Oregon's Children with Special Health Care Needs
Five Year Needs Assessment Findings – August 27, 2025

CHAPTER FOUR

Needs and Experiences of CYSHCN and Their Families in Oregon's Vietnamese Communities

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Introduction

The five-year needs assessment conducted by the Oregon Center for Children and Youth with Special Health Needs is the primary source of information describing Oregon's population of children and youth with special health care needs (CYSHCN).[1] We rely heavily on the National Survey of Children's Health, administered by the U.S. Maternal and Child Health Bureau and the U.S. Census Bureau, to complete our needs assessment. However, the size of the sample of families from Asian or Pacific Islander (API) communities often is too small to estimate the experiences of CYSHCN from these communities. These knowledge gaps limit our understanding of the experience and needs of CYSHCN and their families from these communities, which consequently impedes OCCYSHN's ability to develop responsive strategies for all Oregon CYSHCN and their families.

Consistent with Title V principles of family engagement and partnership (AMCHP & NASHP, 2017; Dworetzky et al, 2024; U.S. DHHS, HRSA, MCHB, Division of State and Community Health, 2023), OCCYSHN routinely collects input from families when conducting its legislatively required, five-year needs assessments. OCCYSHN contracted with APANO CUF to learn more about CYSHCN and their families who are members of Oregon's Vietnamese community for our 2025 needs assessment. APANO CUF recommended we focus on the Vietnamese community because it is one of Oregon's largest Asian populations (APANO CUF, Insight of Action, Willamette Partnership, 2022).[2] Collectively, we developed the following questions to guide our assessment:

- What health care (behavioral, mental, physical, oral) and services do Vietnamese families need to care for their child?
- What has been the experience of Vietnamese families attempting to access care and services?
- What has been the experience of Vietnamese families in accessing family-centered care?
- What differences exist between the experiences of Vietnamese families of CYSHCN and non-CYSHCN when accessing care?

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

[2] The APANO CUF project team has close ties to the Vietnamese community. Additionally, its Project Coordinator and two community leaders are bicultural and bilingual Vietnamese. The two community leaders also have lived experience as caregivers of CYSHCN. Thus, APANO CUF's project team authentically represented the voice of Oregon Vietnamese families of CYSHCN.

Suggested citation: Gallarde-Kim, S., Vo, X., Cordova Nicolas, K., Doan, L., Patterson, L., Nguyen, B., Huynh, T., & Martin, A.J. (2025). *Needs and experiences of CYSHCN and their families in Oregon's Vietnamese communities. Oregon Title V CYSHCN Needs Assessment Chapter 4.* Oregon Center for Children and Youth with Special Health Needs and APANO CUF.

OCCYSHN identified two additional questions for analysis:

1. Who are Vietnamese families of CYSHCN in Oregon?
2. How is the wellbeing of Vietnamese families of CYSHCN in Oregon?

Methods

APANO CUF and OCCYSHN co-developed and co-implemented a community-appropriate needs assessment study to gather information to answer these questions, and co-analyze, interpret, and disseminate the findings. An important aspect of this needs assessment was the creation of a partnership in which decision-making, learning, and resources were shared. In this section, we describe our mixed methods approach.

Quantitative Survey Data Collection

First, we co-developed a survey data collection instrument and administration procedures. Survey items were based on those used in OCCYSHN's 2015 needs assessment (Martin et al., 2015), Oregon Health Authority's 2012 home visiting needs assessment, and the National Survey of Children's Health. OHSU Language Services translated the survey instrument (Appendix B), which was reviewed by the APANO CUF team and a Vietnamese interpreter. The survey instrument included items to determine if the participant's child met the population definition of CYSHCN (McPherson et al., 1998) using a modified version of the accepted population identification method (Bethell et al, 2002; Bethell et al, 2015).[3] Caregiver responses had to meet the following criteria to identify that a survey respondent had a child with a special health care need:

- Reported a number greater than 0 for the question, "Of your children <u>who are younger than 26 years old</u>, how many have high needs for medical care, need mental health care, or use special education support at school?"
- Reported "Yes" to at least one of the following items:
    a. Does your child use medicine prescribed by a doctor?
    b. Does your child use medical care, mental health care, or educational services?
    c. Does your child have any kind of behavioral, developmental, or emotional needs that require treatment or counseling?
    d. Does your child get special medical therapy, such as dialysis, infusions, or therapies like occupational, physical, respiratory, or speech therapy?
- Reported "Yes" to the question, "Will any of your child's health conditions be long-term?"

[3] APANO CUF team members recommended the changes to be more responsive to Vietnamese families.

Participants chose whether to complete the survey in English or Vietnamese and online or on paper.

We recruited caregivers whose (a) family identified as Vietnamese, (b) child was younger than 26 years old, and (c) family lived in Oregon. We recruited Vietnamese caregivers regardless of whether their child(ren) had a special health care need. During project planning discussions, APANO CUF team members recommended against attempting to recruit only families of CYSHCN because families in their community might: not be aware that their child has a special health care need, not identify that their child has a special health care need, or feel embarrassment or shame about their child's health condition and care needs. Literature shows that social stigma and shame associated with having a disability exists among the Vietnamese community (Bui et al, 2018; Ngo et al, 2012).

The APANO CUF team recruited families from Oregon's Vietnamese communities to participate in the survey. Flyers about the survey were shared with APANO CUF's listserv, private Vietnamese community Facebook groups, and businesses that the Vietnamese community frequents, such as churches, nail salons, and grocery stores. The APANO CUF team also shared flyers while tabling at two community events. Ninety-six Vietnamese caregivers completed the survey. Of those, 36 (40%) reported having a CYSHCN. This summary will focus primarily on the results of the 36 survey participants who are caregivers of CYSHCN.

Qualitative Discussion of Survey Results

APANO CUF invited caregivers of CYSHCN to a meeting to co-interpret preliminary survey results with us. APANO CUF selected caregivers from those who completed the survey and indicated that they would be interested in participating in a group discussion. Six caregivers participated in the meeting. We audio recorded the discussion, which was then transcribed and translated into English by the APANO CUF Project Coordinator.

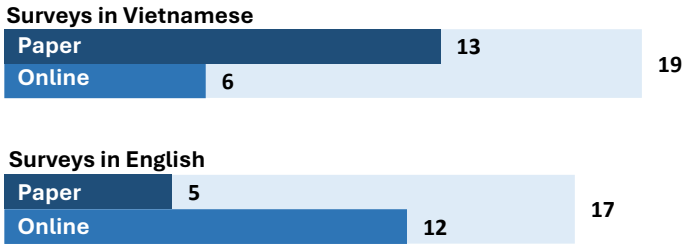
Findings

To answer our questions, OCCYSHN analyzed: (1) survey data using descriptives statistics, and (2) the meeting transcript for major themes using an inductive approach. Findings are organized by study objective. Given small sample sizes, we primarily report counts. For counts greater than 20, we reported percentages in parentheses next to the counts.

Sample Description

Of the 36 total surveys completed by families of CYSHCN, 19 completed the survey in Vietnamese and 17 completed the survey in English (Exhibit 1). Surveys completed in Vietnamese were most frequently completed on paper. Surveys completed in English were most often completed online.

Exhibit 1. Survey Completion: Language and Mode



Survey respondents most frequently reported that their relationship to the child(ren), about whom the survey collected data, is parent (n=33, 92%). They often reported having a high school diploma or GED (n=14) or an Associate or Vocational degree (n=9). On average, survey respondents have two children, and one child with a special health care need. The average age of the child with special health care needs was 13.6 years old, although ages ranged from two to 26 years old. Most survey respondents reported living in the Portland Metro Area (n=35, 97%), particularly Multnomah County. Of the respondents who lived in Portland, an Oregon City zip code was the furthest zip code reported. Additionally, one survey respondent reported a zip code in Hood River County. Analysis of census data for Oregon show that the greatest percentage of individuals who speak Vietnamese live in the following counties: Multnomah, Washington and Clackamas (OHA, 2024).

Survey respondents' CYSHCN are all Vietnamese, per our survey inclusion criteria. Three respondents reported more than one race or ethnicity. These responses specified that their child is also Chinese, Filipino/a, or White.

