Care Coordination for Oregon CYSHCN

Chapter 6

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Introduction

> *"Pediatric care coordination is a patient and family centered, assessment driven, team-based activity, designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes"* (Antonelli, McAllister, & Popp, 2009, p. 8).

Families of CYSHCN need support to coordinate the myriad professionals who work with their child and their family. Receipt of care coordination reduces burden on families and increases access to important services (Vasan et al., 2023). Care coordination is identified as a standard of care for CYSHCN (VanLandeghem et al., 2020), one of the seven aspects of medical home (American Academy of Pediatrics, 2002), and a longstanding, CYSHCN-specific focus of the Title V Maternal and Child Health Services Block Grant (U.S. Social Security Administration, n.d.). Care coordination for CYSHCN and their families has been a persistent need in Oregon. OCCYSHN's 2010, 2015, and 2020 needs assessments identified opportunities for improvement. This chapter spotlights the current status of effective care coordination for Oregon CYSHCN.

We begin our findings with a summary of care coordination needs of Oregon CYSHCN and their families. Findings related to barriers to effective care coordination at organizational- and systems-levels are integrated throughout this chapter. We conclude the chapter with a summary of these findings. Appendix A describes the data sources, methods, and analyses used for this chapter.

Findings

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 (n<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.

Less than half of Oregon CYSHCN and their families received effective care coordination that was needed in 2022-2023 (Exhibit 1). Receipt of effective care coordination decreased nationally and in Oregon since 2016-2017. The greatest percentage point decreases between 2016-17 and 2022-23 are for CYSHCN in Oregon (7%) and nationally (9%).

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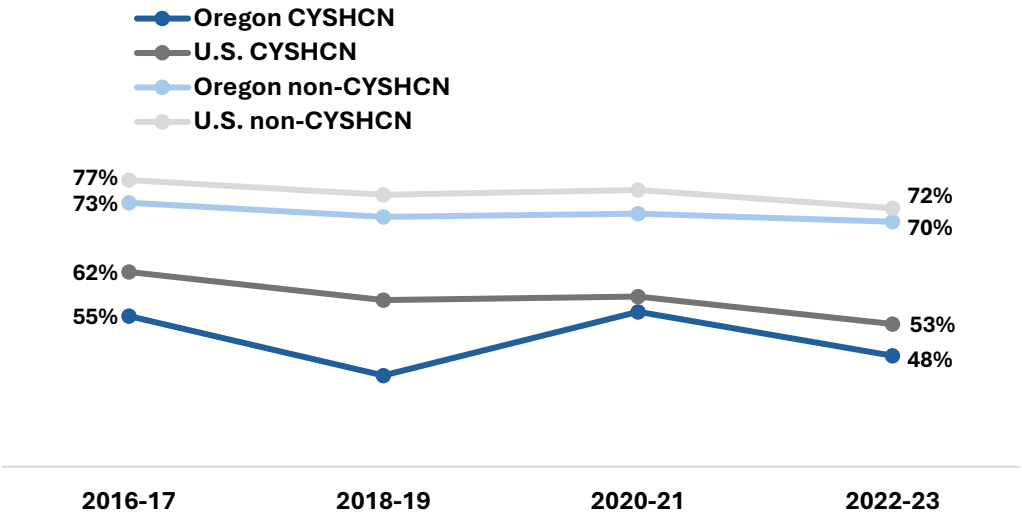
Exhibit 1. Percent of CYSHCN and non-CYSHCN Who Received Effective Care Coordination When Needed in Oregon and Nationally, 2016-2023

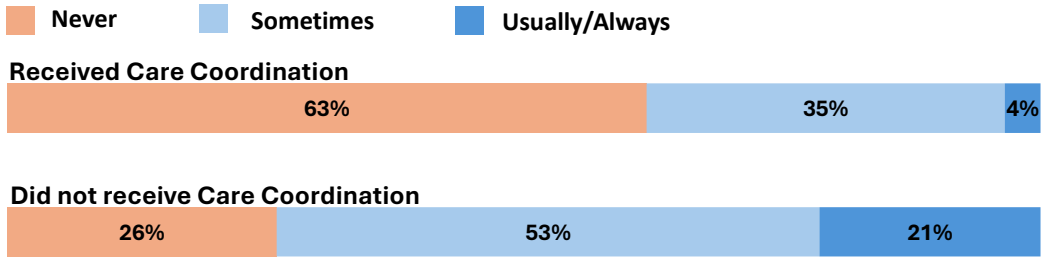


Data Source: Child and Adolescent Health Measure Initiative Data Resource Center's analysis of National Survey of Children's Health data

