "CSHCN" instead.

Additionally, child care providers and administrators have acknowledged that specific program requirements, especially those related to potty training, can be significant barriers to finding child care for CSHCN (Education Northwest, 2022).

Exhibit 22. Percent of Families of CSHCN and Non-CSHCN Who Had Difficulty Finding Child Care Providers Who Met Their Needs, 2022



Data Source: Pears et al., 2022a

There are very few child care slots available for children who receive special education services, particularly in rural regions of the state (Education Northwest, 2022). We also heard about difficulties in finding early learning programs for CSHCN from families in rural communities. In two of the six interviews we conducted with Latina mothers living in rural Oregon, they described finding high-quality child care for their young CSHCN as a challenge.

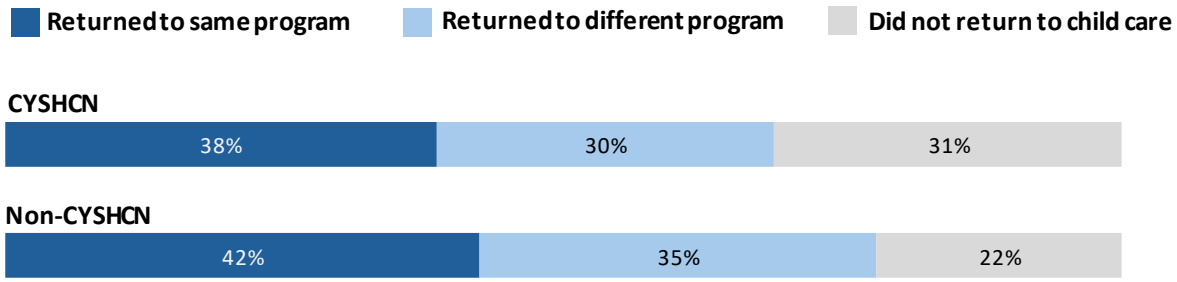
> *"I feel that the hardest part is trying to find a child care provider that will accept a child with high needs."*
>
> – Latino parent of CSHCN in rural Oregon

In addition to difficulties finding providers who can meet families' needs, families of CSHCN face additional barriers related to affordability and program requirements. One report noted that child care providers recognized that the cost of child care is prohibitive for families with children who receive special education services and who do not qualify for state or federally funded preschool (Education Northwest, 2022). The high cost of care was also a top concern for respondents of the statewide survey of families of young children, where about one-fifth of all Oregon families (18.9% of families of CSHCN and 21.4% of families of non-CSHCN) reported cost as a barrier to care (Pears et al., 2022a).

CSHCN are also asked to leave or take a break from child care programs at higher rates than non-CSHCN. Results from the statewide survey of families of young children found that *"children with IFSPs, developmental disabilities or medical needs were 3 times more likely to*

be asked to leave care than their peers without such needs (22.1% vs. 7.1%, respectively)" (Pears et al., 2022a, p. 41). According to survey respondents, CSHCN were asked to leave care most often because the child care provider could not manage their child's behavior (43.6%) or could not meet their child's developmental needs (22.7%; Pears et al., 2022a). CSHCN who were expelled were also less likely to return to care (see Exhibit 23; Pears et al., 2022a).

Exhibit 23. Percent of Families of CSHCN and Non-CSHCN Whose Child Returned to Care After Expulsion, 2022



Data Source: Pears et al., 2022a

Early Intervention and Early Childhood Special Education

Early intervention and early childhood special education (EI/ECSE) services sit at the intersection of healthy development and access to education for many CSHCN. EI/ECSE services provide CSHCN and their families with resources to gain skills and support learning and growth (Northwest Regional Education Service District, n.d.). Services can include coaching and physical, occupational, or speech and language therapies (Northwest Regional Education Service District, n.d.). Therefore, it is critical that CSHCN have access to high-quality EI/ECSE services.

Over half (54.5%) of parents of CSHCN ages 0 to 5 years said that their child needs developmental or special education classroom services (Pears et al., 2022a). This was the third highest need for families of CSHCN in the survey sample, preceded by speech therapy (76.1%) and mental or behavioral health services (54.7%). Over one-third (38.0%) of families of CSHCN had difficulty accessing developmental and special education services, and reports of difficulty were highest among some communities of interest (Exhibit 24, Pears et al., 2022a).