When asked how their CYSHCN's health care is paid for, survey respondents most frequently reported either through Medicaid (n=23, 64%) or private health insurance (n=13). Four survey respondents reported multiple ways that they pay for their child's care. All four reported having private health insurance, and three of the four reported needing to pay out of pocket for their child's care in addition to having private health insurance.

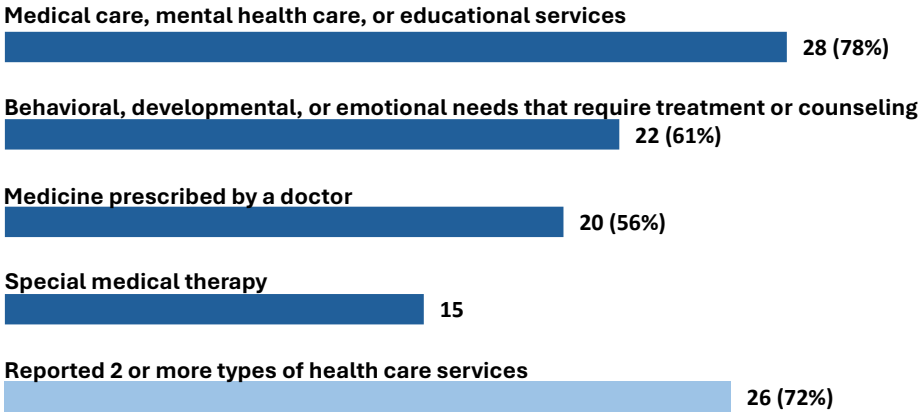
Health Care and Services Use

We asked survey respondents a set of questions about the types of health care and services that their child uses to determine if the survey respondents' child met our special health care needs criteria. Survey respondents most often reported their child uses medical care, mental health care, or educational services (78%, Exhibit 2). Sixty-one percent of survey respondents reported that their child has a behavioral, developmental, or emotional need that requires treatment or counseling.[4]

[4] Of those, 13 respondents reported that their child receives care from a mental health counselor, therapist, psychologist or psychiatrist (Exhibit 5).

Twenty-six (72%) survey respondents reported that their child uses two or more types of health care services. All respondents reported that their child's health conditions will be long-term. Particularly, they most often reported that their child's condition is life-long (n=22, 61%).

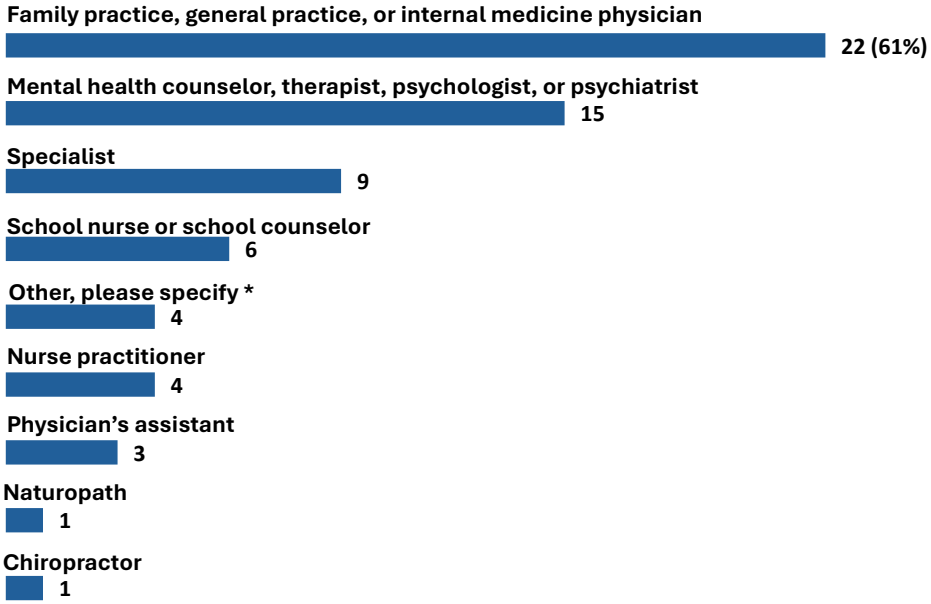
Exhibit 2. Survey Respondents' Reported Health Care Needs of Their Child



Survey respondents most often reported that their child receives care from a family practice, general practice, or internal medicine physician (Exhibit 3). Fourteen respondents reported that their child receives care from more than one type of professional. Of those, survey respondents most often reported that their child receives care from a:

- Family practice, general practice, or internal medicine physician (n=14)
- Mental health counselor, therapist psychologist or psychiatrist (n=8)
- Specialist (n=8).

Exhibit 3. Types of Health Care Professionals Who Provided Care to the Survey Respondents' Child

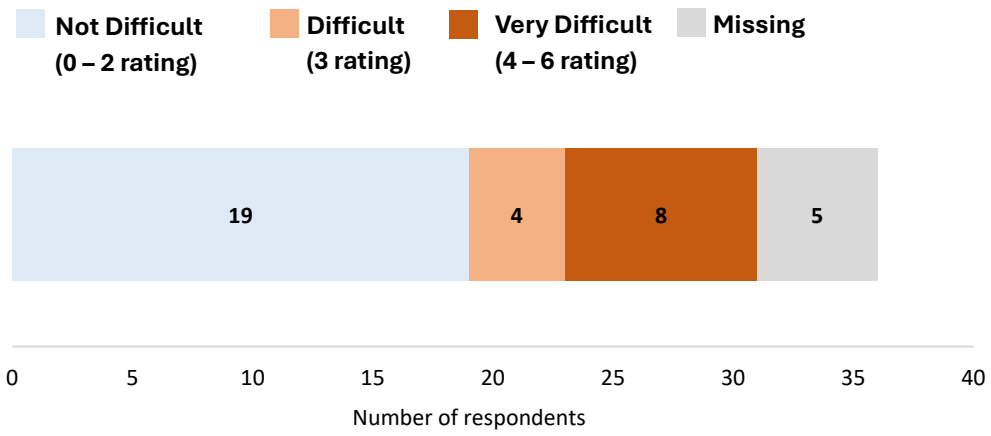


Note. *Other responses were: "*audiologist,*" "*counselor,*" "*Dental [provider name],*" "*PT, OT, ST,*" and "*Speech.*"

Health Care and Services Access

We asked survey participants to rate how difficult it is for their child to get all the health care services that they need. They responded using a seven-point scale with these anchors: 0 = Not at all difficult, 3 = Difficult, and 6 = Extremely difficult. Thirty-one participants responded to the item; Exhibit 4 presents the results. Two-thirds of those respondents (n=19) reported that it is not difficult (0-2 rating) for their child to get all the health services that she or he needs. Although, one-third of respondents report it is difficult (3 rating) or very difficult (84 – 6 rating). The average rating was 2.1.[5]

Exhibit 4. Survey Respondents' Reported Level of Difficulty Getting All the Health Care Services that their Child Needs



We asked survey participants if they had difficulty accessing specific types of health care services. Half of the survey respondents (n=18) reported that it is difficult to get medical care, mental health care, or educational services (Exhibit 5). Of these 18 survey respondents, most (n=11) reported that their child is insured through Medicaid.

Nearly half (n=15) reported that getting treatment or counseling for their child is difficult (Exhibit 5). All 15 of these respondents reported that their child has behavioral, developmental, or emotional needs that require treatment or counseling. This illustrates that for children with behavioral, developmental or emotional needs, it can be difficult to get treatment or counseling for their condition.

About one-third reported difficulty getting special medical therapy for their child. A small number of survey respondents reported difficulty accessing prescriptions.

[5] We computed the average based on the number of participants who responded to this survey item.

Exhibit 5. Number of Survey Respondents who Reported Difficulty Accessing Care for Their Child by Type of Care

During our discussion of survey results with caregivers, they most frequently discussed challenges with health insurance as a major barrier to accessing services. Four of six participants described challenges with in-network restrictions such as difficulty finding providers within network. The quote below illustrates this challenge.