Family Well-Being, Child Quality of Life, and Care Coordination Gaps

When families of CYSHCN do not receive needed care coordination, they assume the burden of coordinating care for their child. Results of OCCYSHN's analyses of 2021-2022 NSCH suggested that families of CYSHCN were 2.6 times more likely than families whose children did not have special health care needs to spend an hour or more coordinating their child's care per week. About 4 percent of families of CYSHCN reported spending 5-10 hours per week, and about 3 percent reported spending 11 or more hours per week. OCCYSHN analyses previously found that not receiving effective care coordination is associated with financial hardship (OCCYSHN, 2022). These results are not surprising given that eleven hours per week is equal to more than one-quarter of a full-time position (0.28 full-time equivalent [FTE]). Additionally, families of CYSHCN who did not receive needed care coordination were more than five times as likely to be frustrated in their efforts to get services for their child than families of CYSHCN who received care coordination (Exhibit 2).

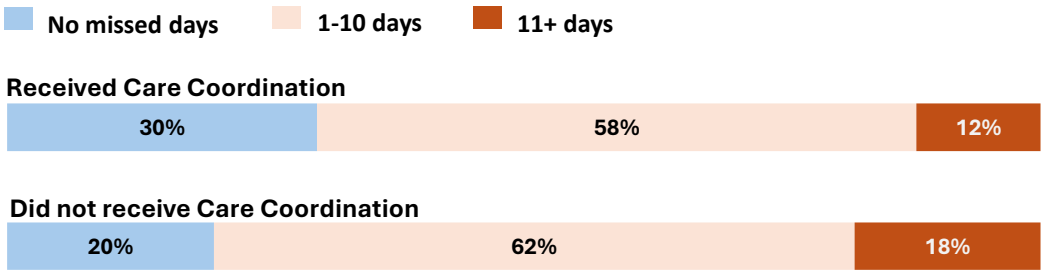
Exhibit 2. Percent of Oregon Families of CYSHCN Who Were Frustrated in Their Efforts to Get Care for Their Child by Care Coordination Receipt, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022

The importance of effective care coordination services for CYSHCN is underscored by our findings that CYSHCN who did not receive care coordination services had more unmet health care needs and missed more school days compared to CYSHCN who received care coordination. Specifically, CYSHCN who did not receive needed care coordination services were 3.9 times more likely to forgo needed health care in the previous year than CYSHCN whose care was coordinated. Additionally, CYSHCN who received needed care coordination services missed fewer days of school compared to CYSHCN who do not receive these services (Exhibit 3).

Exhibit 3. Oregon CYSHCN School Attendance by Receipt of Care Coordination, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022

Communities of Interest

Differences in access to effective care coordination by sociodemographic characteristics exist. The largest proportions of the following groups of CYSHCN reported receiving effective care coordination when needed (Exhibit 4):

- Under the age of 12
- Male
- Hispanic/Latino
- Living in rural communities.

Only half of CYSHCN who are publicly insured received effective care coordination when needed (Exhibit 4). These findings are particularly concerning because Coordinated Care Organizations are charged with providing care coordination for Oregon Health Plan (Medicaid) members. Additionally, Oregon Patient-Centered Primary Care Homes (PCPCH) have care coordination as a standard for recognition (however, the standards do not require care coordination for every population served in a clinic). We examine care coordination for CYSHCN who are publicly insured in more detail below.

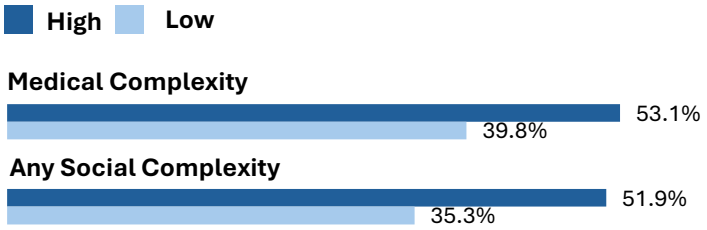
Exhibit 4. Percent of Oregon CYSHCN Who Received and Who Did Not Receive Effective Care Coordination by Sociodemographic Characteristics, 2021-2022

