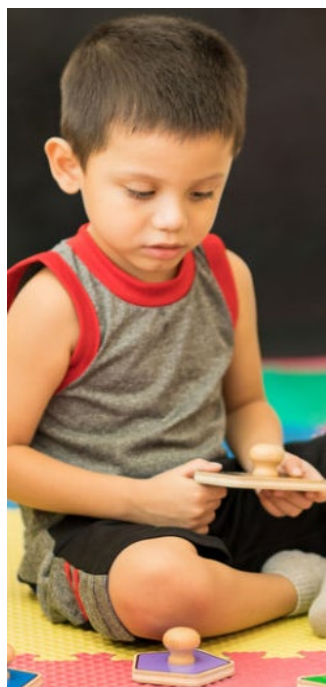


Strengthening the Network of Services for Latino Children with Special Health Care Needs in Oregon's Columbia River Gorge

March 2024



Children and youth with special health care needs (CYSHCN) are those who experience or are at risk for a chronic physical, developmental, behavioral, or emotional condition. Over 20% of Oregon children under the age of 18 are considered CYSHCN.¹

Community Health Workers (CHWs) are frontline health workers who understand and/or are trusted members of the communities they serve.

Providers and educators are professionals who work with and serve CYSHCN, including CHWs, public health nurses, pediatricians, therapists, teacher, early learning providers, and others.

Programs and services include medical, educational, specialty, mental health, and social services for Latino CYSHCN and their families.

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) promotes the health and well-being of Oregon's Children and Youth with Special Health Care Needs (CYSHCN). We do that by helping professionals – such as health care providers, educators, public health officials, and Community Health Workers – to understand the unique strengths and needs of CYSHCN and their families. It is important that the providers and educators who care for CYSHCN and their families work well together. This means that care is coordinated. Coordinated care helps CYSHCN and their families by reducing burden on families and duplication of services. Coordinated care also helps professionals by making sure that they understand the breadth of services received by families. Despite the importance of care coordination, 40 percent of Oregon families of CYSHCN who need care coordination get it.²

One in six Oregon CYSHCN is Latino.¹ Latino families of CYSHCN report that they need more help getting care, education, and services for their children.³ Race, socio-economic status, and citizenship status are additional challenges Latino CYSHCN may face when seeking care.⁴ Latino families get better help when their care focuses on goals identified by the families themselves, and when professionals share or are responsive to the family's language and culture.⁵

Community Health Workers (CHWs)⁶ work together with families, their children, and the providers and educators who serve them. CHWs often speak the same first language and share a similar cultural background with families they serve. This makes communication easier, and helps families get help they most want and need.

Because CHWs offer an opportunity to improve care coordination for Latino CYSHCN and their families, we began a pilot project with new and existing partners in the Columbia River Gorge. The pilot project aims to expand and strengthen care coordination services for Latino CYSHCN. This summary describes the first phase of the pilot project and findings from conversations with community members in the Columbia River Gorge.

The first section introduces the pilot project. Next, we describe how we gathered information and from whom. We then summarize findings from these conversations. The final section of this summary highlights areas of opportunity and pilot project next steps.

¹ [National Care Coordination Standards](#)

² [2022 National Survey of Children's Health](#)

³ [Oregon National Core Indicators](#)

⁴ [Escúchenos! Immigrant Latino Parents of Children and Youth with Special Health Care Needs in Central Oregon Share Their Experiences Accessing Health Care](#)

⁵ [National Center for Cultural Competence; Local Voices on Health Care Communication Issues and Insights on Latino Cultural Constructs](#)

⁶ [Oregon Community Health Worker Association](#)

INTRODUCTION TO THE CROSS-SECTOR CARE COORDINATION PILOT PROJECT

In 2022, we began a pilot project in Oregon’s Columbia River Gorge region focused on supporting the coordination of care for Latino CYSHCN, and the role of CHWs in that work. OCCYSHN was drawn to the Columbia River Gorge because of the existing infrastructure supporting its large Latino community. The region also has a long history of integrating CHWs into services and programs. Our main goals for this pilot were to:

1. Improve experiences with health care and services for Latino CYSHCN and their families, and
2. Support Latino CHWs serving children and families.