"Bảo hiểm ngày càng trở nên hạn chế hơn đáng kể. Ví dụ, con tôi cần giấy giới thiệu từ bác sĩ chăm sóc chính để điều trị mắt. Nếu chúng tôi tìm dịch vụ chăm sóc bên ngoài mạng lưới giới thiệu, chúng tôi phải tự chi trả chi phí.
Bảo hiểm nha khoa của chúng tôi không được nhiều nhà cung cấp chấp nhận, buộc chúng tôi phải đổi gói bảo hiểm. Tuy nhiên, việc thay đổi gói bảo hiểm nha khoa thường ảnh hưởng đến phạm vi bảo hiểm y tế của chúng tôi do những hạn chế về mạng lưới. Một số nhà cung cấp chỉ chấp nhận các chương trình bảo hiểm y tế cụ thể, trong khi những nhà cung cấp khác chỉ chấp nhận các chương trình bảo hiểm nha khoa cụ thể. Điều này dẫn đến tình huống chúng tôi phải điều hướng một hệ thống phức tạp và gặp gỡ nhiều nhà cung cấp khác nhau để đảm bảo con tôi nhận được sự chăm sóc cần thiết. Mặc dù các nhà cung cấp thường kiên nhẫn, nhưng những hạn chế do bảo hiểm tạo ra những thách thức đáng kể. Nhiều liệu pháp thiết yếu không được bảo hiểm đầy đủ và việc giới thiệu thường bị hạn chế. Bảo hiểm không đầy đủ này đặt ra một trở ngại đáng kể cho việc chăm sóc liên tục của con tôi."

- Người trông nom thứ Năm

***Translation:** "Insurance coverage has become significantly more restrictive. For example, my child requires a referral from their primary care physician for eye treatment. If we seek care outside of the referral network, we're responsible for the costs out-of-pocket...Our dental insurance is not accepted by many providers, forcing us to switch plans. However, changing dental plans often impacts our health insurance coverage due to network restrictions. Some providers only accept specific health insurance plans, while others only accept specific dental plans. This has led to a situation where we have to navigate a complex system and see a variety of providers to ensure our child receives the necessary care. While providers are generally patient, the limitations imposed by insurance coverage create significant challenges. Many essential therapies are not adequately covered, and referrals*

are often limited. This inadequate insurance coverage poses a significant obstacle to our child's ongoing care."

– Caregiver 5

Three participants also discussed challenges with their child's health insurance putting limitations on the number of therapy or treatment visits their child receives. One parent reported:

"Chính phủ thường giới hạn số buổi trị liệu bạn có thể có trong một tháng. Tôi cảm thấy như thế là không bao giờ đủ. Tôi đồng ý, nếu chúng ta có nhiều buổi trị liệu hơn, tôi nghĩ sẽ tạo ra sự khác biệt lớn. Những buổi trị liệu thực sự cần sự kiên nhẫn và cả kiên trì."

- Người trông nom thứ Ba

***Translation:** "The government often limits how many therapy sessions you can get in a month. I feel like that's never enough. I agree, if we could have more sessions, I think it would make a big difference. It really takes patience and consistency."*

– Caregiver 3

Additionally, we asked survey participants, "What are three things that your child or family needs most but has a hard time getting?" Twenty survey respondents (56%) answered this question. Access to quality care was frequently reported as one of three things that their child or family needs most but has a hard time getting (n=9). Survey respondents described needing health care services generally and needing specific providers such as a counselor or dental care for their CYSHCN. One respondent reported challenges accessing mental behavioral health care, *"...Psychiatrist that isn't only medication focus[ed] and will accept new patients and is [Asian or Pacific Islander]..."* Another respondent reported needing "*Dental care for autistic teenagers."*

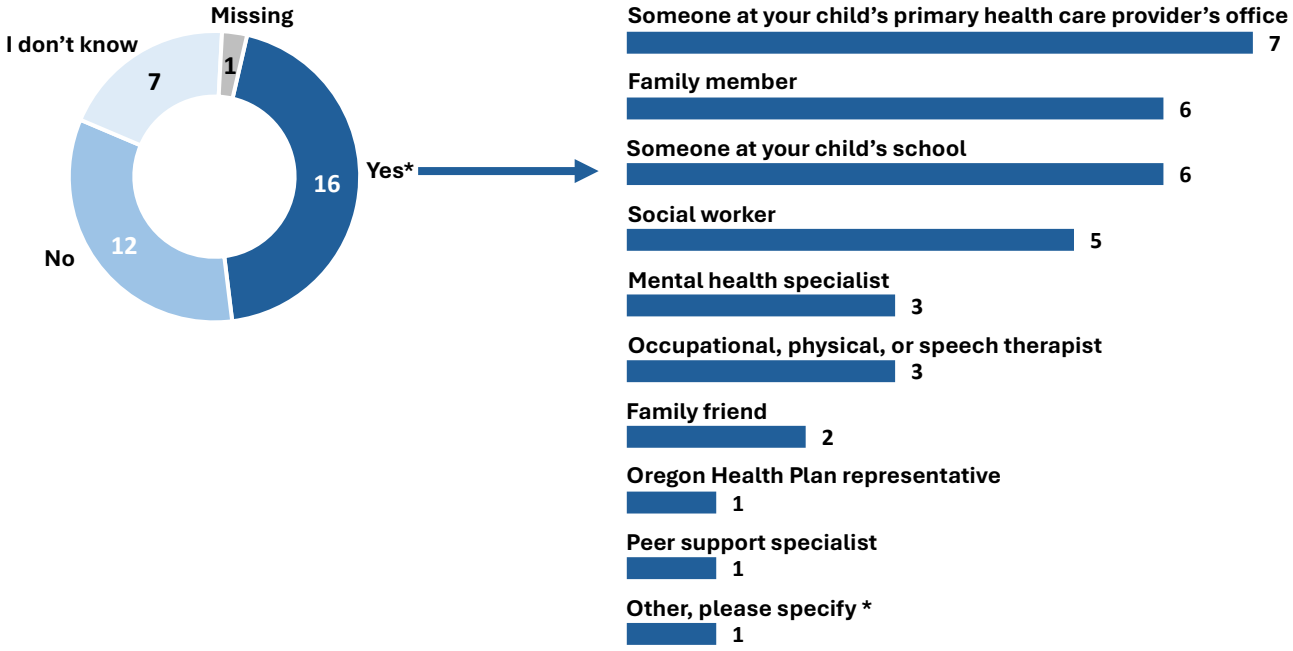
Care Coordination

> *"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...to achieve positive health and wellness outcomes"* (Antonelli, McAllister, and Popp, 2009, p.8).

We asked survey participants about their experience with coordinating care for their CYSHCN. Of the 35 survey respondents who answered this question, slightly more than half (n=19) reported that they "Often" or "Sometimes" got as much help as they wanted arranging or coordinating their child's care. A quarter (n=9) reported that they "Rarely" or "Never" got as much help as they wanted arranging or coordinating their child's care.

Exhibit 6 presents responses to the question, "In the last year, did anyone help you arrange or coordinate care for your child?" Thirty-five participants answered this question. Of those, almost half (n=16) reported, "Yes." Of the 35, respondents most frequently reported that someone at their child's primary health care provider's office, a family member, or someone at their child's school, helped them arrange or coordinate their child's care (Exhibit 6).

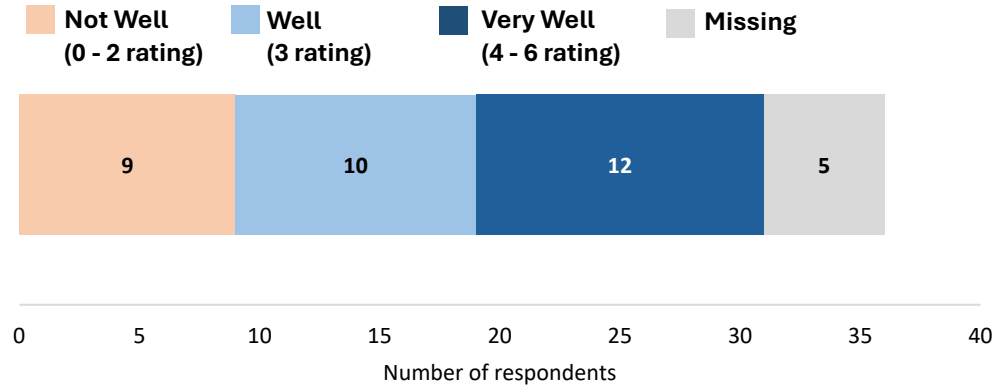
Exhibit 6. Survey Respondents' Reported If Anyone Helped Them Arrange or Coordinate Care for Their Child and Types of People Who Helped



Note. Survey respondents could provide multiple types of people who helped them with care coordination, which is why the total is more than 16.
*Other response: *"[Specialty Clinic Name]"*

We asked participants, "How well do your child's different health care providers work together to meet your child's needs?" Survey respondents responded using a seven-point scale with these anchors: 0 = Not at all well, 3 = Well, 6 = Extremely Well. Exhibit 7 shows that over a third of the respondents reported that their providers work very well together (i.e., they reported a rating of 4 – 6). The average rating was 3.4, or "well."