	Received Effective Care Coordination			**Received Effective Care Coordination**	
	Yes	**No**		**Yes**	**No**
Age group (years)			**Metropolitan statistical area**		
0-5	55.1%	44.9%	Metropolitan Statistical Area	48.6%	51.4%
6-11	54.9%	45.1%	Not Metropolitan Statistical Area	58.9%	41.1%
12-17	43.3%	56.7%	**Insurance type**		
Biological sex			Public health insurance only	50.0%	50.0%
Male	53.1%	46.9%	Private health insurance only	50.8%	49.2%
Female	45.7%	54.3%	Public and private insurance	43.8%	56.2%
			Uninsured	**	**
Race and ethnicity			**Income based on Federal Poverty Level**		
Asian NH	**	**	0-99%	45.6%	54.4%
Black NH	**	**	100-199%	47.7%	52.3%
Latino, Hispanic	56.7%	43.3%	200-399%	49.2%	50.8%
White NH	48.8%	51.2%	≥400%	52.2%	47.8%
Other/Multi-racial NH	41.9%	58.1%			

Data Source: OCCYSHN Analysis of NSCH 2021-2022
*Notes. NH = Non-Hispanic/Latino. ** There is an insufficient sample size to produce a reliable estimate*

Results of our analysis of NSCH data also showed that CYSHCN with high medical and high social complexity more often go without receipt of effective care coordination that is needed than CYSHCN with fewer complexities (Exhibit 5).

Exhibit 5. Percent of Oregon CYSHCN Who Did Not Receive Effective Care Coordination, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022

Components of Effective Care Coordination

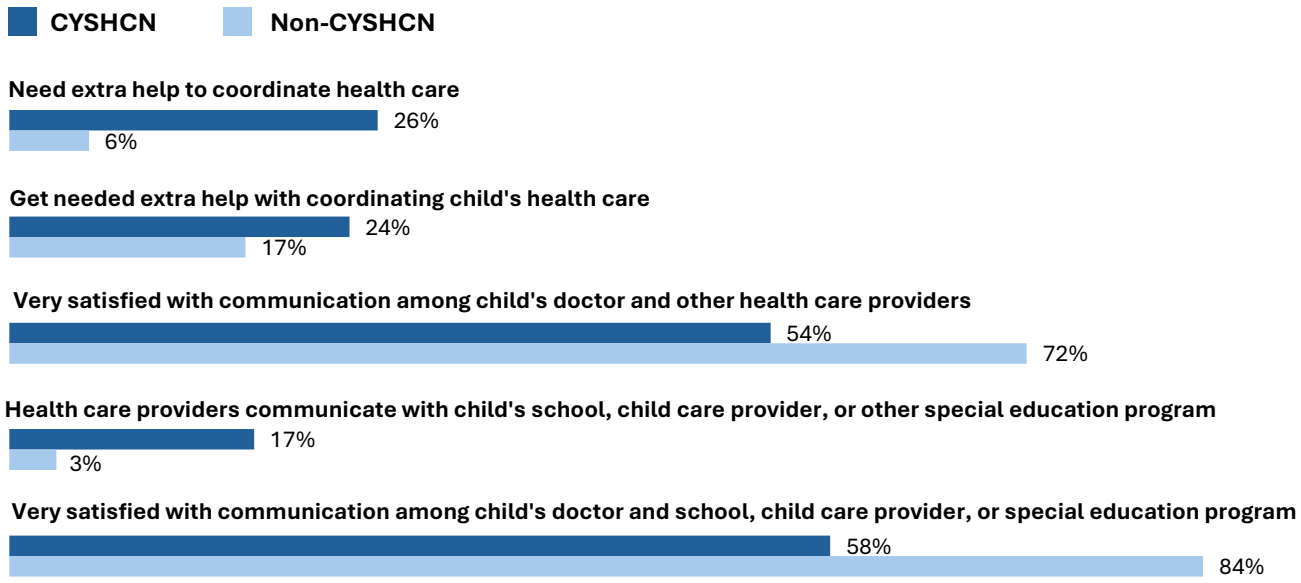
The Maternal and Child Health Bureau (MCHB) and CAHMI compute effective care coordination using five NSCH items. Those are:

1. Families report needing extra help to coordinate their child's health care.
2. For those who need it, families report getting extra help with coordinating their child's health care.
3. Families report being satisfied with the communication among their child's doctor and other health care providers.
4. Families report that their child's health care providers communicate with their child's school, childcare provider, or special education program.
5. Families report being satisfied with communication among the child's doctor and school, childcare provider, or special education program.