WHO WE SPOKE WITH & HOW WE COLLECTED DATA

We began information gathering in the Fall of 2022 by talking with OCCYSHN’s existing partners. We also worked on developing relationships with new partners to solidify the pilot’s goals. A timeline of our conversations with community members appears below. The sections that follow describe who we spoke with and how we gathered data.



INFORMAL MEETINGS WITH LOCAL PARTNERS

Our first set of conversations focused on understanding existing programs and services, and their strengths and needs. We spoke with a variety of professionals to learn about their experiences with Latino CYSHCN, care coordination, and working with CHWs. We spoke with:



Four primary care and behavioral health providers from Adventist Health Columbia Gorge, One Community Health, and Mid-Columbia Center for Living.



Eight educators, school or district administrators, and staff from Early Intervention/Early Childhood Special Education and Special Education.



Seven representatives from community-based social service organizations including Bridges to Health (B2H), The Next Door, Inc. and Oregon Community Health Workers Association (state-level).



Four representatives of local public health departments (North Central and Hood River Public Health).



Two representatives of insurance and payor organizations, including PacificSource Coordinated Care Organization.

INTERVIEWS & GROUP DISCUSSION WITH LATINO CHWS



After our initial conversations, we spoke with Latino CHWs because they have intimate knowledge of Latino family needs. They understand and share many of the same cultural values as the families they serve. In addition, they live and work within a shared community, and often experience similar challenges in meeting their own families’ educational, health, and well-being needs.

Latino CHWs’ work is broad and includes helping with medical, educational, social service, and social and emotional needs. CHWs can work directly with

CYSHCN or with their family members. To help us understand how they coordinate care for CYSHCN in the Columbia River Gorge, we spoke with seven CHWs⁷ from Bridges to Health, North Central Public Health, One Community Health, and The Next Door, Inc in Spring 2023. Six CHWs were bilingual (Spanish, English) and identified as Latino. One CHW identified as White and was English-speaking only.

Later we invited the six Latino CHWs⁸ to participate in a group discussion. The purpose of the discussion was to confirm preliminary findings from the interviews, make meaning of the findings, and continue to expand our understanding of their work. Five CHWs joined us for the group discussion.

INTERVIEWS WITH LATINA MOTHERS



Parents of CYSHCN know their children and family's needs best, and how well health care, education, and social services are meeting those needs. To learn more, in the summer of 2023, we spoke with six Latina mothers of CYSHCN ages 0 to 26 years about their experiences with services in the Columbia River Gorge. Two of the six mothers had two children, and the other four had one child, with a special health care need. There were between two and six children total in each family. Mothers talked about a number of different conditions and diagnoses for their children including ADHD, Autism, epilepsy, intellectual disabilities, and Rett's Syndrome. However, not every child had a clear diagnosis. CYSHCN were described by their mothers as independent, calm, happy, active, and chatty. They used words like "special," having "special needs," and "disability"⁹ to describe their children's conditions.

⁷ One participant was trained as a CHW and is currently working as a Youth Outreach Worker (YOW). The participant acknowledged that there is a lot of overlap between the work of YOWs and CHWs, with a specific focus on youth.

⁸ The White, English-speaking CHW did not attend the group discussion because it was focused on learning more from Latino CHWs in the Columbia River Gorge.

⁹ The translation of these terms does not adequately capture the cultural significance behind them.

Mothers talked with us about the kinds of services and programs their CYSHCN and family needed and used. They also shared with us what was going well for their family and challenges they had meeting their families' needs.

PROVIDER AND EDUCATOR EVENT



In September 2023, we held a Provider and Educator Event where we shared what we learned in the first year of the pilot and offered a chance for providers, educators, CHWs, and others in the community to connect. Professionals shared their experiences and perspectives during small group discussions, and we ended our time with a voting exercise to prioritize potential pilot work.

FAMILY EVENT & GROUP DISCUSSIONS WITH LATINO FAMILIES OF CYSHCN



In November 2023, we invited all six families to participate in a Family Event to share with one another, to learn from a Columbia River Gorge CHW and an Oregon [Family-to-Family Health Information Center](#) Parent Partner, and to discuss preliminary findings from the six interviews. At the end of the Family Event, families worked together to prioritize their needs to inform our next steps. Five families attended the Family Event, including mothers and fathers. One family also brought their niece.