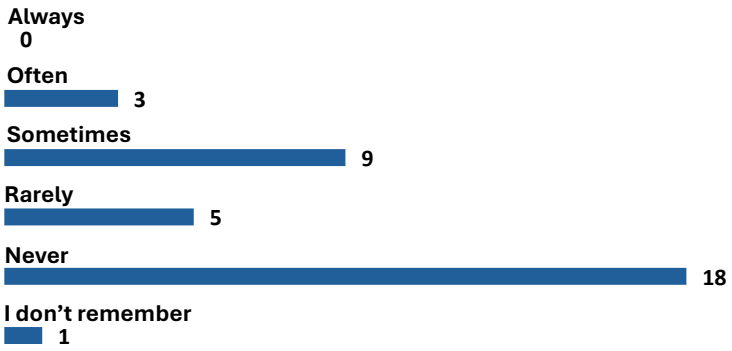
Exhibit 7. Survey Respondents Reported How Well Their Child's Health Care Providers Work Together to Meet Their Child's Needs



Family-Centered Care

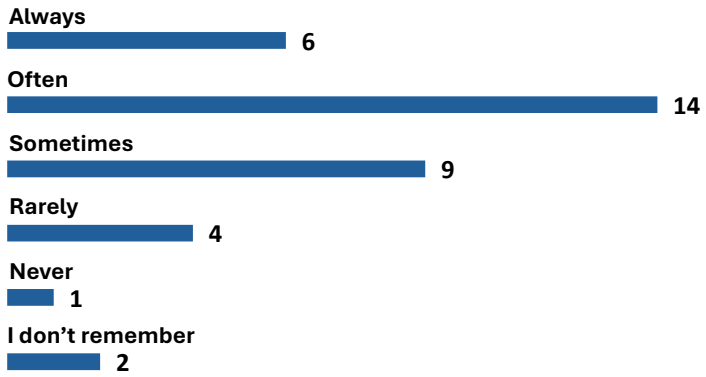
Family-centered care is a partnership approach to health care decision-making between the family and health care provider (Kuo et al., 2012). Overall, survey respondents reported positive experiences with family-centered care. For example, Exhibit 8 presents results to the question, "In the last year, how often were you confused by what your child's doctors or nurses told you?" Half (n=18) of survey respondents reported that they were "Never" confused by what their child's doctors or nurses told them; no respondents reported "Always." About one-third of respondents reported that they were "Often" or "Sometimes" confused by what their child's doctors or nurses told them.

Exhibit 8. Survey Respondents' Reported Frequency of Confusion in Communicating with Their Child's Doctors or Nurses



We also asked, "In the last year, how often did you feel like your child's health care provider understood what you had to say about your child?" Almost two-thirds (n=23) of respondents reported that they "Often" or "Sometimes" felt like their child's health care provider understood what they had to say about their child (Exhibit 9).

Exhibit 9. Survey Respondents' Reported Frequency of Feeling Understood by Their Child's Providers



During our discussion of results, caregivers described both negative and positive experiences with family-centered care. Three caregivers described experiencing a lack of family-centered care from their child's providers. For example, they described encountering providers who do not listen to the family's concerns and do not ensure the family understands them. One caregiver described that when communicating with their child's providers, the provider seems to understand the parent, but the parent doesn't fully understand their child's providers.

Người trông nom thứ Hai: Tôi hiểu rằng các chuyên gia y tế có thể sử dụng thuật ngữ mà tôi không quen thuộc. Tôi đánh giá cao việc họ sẽ dành thời gian giải thích rõ ràng các thuật ngữ này và đảm bảo tôi hiểu tình hình y tế.
Người điều phối: Vậy bạn đang nói rằng mọi người hiểu?

Người trông nom thứ Hai: Vâng, họ hiểu. Chỉ là chúng tôi không hiểu họ.

Người điều phối: Tôi hiểu rồi. Bạn đang nói rằng việc giao tiếp có thể không hiệu quả theo cả hai chiều. Nhà cung cấp dịch vụ hiểu con bạn, nhưng bạn có thể chưa hiểu đầy đủ các giải thích của nhà cung cấp.

Người trông nom thứ Hai: Vâng.

Translation:
Caregiver 2: I understand that medical professionals may use terminology that is unfamiliar to me. I appreciate that they will take the time to explain these terms clearly and ensure I understand the medical situation.

Facilitator: So you're saying that people understand?

Caregiver 2: Yes, they understand. We just don't understand them.

Facilitator: I see. You're saying that the communication may not be effective in both directions. The provider understands your child, but you may not fully understand the provider's explanations.

Caregiver 2: Yes.

Another participant described experiencing discrimination from their child's provider:

"Có một bác sĩ đã giúp con tôi từ lúc 5 tuổi đến 21 tuổi. Gia đình tôi và tôi rất thoải mái và vui vẻ khi đi khám cô ấy. Sau 21 tuổi, cô ấy không thể giúp nữa vì bảo hiểm không còn chi trả. Tôi phải chuyển con trai tôi đến một bệnh viện khác, nhưng họ cũng từ chối. Thái độ của họ đối với gia đình tôi và tôi cảm thấy thờ ơ, và tôi cảm thấy bị phân biệt đối xử. Điều đó rất khó chịu. Tôi hiểu rằng sự phân biệt đối xử này có thể là vấn đề của riêng bác sĩ đó, vì mỗi bác sĩ có cách làm việc riêng của họ."

- Người trông nom thứ Nhất

***Translation:** "One doctor helped my child from age 5 to 21. My family and I were very comfortable and happy going to see her. After 21, she couldn't help anymore because the insurance coverage ended. I had to transfer my son to a different hospital, but they also refused. Their attitude towards my family and me felt indifferent, and I felt discriminated against. It was very upsetting. I understand that this discrimination is likely an issue with that particular doctor, as each doctor has their own way of working."*

- Caregiver 1

The same participant described their experience with another provider who is Vietnamese.

"Con tôi đã đi khám một bác sĩ người Việt và suýt nữa thì không qua khỏi. Tôi phải chuyển sang một bác sĩ khác. Tôi đã đi khám trong 3 tháng, và tình trạng của con tôi hơi lạ. Bác sĩ nói đó là do con tôi sinh non, không có gì phải lo lắng. Nhưng tình trạng của con tôi ngày càng tệ hơn. Vì vậy, tôi đã chuyển sang một bác sĩ người Mỹ... Kể từ đó, tôi không giới thiệu khám bác sĩ người Việt đó vì tôi không tin tưởng họ."

- Người trông nom thứ Nhất

***Translation:** "My child saw a Vietnamese doctor and almost didn't make it. I had to switch to a different doctor. I went for 3 months, and my child's condition was a bit strange. The doctor said it was because my child was premature, that it was nothing to worry about. But my child's condition got worse and worse. So I switched to an American doctor... Since then, I don't recommend seeing that Vietnamese doctor because I don't trust them."*

- Caregiver 1

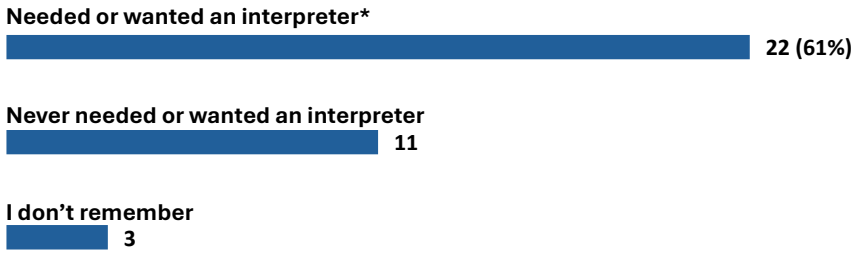
In contrast, three participants described experiences with dedicated and compassionate providers who communicate clearly with the family to ensure they understand their child's condition and care. One participant reported that in their experience, working with a compassionate provider is not common.