About one quarter (26%) of Oregon families of CYSHCN reported needing extra help to coordinate their child's health care (Exhibit 6). A greater percentage of families of CYSHCN reported needing extra help compared to families whose child does not have a special health care need. Of the families of CYSHCN who reported needing help, only one quarter (24%) reported getting it.

About half (54%) of the families of CYSHCN who received two or more services in the previous year were very satisfied with communication with their child's doctor and other health care providers (Exhibit 6). However, nearly three-quarters (72%) of the families whose children do not have special health care needs reported being very satisfied with communication between providers (Exhibit 6). Similarly, fewer families of CYSHCN were very satisfied with communication between their child's doctor and educators (58%) than families whose children did not have special health care needs (84%), when communication was needed. We explore these results by communities of interest in the next sections.

Exhibit 6. Percent of Oregon CYSHCN and Non-CYSHCN Who Had Access to Each Component of Effective Care Coordination, 2021-2022



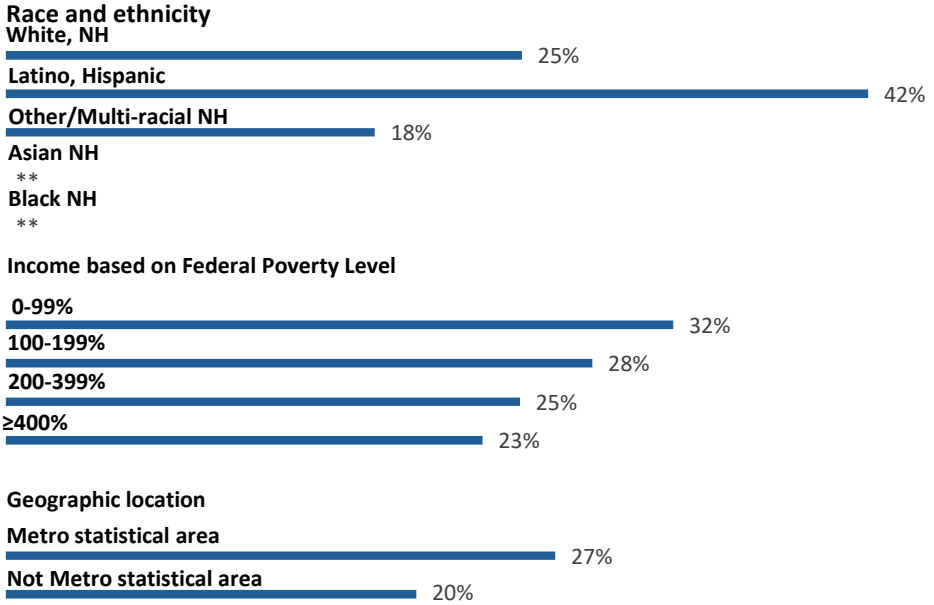
Data Source: OCCYSHN Analysis of NSCH 2021-2022

Need Extra Help to Coordinate Child's Health Care

About one in four (26%) families of CYSHCN needed extra help coordinating their child's health care (Exhibit 6). Results of our analysis of 2021-2022 NSCH showed that Latino families of CYSHCN were over 1.5 times more likely to report needing extra help coordinating their child's health care compared to White, non-Hispanic (NH) families of CYSHCN (Exhibit 7). Small sample sizes for Black, NH and Asian, NH CYSHCN preclude us from reporting findings. However, care coordination was identified as a need by Black and African American families of CYSHCN in about half of the focus groups conducted in our 2020 Needs Assessment (Gallarde-Kim et al., 2020). Additionally, more information about needed help coordinating care for Vietnamese CYSHCN and their families is found in Chapter 4 (Gallarde-Kim et al., 2025).

Exhibit 7 also shows a negative relationship between income and needing extra help coordinating care: the greatest proportion of families of CYSHCN who reported needing extra help coordinating their child's health care (32%) was from families whose households have fewest economic resources. A greater proportion of families of CYSHCN living in urban areas reported needing extra help coordinating their child's health care than CYSHCN families living in rural areas (27% vs. 20%, respectively).