RESULTS FROM COMMUNITY CONVERSATIONS

We reviewed our notes from all of these discussions to identify important themes. The next two sections summarize our findings and focus on community strengths and needs.

COMMUNITY STRENGTHS & WHAT IS GOING WELL

LOCAL LATINO COMMUNITY. The local Latino community is large and close-knit. Latino families of CYSHCN find support from one another by advocating for each other and sharing stories, resources, and tips. CHWs are embedded in the community and have many personal connections with Latino families.

“...they [clients] know me in the community...I mean, they invite me to places like that [quinceañeras]...And when you go to those parties, you see most of the family there, most of the kids there. I was there when they were born. It's like one of those experiences that it's your community.” – CHW

DESIRE TO PARTNER TOGETHER. Professionals are eager to learn from one another and work with families to better meet the child and family's needs. CHWs are constantly looking for new ways to partner with other CHWs, providers, and educators so that they can serve the families they work with better. Parents, too, are eager to work with providers and educators to help their children learn and grow.

INFRASTRUCTURE FOR COLLABORATION. Bridges to Health provides important infrastructure that allows CHWs to coordinate and collaborate across programs. The B2H program has statewide recognition, and there is interest in expanding and using it in other parts of Oregon. The model aligns with families' requests for one central place to get care navigation services (see below).

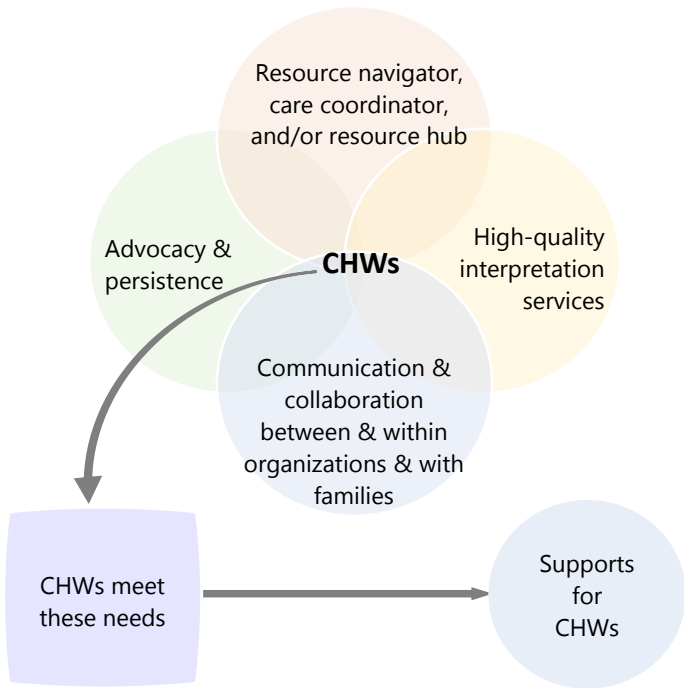
“There was this huge win where we were able to provide funding [for childcare before parent underwent surgery]. It happened because of One Community Health, having [another CHW] that was in contact with me. We were tag teaming it, and we were like trying to do the best that we could together.” – CHW working within B2H

GROWING SUPPORT FOR CHWS. Many professionals recognize the important role that CHWs play in supporting Latino families of CYSHCN. There is a shared sense of responsibility in supporting CHWs. There are a number of ways that CHWs can meet with, share, and learn from one another and from providers, including the Gorge Collaborative, the Gorge Resource Huddle, and the Providence Ethics Committee. Career advancement opportunities for CHWs working in the B2H program were developed and these CHWs are provided incentives for their lived experience and being bilingual. Some CHWs noted the wonderful supervision they receive that includes professional and emotional supports.

COMMUNITY NEEDS

Latino families of CYSHCN, Latino CHWs, providers, educators, and other partners all agree that there are gaps in the systems that serve Latino CYSHCN. Four main needs came up during interviews and discussions: (1) resource navigators, care coordinators, and/or a resource hub, (2) high-quality interpretation services, (3) communication and collaboration between and within organizations and with families, and (4) advocacy and persistence. The figure below highlights these needs and where CHWs can and do fit in. A description of these needs, CHWs' roles in filling the needs, and challenges to CHWs follows.