"... Có một số người tốt bụng và có lòng trắc ẩn, nhưng họ rất hiếm."
- Người trông nom thứ Bốn

***Translation:** "... There are some good and compassionate ones, but they are few and far between."*
- Caregiver 4

We asked survey respondents about their interpretation needs, "In the last year, how often did you need or want an interpreter when you were at a health care appointment for your child?" Exhibit 10 shows that over half (n=22) of survey respondents needed or wanted an interpreter in the last year. Approximately one-third (n=11) of survey respondents reported that they never needed or wanted an interpreter in the last year. One survey respondent, who reported that they never needed or wanted an interpreter in the last year, noted on the paper survey that their child is their interpreter.

Exhibit 10. Survey Respondents Reported Frequency in Needing or Wanting an Interpreter Need at Their Child's Health Care Appointments

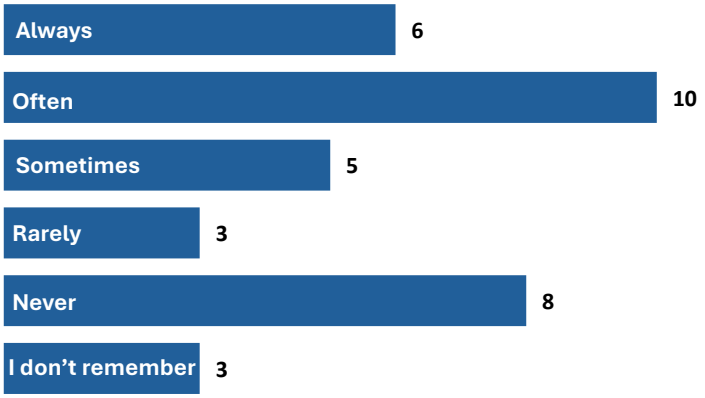


* We combined responses for "Always," "Often," "Sometimes," and "Rarely"

We asked caregiver meeting participants to elaborate on their experiences with interpretation services. Three participants discussed the availability of an interpreter for their child's health care appointments. One parent reported that there was always an interpreter available at all appointments. Another parent described that they are not able to choose their interpreter.

We asked survey participants about the quality of interpretation services they received, "In the last year, how often did interpretation services meet your family's needs?" Exhibit 11 presents results. Thirty-five survey respondents answered this question. Of those, nearly half (n=16) reported that interpretation services "Always" or "Often" met their family's needs. Of those that needed or wanted an interpreter as shown in Exhibit 10 (n=22), 15 respondents reported that the interpretation services they received "Often" or "Sometimes" met their family's needs.

Exhibit 11. Survey Respondents Reported Frequency of Interpretation Services Meeting Their Family Needs in the Last Year



We asked caregiver meeting participants to elaborate on these results and describe their experience using interpretation services in their child's health care appointments. Four caregiver meeting participants described mixed experiences. One caregiver reported that they use a video interpreter for appointments and the quality of their service was just "*ok*." Two caregivers reported receiving low quality interpretation services, they emphasized the importance of learning medical terms to advocate for their child in health care appointments.

"Tôi đã có những trải nghiệm tiêu cực với một vài người thông dịch, khiến tôi ít tin tưởng vào họ hơn. Tôi đã bắt đầu học các thuật ngữ y tế và hỏi y tá để làm rõ. Trong một trường hợp, bản dịch không chính xác của một người thông dịch cho con tôi càng củng cố quyết định của tôi là hạn chế tối đa việc phụ thuộc vào dịch vụ này."

- Người trông nom thứ Bốn

***Translation:** "I've had negative experiences with several translators, leading me to rely less on them. I've started learning medical terms and asking nurses for clarification. In one instance, an inaccurate translation by a translator for my child further solidified my decision to minimize reliance on this service."*

– Caregiver 4

Another caregiver also described experiences with misinterpretations and their preference to communicate directly with their child's provider.

"Tại [hệ thống chăm sóc sức khỏe], tôi đã gặp một vài một vài người thông dịch, lớn tuổi đặc biệt xuất sắc. Bản dịch của họ luôn chính xác, truyền đạt đúng suy nghĩ của tôi. Thật không may, những dịch giả khác thường xuyên hiểu sai lời tôi nói. Tôi thường xuyên phải nói với nhà cung cấp dịch vụ rằng: "Tôi muốn nói chuyện trực tiếp với bạn." Khi được hỏi lý do, tôi giải thích rằng tôi lo ngại về việc bị hiểu sai. Tôi muốn giao tiếp trực tiếp, ngay cả khi tiếng Anh

của tôi có thể không hoàn hảo. Tôi hiểu rằng một số thuật ngữ y tế có thể không quen thuộc. Trong những trường hợp đó, tôi sẽ ghi lại thuật ngữ tiếng Việt vào điện thoại, dịch bằng ứng dụng dịch thuật, sau đó hỏi nhà cung cấp dịch vụ về thuật ngữ tiếng Anh tương đương. Tôi đã học cách tự mình tin tưởng hơn và ít phụ thuộc vào các dịch giả. Tôi chủ động học các thuật ngữ y tế và hỏi trực tiếp nhà cung cấp dịch vụ để làm rõ. Cách tiếp cận này đã hiệu quả hơn nhiều đối với tôi."

- Người trông nom thứ Nhất

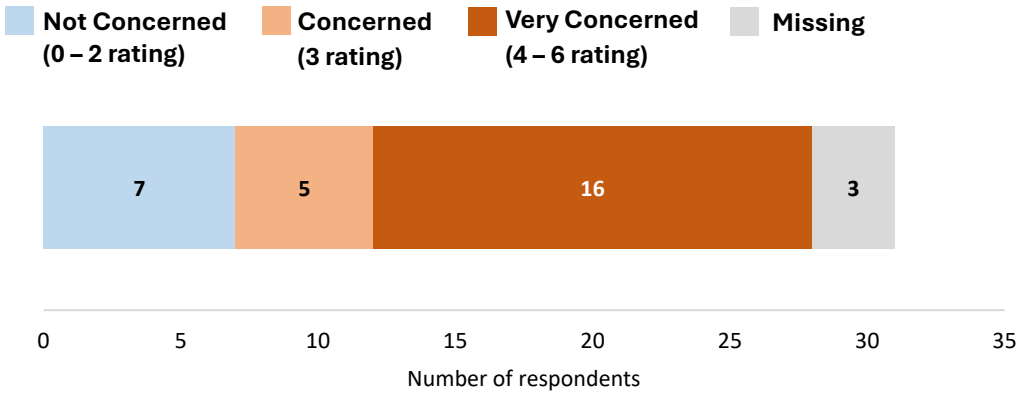
"At [health care system], I encountered a couple of older translators who were exceptional. Their translations were always accurate, conveying my thoughts precisely. Unfortunately, other translators often misinterpret my words. I've often found myself telling the provider, 'I'd like to speak with you directly.' When asked why, I explain that I'm concerned about misinterpretations. I prefer to communicate directly, even though my English may not be perfect. I understand that some medical terms might be unfamiliar. In those cases, I'll write down the Vietnamese term on my phone, translate it using a translation app, and then ask the provider about the English equivalent. I've learned to rely more on myself and less on translators. I actively learn medical terms and ask for clarification directly from the provider. This approach has been much more effective for me."

– Caregiver 1

Child Quality of Life and Family Well-being

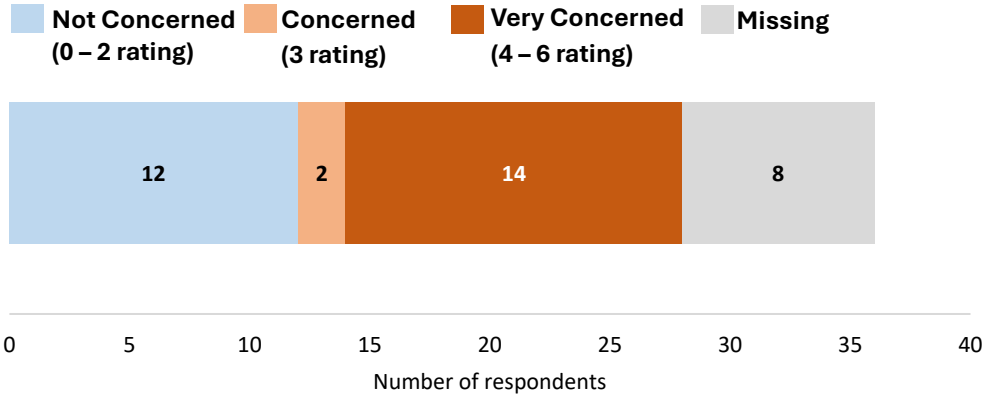
Of the survey participants who reported that their child attends school (n=31), we asked, "how much are you concerned about your child being bullied at school?" Participants responded using a seven-point scale with these anchors: 0 = Not at all concerned, 3 = Concerned, and 6 = Extremely Concerned. Almost half (n=16) of respondents reported a rating of 4 – 6: they are very concerned about their child being bullied at school (Exhibit 12). The average rating was 3.8, "very concerned."