Exhibit 7. Percent of Oregon CYSHCN Who Needed Extra Care Coordination Help by Community of Interest, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022
*Notes. NH = Non-Hispanic/Latino. ** There is an insufficient sample size to produce a reliable estimate*

Get Extra Care Coordination Help

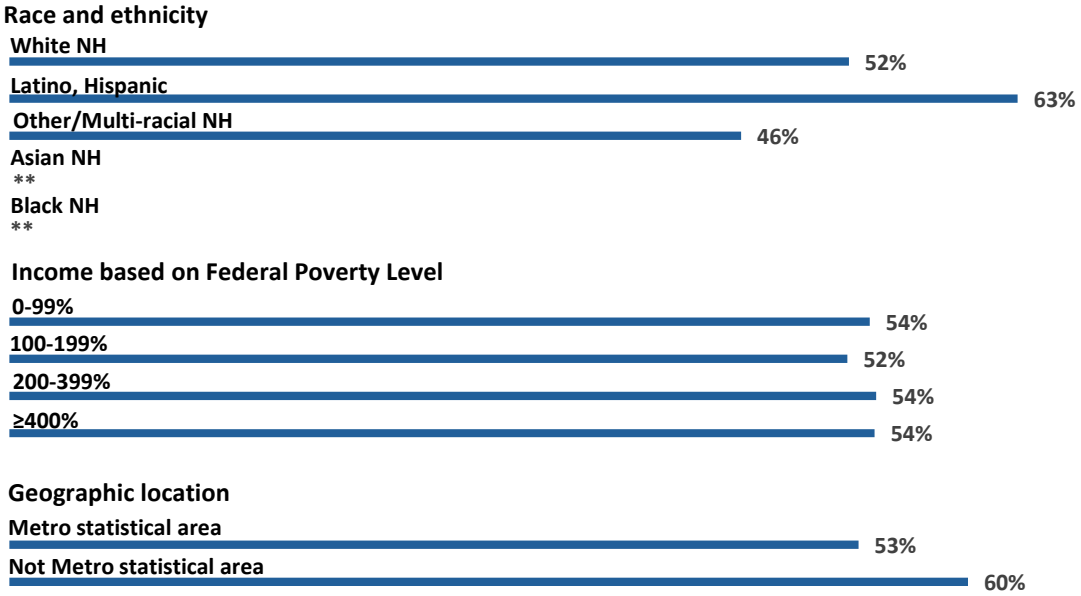
For those families of CYSHCN that needed extra help coordinating their child's health care, less than one-quarter (23.9%) received it (Exhibit 6). The sample sizes of each community of interest were too small to report population estimates. However, the pattern in sample counts suggest that fewer families of CYSHCN in the following communities received extra care coordination help: White, NH families of CYSHCN, families with higher household incomes, and families living in rural communities.

Satisfaction With Communication Among Child's Health Care Providers

Just over half (54%) of families of CYSHCN reported being very satisfied with communication between their child's doctor and other health care professionals (Exhibit 6). Exhibit 8 shows that more Latino families of CYSHCN than CYSHCN from other race and ethnicity community, and families living in rural communities (vs. urban communities) reported satisfaction with

communication among their child's health care providers. There were no substantive differences based on family income.

Exhibit 8. Percent of Oregon Families of CYSHCN Who Were Very Satisfied with Communication Among Their Child's Health Care Providers by Community of Interest, 2021-2022