Exhibit 24. Access to Developmental and Special Education Services for Communities of Interest

Group	Access to Mental and Behavioral Health Services Findings
Rural and remote Oregonians	• About two in five (43.0%) CSHCN who live in urban regions of the state reported difficulties in accessing developmental or special education services, and nearly one-third (29.4%) of

Group	Access to Mental and Behavioral Health Services Findings
	families of CSHCN in rural regions experienced this difficulty (Pears et al., 2022a). • A greater percentage of families of CSHCN living in Frontier regions of Oregon reported having trouble accessing developmental or special education services (Pears et al., 2022a).[7]
Race and ethnicity	• Over half of parents of CSHCN from Latino (52.4%), Asian, American Indian or Alaska Native, and African American or Black (60.6%) backgrounds said that they were not able to access needed mental or behavioral health services for their child (Pears et al., 2022a).[8] • Substantially fewer White parents of CSHCN (40.2%) reported difficulty accessing mental or behavioral health care services for their child (Pears et al., 2022a).

Navigating the EI/ECSE referral and intake process is challenging, particularly for families in households with fewer economic resources, families living in rural communities, and migrant families (Education Northwest, 2022). Wait times for an evaluation or for receiving services can be up to 3 months, and this can be even longer for families in households with fewer economic resources and families from migrant communities (Education Northwest, 2022). Migrant families working in agricultural communities often need EI/ECSE services during the summer when their seasonal work peaks, but services are limited during that time (Education Northwest, 2022). These challenges create barriers to prompt evaluation and delays in service access, which ultimately negatively affect a child's development and condition management (Batz & Yadav, 2024).

Families who speak a language other than English also face challenges accessing EI/ECSE services. EI/ECSE providers reported that it is "*burdensome and challenging*" to find interpreters, especially for languages other than Spanish (Education Northwest, 2022, p. 45). They reported that intake coordinators experience challenges when families return calls in a language other than English and an interpreter might not be available. Early childhood education providers reported that they did not have capacity to provide translation or interpretation during IFSP meetings and the EI/ECSE contractor did not always provide these services (Education Northwest, 2022). They also identified a need for bilingual instructional assistants and staff members in ECE settings (Education Northwest, 2022). As a result of these challenges, an EI/ECSE administrator reported that, "*sometimes we have family members translating for us*" (Education Northwest, 2022, p. 45). Using family members as interpreters is against the law. According to the U.S. Departments of Justice and Education

[7] We excluded percentages for families of CSHCN living in Frontier regions of Oregon due to small sample sizes.
[8] We excluded percentages for families of CSHCN from Asian and American Indian or Alaska Native backgrounds due to small sample sizes.

(n.d.), schools may not ask the students, friends, family members, or unstrained school staff to interpret for parents. Schools are required to provide effective language assistance through a competent interpreter at no cost to the parents.

Once families enroll their CSHCN in special education services, there is no guarantee that the services will meet their child's needs. An audit of Oregon's special educational system found that *"students do not receive the level of services needed, and the needs of students with high needs are met least often"* (Garber et al., 2020a, pp. 9-10). While about two-thirds (61.2%) of CSHCN with low service needs received adequate service levels, less than one percent of young CSHCN with the highest needs received adequate service levels (Exhibit 25, Garber et al., 2020a).

Exhibit 25. Percent of Families of Young CSHCN Who Received Adequate Service Levels by Level of Need, 2018-2019