Exhibit 12. Survey Respondents' Reported Level of Concern About Their Child Being Bullied at School



We asked survey participants, "how much are you concerned about getting physical or mental health care for yourself?" They responded using a seven-point scale with these anchors: 0 = Not at all concerned, 3 = Concerned, and 6 = Extremely concerned. Exhibit 13 presents results. More than one-third (n=14) of respondents reported a rating of 4 – 6: they are very concerned about getting physical or mental health care for themselves. The average rating was 3.3, "concerned."

Exhibit 13. Survey Respondents' Reported Level of Concern About Getting Physical or Mental Health Care for Themselves



We asked survey participants, "how much are you concerned about finding affordable housing that meets your family's needs?" They responded using a seven-point scale with these anchors: 0 = Not at all concerned, 3 = Concerned, and 6 = Extremely concerned. Exhibit 14 presents results. Half (n=18) of survey respondents reported a rating 0 – 2: not concerned. Nearly a third (n=10) of respondents reported a rating of 3 - 6: they are concerned or very concerned about finding affordable housing that meets their needs. The average rating was 2.0, "not concerned."

Exhibit 14. Survey Respondents' Reported Level of Concern About Finding Affordable Housing That Meets Their Family's Needs

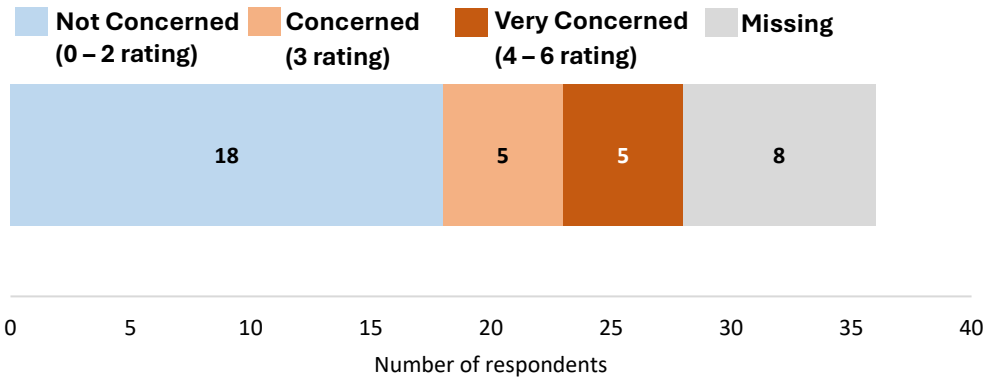
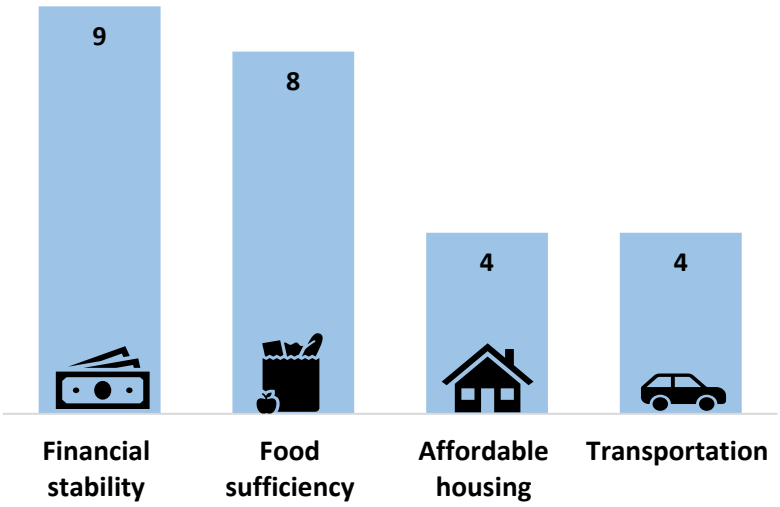


Exhibit 15 shows that basic needs were frequently reported as one of three things that the survey participants' child or family needs most but has a hard time getting. Of those that responded to the question (n=20), nine reported a need related to financial stability. They described needing job stability, financial assistance, help paying for bills including utilities, and help paying for home necessities such as appliances. Respondents' second most reported need was related to food sufficiency. They reported needing food or groceries generally, and financial support to buy food.

Other responses included a range of additional basic and essential needs. These included support for their children to be successful in school, access to emotional and behavioral services, housing stability, insurance, and transportation.

Exhibit 15. Number Of Respondents Who Reported Basic Needs as One of Three Things Their Child or Family Needs Most But Has a Hard Time Getting



Additionally, government assistance can support a family's well-being. Two caregiver meeting participants discussed their perceptions and feelings about receiving government assistance. One participant reported feeling like a burden on society, as illustrated in the quote below.

"... Gia đình tôi hiện đang ở đây bằng thẻ xanh. Tôi đã tìm hiểu, nhưng vẫn không chắc chắn. Nếu con tôi mắc chứng tự kỷ, liệu con và gia đình tôi có trở thành gánh nặng cho xã hội không? Mỗi lần nghĩ đến điều này, tôi lại thấy rất khổ tâm... Tôi không muốn con mình như vậy. Tôi làm việc và đóng thuế, nhưng tôi không biết điều này sẽ ảnh hưởng đến tôi như thế nào khi tôi trở thành công dân. Nhiều người đã khuyên tôi đừng quá lo lắng vì chính phủ hiểu và thông cảm. Tôi đến Mỹ qua diện visa việc làm EB3, không phải diện bảo lãnh gia

đình. Hai con tôi sinh ra tại Mỹ và là công dân Mỹ. Đó là lý do vì sao tôi cảm thấy chúng là gánh nặng cho Hoa Kỳ."

- Người trông nom thứ Ba

Translation: "*...My family is currently here on a green card. I've looked into it, but I'm not sure. If my child has autism, would my child and my family become a burden on society? Every time I think about it, I'm so distressed...I don't want my child to be like this. I work and pay taxes, but I don't know how this will affect me when I become a citizen. Many people have advised me not to worry too much because the government understands and empathizes. I came to the US through the EB3 employment-based visa, not as a family member. I had to go through an interview to get my green card, not as a family member of a sponsor. My two children were born in the US and are US citizens. That's why I feel like they're a burden on the United States."*

– Caregiver 3

Another participant reported feeling grateful that these services exist for families like theirs. They reported:

"Giống như con tôi đã nằm viện một năm, và chi phí y tế có thể lên tới một triệu đô la, nhưng tôi vẫn thi đậu bài kiểm tra quốc tịch của mình. Thành thật mà nói, không có cha mẹ nào muốn con mình mắc chứng tự kỷ hay khuyết tật. Nhưng đối với tôi, tôi cảm thấy mình nợ nước Mỹ rất nhiều. Thật khó khăn, và tôi cảm thấy mắc nợ những người làm việc và đóng thuế để chi trả cho chi phí chăm sóc con tôi. Tôi mắc nợ tất cả những người đã đóng thuế để hỗ trợ bảo hiểm của chính phủ, giúp đỡ những người khác. Tôi nợ họ một lời xin lỗi và một lời cảm ơn."