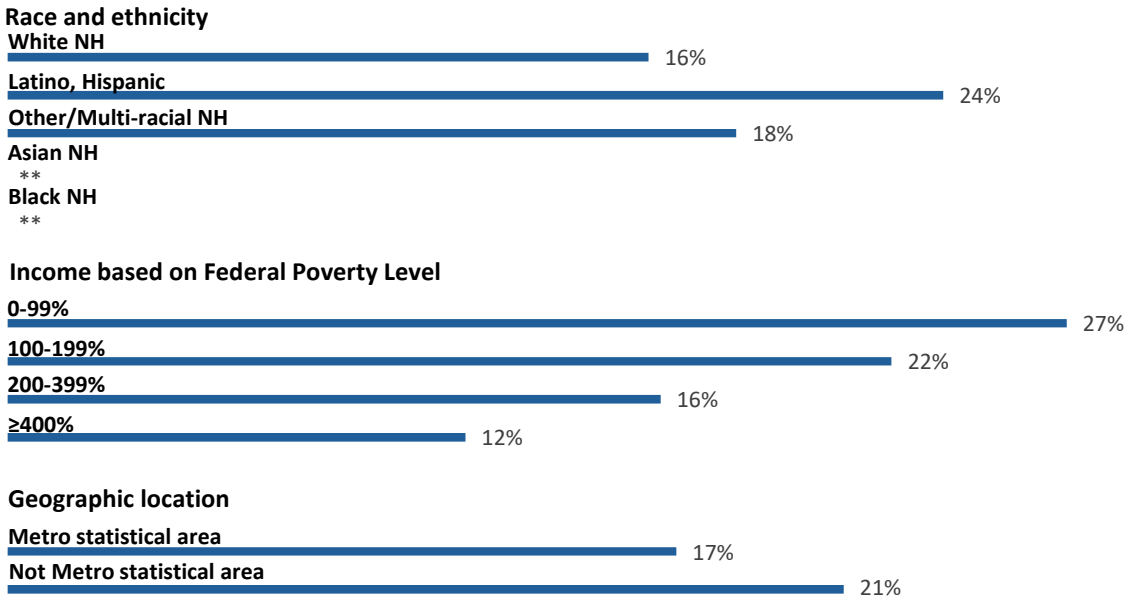


Data Source: OCCYSHN Analysis of NSCH 2021-2022

Health Care Providers Communicate with Child's School, Childcare Providers, or Special Education Providers

Fewer than one in five (17%) families of CYSHCN reported that their child's medical provider communicates with their child's educational provider (Exhibit 6). Latino families of CYSHCN, families living below the FPL, and families in rural communities were *most likely* to report communication between these child health team members (Exhibit 9).

Exhibit 9. Percent of Oregon Families of CYSHCN Who Reported That Their Child's Health Care Provider Communicates with Their Child's Educators by Community of Interest, 2021-2022



Data Source: OCCYSHN Analysis of NSCH 2021-2022

Satisfaction with Communication Between Child's Health Care Providers and Educators

Slightly more than half (58%) of families of CYSHCN reported feeling very satisfied with communication between their child's medical and educational providers, when communication was needed (Exhibit 6). Again, small sample sizes for each community of interest precludes us from reporting population estimates. However, the pattern in the sample counts suggests that fewer White, NH and Multi-racial/Other families of CYSHCN and families living in urban communities reported feeling satisfied with communication between medical and educational providers serving their child.

Qualitative Results

The previous NSCH results suggest that families of CYSHCN from Latino backgrounds and living in rural Oregon communities reported greater access to care coordination and were more satisfied with communication among their child's care team. In contrast, findings from our 2023 interviews and facilitated discussions with Community Health Workers (CHWs) and Latino parents of CYSHCN in a rural area of Oregon indicate that need for care coordination for CYSHCN exists in some rural, and Latino, communities. Analyses of these qualitative data revealed needs for resource navigation and communication and collaboration between organizations (Patterson et al., 2025). The highest priority need, as reported by Latino families of CYSHCN, was resource navigation. Families expressed a desire for a person or an organization to help identify, understand, and secure access to resources in their community.

> *"What's important, personally, is knowing that there's somebody actually trying to help parents like us in the small community with limited resources. So, like for me, I feel like if you could provide at least information…just knowing resources, I think that that's my biggest [request]."*
>
> – Parent

> *"Es como que el pueblo aquí necesita un grupo o un lugar donde la gente puede llegar a pedir información sobre los recursos que realmente hay."*
>
> *– Padre*
>
> English Translation: *It's like our town needs a group or a place where people can go to ask for information about resources that realistically exist [in the community].*
>
> – Parent

Additionally, Latino families noted that they would like help with navigation and coordination from someone who understands their needs and family dynamics and is "*trustworthy*," "*responsive*," "*communicative*," and "*empathetic*" (OCCYSHN, 2024).

In interviews, CHWs and community partners cited the need for improved communication and collaboration between organizations (Patterson et al., 2025). One pediatric nurse working in the rural community stated that "*There's a lot to work on in supporting good communication and coordination between organizations…*" (Patterson et al., 2025). Discussions with Latino families of CYSHCN reinforced providers' perspectives that communication between partners should be strengthened.