Data Source: Garber et al., 2020a

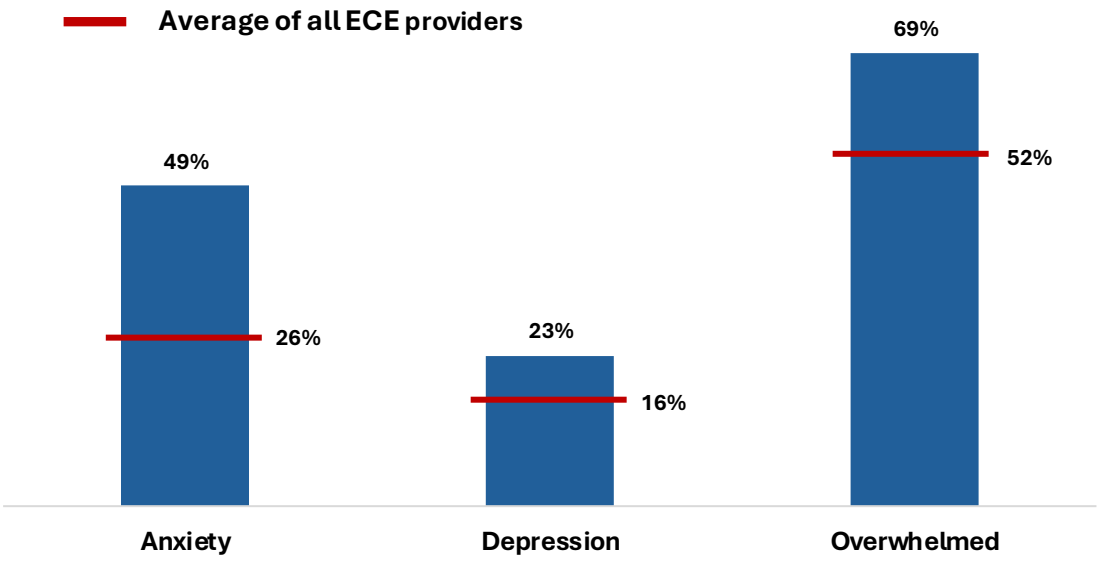
Unfair Barriers to Access

Several reports found that specific systems failures, including high caseloads, burnout and turnover, and lack of funding, may be to blame for inadequate service provisions. First, special education service providers have high caseloads and are unable to keep up with demand (Education Northwest, 2022; OSS, 2020). Second, the stress of high caseloads may be causing special education service providers to leave the field (OSS, 2020). In a statewide survey of early childhood providers, EI/ECSE specialists consistently reported the highest levels of anxiety, depression, and feelings of being overwhelmed (see Exhibit 26, Pears et al., 2022b). Subsequently, there is high turnover in these positions and insufficient staffing results in the needs of CSHCN, particularly those with complex needs, going unmet (Education Northwest, 2022).

Finally, although the state can waive the funding cap for special education services, *"the state was only able to provide about a third of the total dollars needed to fully fund the cap waivers"* (Garber et al., 2020a, p. 12). While it was anticipated that the Student Success Act (SSA) would provide increased funding, it was not expected to fully cover the cost of the cap waivers for special education services (Garber et al., 2020a). In the 2023-2025 biennium, SSA funds for EI/ECSE totaled $93.8 million (SSA, 2023); however, funding continues to be

inadequate (Oregon School Boards Association, 2025). Current legislation (Senate Bill 868, House Bill 2953, House B 2448, and House Bill 2682) seeks to address inadequate funding for special education services, including EI/ECSE (Oregon School Boards Association, 2025).

Exhibit 26. Percent of EI/ECSE Providers Who Reported Feelings of Anxiety, Depression, and Being Overwhelmed at Levels of Possible Clinical Diagnosis Compared to All Early Childhood Providers, 2022



Data Source: Pears et al., 2022b

Summary

We summarize key findings for access to services for CYSHCN and their families:

- CYSHCN persistently have difficulty accessing the following services:
  - Mental and behavioral health care
  - Specialty care from subspecialists
  - Specialty services such as allied therapies
  - High-quality child care, and
  - EI/ECSE services.
- Service access is consistently more difficult for the following communities of interest:
  - Latino CYSHCN and their families,
  - Black/African American CYSHCN and their families,
  - Alaska Native/American Indian CYSHCN and their families,

    - Families of CYSHCN living in rural communities, and
    - Families of CYSHCN with fewer economic resources.
- Interpretation and other language services, which are important facilitators of service access, are often unavailable or poor quality.
- The systems that serve CYSHCN and their families are challenging to navigate generally, and families from households with lower incomes, rural communities, and racial and ethnic communities other than White, experience greater barriers to system navigation.
- There are chronic issues with Oregon's fragmented mental and behavioral health system, which negatively affects CYSHCN, especially those from households with lower incomes, rural communities, and racial and ethnic communities other than White.

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