- Người trông nom thứ Nhất

Translation: *"It's like my child was hospitalized for a year, and the medical expenses could have reached a million dollars, but I still passed my citizenship test. Honestly, no parent wants their child to have autism or a disability. But for me, I feel like I owe the US a lot. It's difficult, and I owe it to the people who work and pay taxes to cover the costs of my child's care. I owe all those who pay taxes to support government insurance that helps others. I owe them an apology and a thank you."*

– Caregiver 1

Differences Between Vietnamese families of CYSCHN and non-CYSHCN

OCCYSHN compared survey responses from caregivers of CYSHCN and those of non-CYSHCN. The following are results that show meaningful differences between families of CYSHCN (n=36) and families of non-CYSHCN (n=60). By "meaningful difference," we mean that (a) a 20-percentage point difference between frequencies for CYSHCN and non-CYSHCN existed, or (b) the average ratings for CYSHCN and non-CYSHCN equated to a

change in rating (e.g., an average of 3.8 equates to "very concerned" and an average of 2.5 equates to "concerned").

Exhibit 16 presents results for the CYSCHN identification questions, and differences in responses are evident as would be expected. Overall, families of CYSHCN more often reported using health care services than families of non-CYSHCN. For example, nearly twice as many families of CYSHCN reported using medical care, mental health care, or educational services compared to families of non-CYSHCN. More than four times as many families of CYSHCN reported that their child has behavioral, developmental, or emotional needs that require treatment or counseling compared to families of non-CYSCHN. More than seven times as many families of CYSHCN reported using special medical therapy compared to families of non-CYSHCN.

Exhibit 16. Survey Respondents' Reported Health Care Needs of Their Child

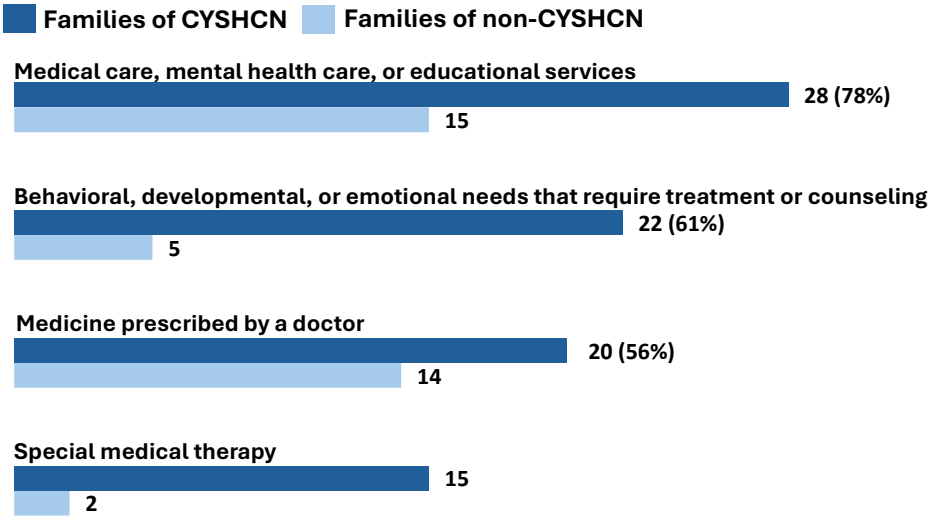
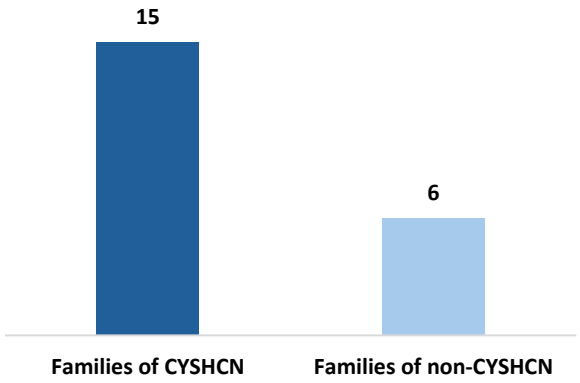


Exhibit 17. Survey Respondents Who Reported That Their Child Received Care from a Mental Health Counselor, Therapist, Psychologist, or Psychiatrist

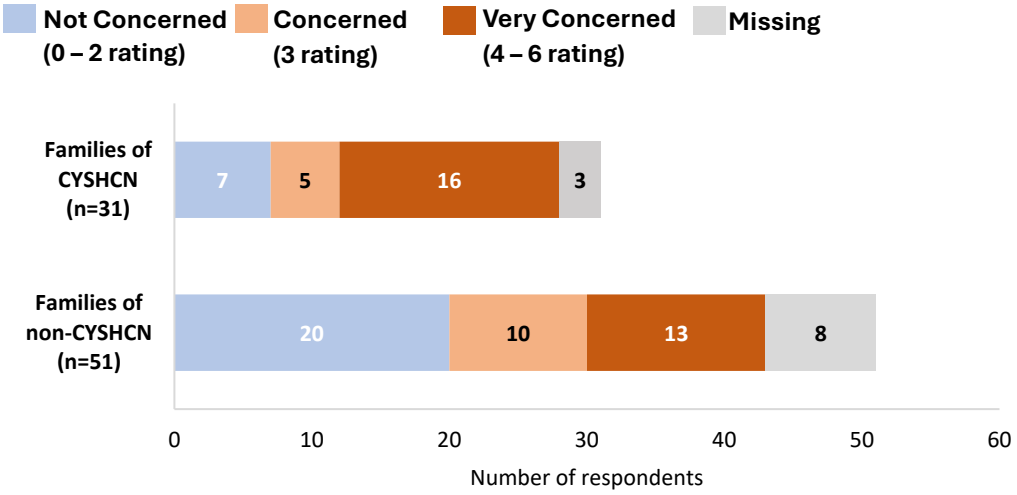


Additionally, families of CYSHCN more frequently reported that a "mental health counselor, therapist, psychologist, or psychiatrist" was one type of professional their child received care from than families of non-CYSHCN (Exhibit 17).

We identified differences in reported concern about survey respondents' child being bullied at school. Exhibit 18 shows that families of CYSHCN more frequently reported a rating of 4 –

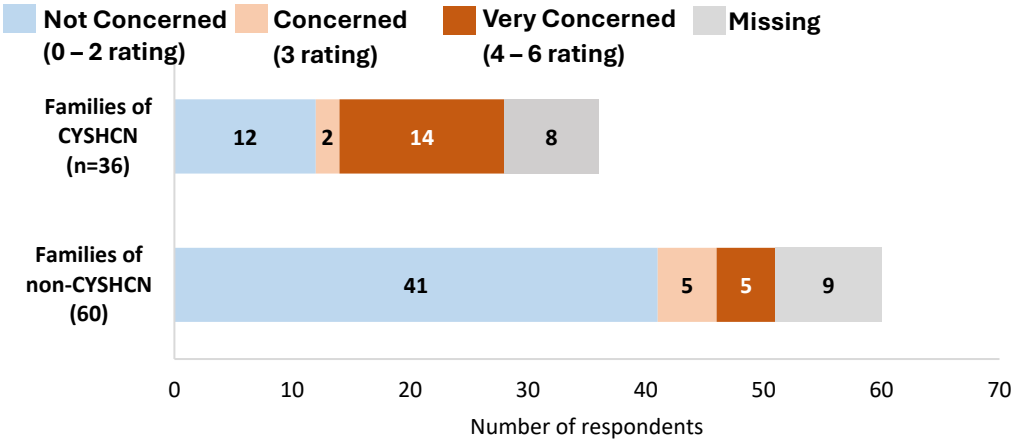
6 (n=16, average rating of 3.8) than families of non-CYSHCN, who more frequently reported a rating of 0 – 2 (n=20, average rating of 2.5). In other words, families of CYSHCN more frequently reported concern about their child being bullied at school. That said, about one-quarter of the families of non-CYSHCN who responded to this question reported being "very concerned" about their child being bullied at school.

Exhibit 18. Survey Respondents Reported Level of Concern About Their Child Being Bullied at School



We also identified differences in survey respondents reported concern about getting physical or mental health care for themselves. Exhibit 19 shows that families of CYSHCN more often reported a rating of 4 – 6 (n=14, average rating of 3.3), than families of non-CYSHCN who more often reported a rating of 0 – 2 (n=41, average rating of 1.6). In other words, families of CYSCHN more frequently reported that they are very concerned about getting health care for themselves.

Exhibit 19. Survey Respondents Reported Level of Concern About Getting Physical or Mental Health for Themselves



Discussion

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) collaborated with APANO CUF to better understand the care needs and experiences of Vietnamese families of CYSHCN. We sought to answer the following questions:

(1) What health care (behavioral, mental, physical, oral) and services do Vietnamese families need to care for their child?