> *[Parent Partner Facilitator] "He tenido que estar abogando en las sistemas médicos y escolares. Son dos cosas muy diferentes. Algo estoy escuchando es la comunicación entre los sistemas no hay."*
>
> *[Parent] "Aquí no hay."*
>
> *English Translation: [Parent Partner Facilitator] "I have had to advocate in the medical and school systems. They're two very different things. Something that I am hearing is that there is no communication between these systems."*
>
> *English Translation: [Parent] "There isn't here."*

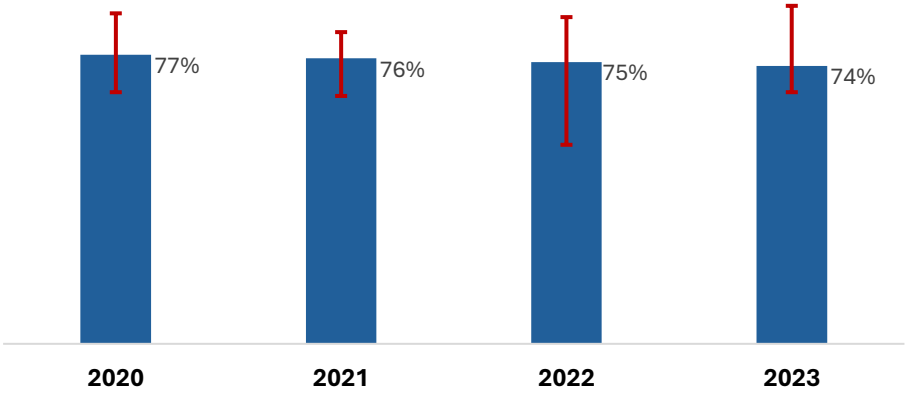
Care Coordination for Publicly Insured CYSHCN

Our analysis of 2021-2022 NSCH data showed that about 35% of Oregon's CYSHCN younger than 18 years were publicly insured. Public insurance coverage includes the Oregon Health

Plan (Medicaid). Oregon's sixteen Coordinated Care Organizations (CCO) are tasked with integrating care for Oregonians who are covered by the Oregon Health Plan, including CYSHCN.

The Oregon Health Authority (OHA) administers the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey to assess Medicaid covered members' experience with health care.[1] Results of an analysis of CAHPS data found that one in four (26%) CYSHCN on the Oregon Health Plan did not receive care coordination services in 2023 (Exhibit 10; Center for the Study of Services, 2020; 2021; 2022; 2023).

Exhibit 10. Percent of Oregon CYSHCN on the Oregon Health Plan Who Received Care Coordination Services, 2020-2023



Data Source: Center for the Study of Services

Six CCOs consistently performed better than the state average for care coordination for CYSHCN from 2020 through 2023 (Exhibit 11). However, fewer families of CYSHCN covered by three CCOs and Fee-For-Service reported receiving care coordination services (Exhibit 11; Center for the Study of Services, 2020; 2021; 2022; 2023). There were no CCOs, however, that met care coordination compliance regulations in 2023 (OHA, 2025). The statewide average for compliance with care coordination regulations was 85%, which was a decrease from 89% in 2020 (OHA, 2025).[2] Care coordination compliance scores were lowest for Advanced Health (72%), Cascade Health Alliance (72%), and Health Share of Oregon (44%; OHA, 2025). The difference between CAHPS survey results (Exhibit 11) and the compliance score for Health Share of Oregon is particularly interesting to note because they received higher than average ratings from Medicaid members on care coordination, and they were given the lowest compliance score of any CCO for care coordination. OHA (2025) recommended "continued

[1] Appendix A describes this data collection in more detail, including the sampling strategy.
[2] The state compliance standard for care coordination is 100%.

monitoring, targeted interventions, and a commitment to ongoing improvement" of care coordination services for people with special health care needs (p. 44).

Exhibit 11. High and Low CCO Performers for Care Coordination for CYSHCN, 2020-2023

Higher Than State Average	Lower Than State Average
• Eastern Oregon CCO	• Advanced Health
• Health Share of Oregon	• OHA Fee-For-Service
• InterCommunity Health Network CCO	• Trillium Community Health Plan – North
• PacificSource – Columbia Gorge	• Trillium Community Health Plan – South
• Umpqua Health Alliance	
• Yamhill Community Care	

Data Source: Center for the Study of Services

Oregon's Medicaid Ombuds program found that care coordination was the second most frequent complaint among children, youth, and young adults with mental health care needs; one-quarter (24.4%) of complaints from this population focused on care coordination. (OHA Ombuds Program, 2023a). The Ombuds program has called for improvements to address the lack of coordination across siloed sectors. Specifically, they note that better coordination is needed between OHA's Medicaid and Behavioral Health Divisions, and between OHA and the Oregon Department of Human Services (OHA Ombuds Program, 2023b).

Additionally, systems-level leaders need to address lag time in follow-ups for Black or African American children with mental health concerns after Emergency Department stays and strengthen the network of culturally responsive, local mental health services (OHA Ombuds Program, 2023a; OHA Ombuds Program, 2023b). Leaders also need to lessen high caseloads that prevent providers, specifically special education providers, from coordinating with other specialists (Education Northwest, 2022).

Examples of Effective Care Coordination

Several data sources found evidence of effective care coordination for CYSHCN happening around the state. A report on the EI/ECSE system by Education Northwest (2022) described that some early learning programs had success in partnering with special education specialists in their community, and that the partnerships benefited early learning providers and community partners. We also heard from CHWs working in a rural Oregon community that a local hub model of care supported efficient resource navigation and care coordination (Patterson et al., 2025).

> *"There was this huge win where we were able to provide that funding [for childcare before the parent underwent surgery]. It happened because of [another*

> *CHW employed by the Hub who worked in a the client's clinic] was in contact with me. We were tag-teaming it, and we were like trying to do the best that we could together."*
>
> *– CHW*

> *"...So, a student gets referred to me, and I'm going to build rapport. We're not going to know, right off the bat, what's going on... [The student] comes across and says, 'I heard my mom and dad talking, and they're behind on the utility bills, or something like that. If they need help, I can refer [the family] to [a CHW working for the Hub]. I can get you a [Hub] CHW, and they can see what they can do [to help the family]...So now [the CHW working for the hub is] focusing on the family. I'm focusing on the students' need, and they focus on families."*
>
> *– CHW*

Community Health Worker Value

The National Care Coordination Standards for CYSHCN call for the use of CHWs to support CYSHCN and their families in navigating and coordinating service systems (Randi et al., 2022). However, several barriers to CHWs serving CYSHCN exist, including low recognition and pay, health care providers not understanding the role of CHWs, and limited access to other service providers. Low recognition and pay were prominent themes in our interviews and a facilitated discussion with CHWs in a rural region of Oregon. CHWs discussed feeling disempowered and devalued by partners, particularly in the medical field (OCCYSHN, 2024).

> *"Sometimes we feel powerless because we don't have that extra education... Some of us have a college degree and others don't even have a degree. It's not like we're just going to be promoting our higher education, but yeah, definitely we feel like sometimes they unfortunately use that label as 'I have more power than you and I know more than you.'"*
>
> – CHW in rural Oregon

There was also agreement among CHWs that pay is too low for the work that they do, including work that they are expected to do regardless of whether it fits within their scope of work (OCCYSHN, 2024).

> *"We've had a lot of turnover ourselves because of pay...You know, [it is] unfortunate that sometimes a community health worker does a lot and for them to get underpaid, it's not worth it. It's not worth for you to really put all that effort in. If you're... struggling and have to get multiple other jobs, you're gonna be burning yourself out."*
>
> – CHW in rural Oregon

In addition to feeling undervalued, CHWs noted that many local providers do not understand the role of CHWs. For example, all bilingual CHWs we spoke with said that they are regularly called upon to serve as interpreters, which is, according to their employers and the Oregon Community Health Worker Association, out of their scope of practice. CHWs also noted that, as they interact with the providers who ask them to interpret, they find themselves having to educate partners about how CHWs can support clients (Patterson et al., 2025). There was strong agreement among CHWs that partners should be trained on the value and role of CHWs in their community (Patterson et al., 2025).

Finally, we observed a clear distinction between CHWs who could and could not coordinate care with local health providers (Patterson et al., 2025). Three CHWs who work in public health and medical clinic settings reported working directly with providers. Two CHWs who work for a local non-profit organization, one who works for the local health council, and another who works for a Federally Qualified Health Center, did not have direct access to working with providers. CHWs who do not work in public health or medical settings faced additional barriers to coordinating care for CYSHCN because they were only able to work with administrative staff in health care facilities.

Summary

In sum, results using a range of data sources show that care coordination services are increasingly difficult for CYSHCN to access, especially CYSHCN from Hispanic/Latino, low income, and rural communities. Coordinated Care Organizations have not met the demand for care coordination services in the last four years. Additionally, CHWs experience multiple organizational- and systems-level barriers to coordinating care for CYSHCN, including low pay and recognition, providers' lack of understanding of the CHW role, and limited access to direct care medical providers.

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