(2) What has been the experience of Vietnamese families attempting to access care and services?

(3) What has been the experience of Vietnamese families in accessing culturally responsive care?

(4) What differences exist in the above experiences between Vietnamese families of CYSCHN and non-CYSHCN?

A discussion of findings for each of these questions follows.

Health Care and Services Use and Access

Results from analysis of the APANO CUF-OCCYSHN survey suggest that CYSHCN in the Vietnamese community experience mental and behavioral health conditions that require counseling or treatment. These children and their caregivers also experience challenges attempting to access this health care. A greater portion of our survey respondents (half) reported barriers accessing mental health care than families of CYSHCN generally (26%, NSCH 2021-2022). This may result from systemic barriers faced by CYSHCN in the Vietnamese community compared to the broader population, although it also may result from the different sampling methods used for each data collection. However, CYSHCN in Oregon's Vietnamese community, as well as other racially and ethnically minoritized communities, face the added barrier of trying to seek care in a mental health system that does not have adequate supports to meet culturally specific care needs (Garber et al, 2020).

Caregivers who reviewed survey findings with us described that health insurance can be a considerable barrier to accessing services. At the recommendation of our APANO CUF team members, we did not ask survey participants about their health insurance (current insurance status and type); however, the experiences described during the caregiver discussion align with Oregon families of CYSHCN more generally. About one-third of Oregon families of CYSHCN reported that their child's current insurance is not adequate (CAHMI, 2024). Caregivers from the Vietnamese community emphasized that in-network restrictions present a barrier to accessing services.

Family-Centered Care

Overall, our findings suggest that Vietnamese families of CYSHCN do not consistently receive family-centered, culturally responsive care. Survey participants tended to report positive communication with their child's health care providers. A meaningful portion of respondents reported feeling confused when communicating with their child's providers, felt that they were not listened to, and experienced considerable challenges with interpretation services. Caregiver meeting participants described needing to advocate for themselves and their children because of negative experiences with an interpreter. These experiences align with results from a study of the experiences of twenty Vietnamese families of CYSHCN across the US who worked with interpreters in their child's school (Nguyen, 2020). These families similarly reported experiencing inaccurate interpretations by interpreters, and even discrimination. One parent preferred having a family member be their interpreter (Nguyen, 2020).

One respondent to our survey, who reported never needing or wanting an interpreter, wrote that their child serves as their interpreter. Our survey did not ask caregivers who provides interpretation support for them; however, children frequently serve as interpreters for caregivers who do not speak English (Rodriguez, 2021). Challenges with interpretation services are experienced by many non-English speaking families, which is a significant system of care issue. Section 1557 of the Affordable Care Act requires that health care entities that receive federal assistance from the U.S. Department of Health and Human Services are required to

> *"…adhere to certain quality standards in delivering language assistance services. For instance, a covered entity may not: Require an individual to provide his or her own interpreter. Rely on a minor child to interpret, except in a life threatening emergency where there is no qualified interpreter immediately available. Rely on interpreters that the individual prefers when there are competency, confidentiality or other concerns. Rely on unqualified bilingual or multilingual staff. Use low-quality video remote interpreting services"* (DHHS, 2016).

Our findings show that quality interpretation services are not consistently provided for Vietnamese families of CYSHCN in Oregon. Utilizing family members as interpreters is often a common workaround for families who either cannot access an interpreter in a timely manner or prefer not to rely on interpreters given past experiences with poor quality interpretation.

These results align with findings from our 2020 participatory needs assessment with immigrant Latino families of CYSHCN in Central Oregon (Gallarde-Kim et al, 2020). Like our findings among Vietnamese families of CYSHCN, immigrant Latino families of CYSHCN also experienced challenges with the quality of interpretation services, providers dismissing parents' concerns, and racism from providers.

Child Quality of Life and Family Well-Being

Basic needs such as financial support, housing, and food security emerged as important needs among survey respondents. A considerable portion of APANO CUF-OCCYSHN survey respondents reported concern about finding affordable housing that meets their needs. Navigating Oregon's housing system is complex for families of CYSHCN (see Chapter 3, Vega-Juárez et al, 2025). Additionally, one in four Asian American and Pacific Islander households pay more than half of their income towards housing compared to White households (National Coalition of Asian Pacific American Community Development & University of California Los Angeles, 2021). Further, 54% of Asian households experiencing severe housing cost burden have limited English proficiency. Language and cultural barriers create additional challenges to accessing housing and underscores the importance of culturally responsive support within the housing system.

APANO CUF-OCCYSHN survey respondents also reported a high level of concern for getting physical and mental health care for themselves. This aligns with NSCH estimates that show that parents of CYSHCN generally often reported having fair or poor mental and physical health (CAHMI, 2024). These results can be linked to family challenges getting their basic needs met. When families' basic needs, like food, housing, income, and job security, are met, caregivers experience less stress and can provide better care for their child (Masten, Lombardi, & Fisher, 2021). Care coordination provided to families of CYSHCN in Vietnamese communities must be prepared to engage community-based supports in addition to health providers (for child and caregivers) and educators.

Differences between Vietnamese families of CYSHCN and non-CYSHCN

In comparing responses from APANO CUF-OCCYSHN survey respondents of CYSHCN and respondents of non-CYSHCN, we identified differences in use of health care services, receipt of mental health care, concerns with bullying, and caregiver well-being. Survey respondents of CYSHCN more frequently reported:

- Their child received care from a mental health provider than survey respondents of non-CYSHCN. NSCH results showed similar findings, Oregon CYSHCN generally were meaningfully more likely than non-CYSHCN to not receive needed mental and behavioral health services (CAHMI, 2024).
- A higher level of concern that their child will be bullied at school than survey respondents of non-CYSHCN. These results are consistent with findings that CYSHCN are more likely to be bullied. Oregon students in 6th, 8th, and 11th grades with disabilities more often reported being bullied at school than students in those grades without disabilities (Oregon Student Health Survey, 2022). Additionally, three times as many Oregon CYSHCN, ages 6-17 years, are likely to be victims of bullying as same-age peers without special health care needs (Oregon Student Health Survey, 2022).

- Concern about getting care for themselves than caregivers of non-CYSHCN. Caregivers of CYSHCN have more unmet health needs and need more supports than caregivers of children without special health care needs, possibly due to the multiple needs of their child (Hoover et al, 2021). These unmet needs may contribute to poor caregiver health: Oregon mothers who care for CYSHCN are two times more likely to experience fair or poor mental health compared to mothers of non-CYSHCN (CAHMI, 2024).

Community Reflections

APANO CUF team members exclusively wrote the following section. This section describes their experience working with Vietnamese families of CYSHCN and provides important context about the Vietnamese community.

For many Vietnamese immigrants, especially the older generation, language barriers present a significant challenge when trying to access and navigate healthcare systems in English-speaking countries. Even with an interpreter, cultural differences in communication can lead to misunderstandings or non-adherence to treatment plans. For instance, there's often a tendency to avoid directly saying "no" or to refrain from asking questions to authority figures, which can complicate effective medical dialogue. Vietnamese caregivers, especially recent immigrants or those with less formal education, may lack information about available services and supports for CYSHCN. They often struggle to navigate a complex and fragmented system.

Caring for CYSHCN can create a significant financial burden. Due to the insurance limitations mentioned earlier, many families have to pay for treatments and therapies that are beyond their financial means.

Additionally, within the Vietnamese community, there is a big feeling of shame connected to being sick, especially with mental health problems or disabilities. Families might decide to keep these issues a secret, so they don't feel judged or "lose face." Because of this, people might wait too long to get help from doctors or other helpers. They also might not tell everything to their healthcare providers. There's a strong desire to keep things private, and this can stop people who are taking care of others from finding the help and support they need.

It's really important to remember that the Vietnamese community isn't all the same. People have different levels of how much they've taken on American culture. For example, a Vietnamese person who came to the U.S. in 1975 will likely have very different experiences and ideas than someone who was born and grew up in the U.S. Our findings make more sense when you think about all these different life stories.

Overall, we were touched by hearing these families' feelings and the challenges they're currently facing. We hope this report will help CYSHCN and their families who identify as Asian American or Pacific Islander, in ensuring each family receives the support they need.

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