Gaps in Services for Latino CYSHCN & Where CHWs Fit In



RESOURCE NAVIGATOR, CARE COORDINATOR, AND/OR RESOURCE HUB. Latino families of CYSHCN agreed that one central place to get information and care coordination would be very helpful. Currently, families have to navigate services and programs that don't talk to each other, and they are often bounced around from service to service or provider to provider. Problems connecting with services are exacerbated by outdated contact information, especially for clinics and organizations that have closed or moved. Latino families are specifically looking for one knowledgeable person who understands their needs and family dynamics, is "trustworthy," "responsive," "communicative," and "empathetic" to help them navigate and coordinate care. With support from one person (like a CHW or public health nurse) or one organization, families could more easily access healthcare and social, educational, and other services. B2H offers navigation and coordination services that meet these needs, but these services are focused primarily on adults at this time.

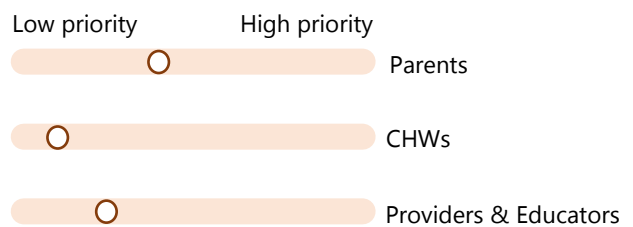
We also heard that public health nurses have been the main source of care coordination for CYSHCN in the past. With public health and primary care staffing shortages, families have been left without much help with care coordination.

"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." – Parent

Translation: *"It's sort of like the people here need a group or a place where people can come to ask for information about resources that are actually current."* – Parent

At the end of both the Provider and Educator Event and the Family Event, people were asked to vote on their priorities for supporting Latino families of CYSHCN and CHWs. Results showed that having a resource navigator, care coordinator, and/or resource hub was most important to Latino families of CYSHCN. Some providers, educators, and CHWs included it as a priority as well.



HIGH-QUALITY INTERPRETATION SERVICES. Latino families and CHWs reported a lack of high-quality language interpretation services for Latino families. Latino families shared stories about struggling to understand medical providers and educators at appointments either because there was no

interpreter, or the interpreter was not qualified.¹⁰ Latino families and CHWs noted that medical and educational language (especially language used during Individual Education Plan and 504 plan meetings), is specific. Certified interpreters are needed to relay the information accurately and in ways that families can understand. Even when an interpreter is provided, documents like the Individual Education Plan or 504 Plan are often in English. If translated, these documents are not in plain language and are difficult to understand.

Latino families of CYSCHN and CHWs talked about negative outcomes that resulted from the lack of high-quality interpretation by qualified, certified interpreters. Families missed or misunderstood important information, and there were misunderstandings between families and professionals serving them.

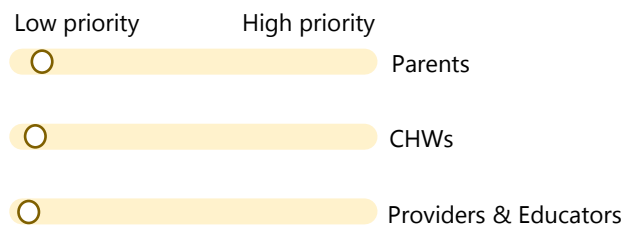
“...cuando...no más es una aide que llevan o a veces es el niño, el hijo de la escuela más grande que llevan [los padres]. Y es donde pienso que en la comunidad debería de haber un intérprete para las escuelas también, especialmente cuando los niños tienen ese tipo de IEP para que todos estén en el mismo lugar.” - Parent

Translation: *“...when...it's just an aide that they provide or sometimes it's the oldest child that attends the school that [the parents] take. And that's where I think in the community there should be an interpreter for the schools too, especially when the kids have that type of IEP so that everyone is in the same place.” – Parent*

“[Linguava is] really not difficult to use, but I understand if you're not familiar with it, then it would be a pain in the butt. So it's easier for people to come to myself, a coworker...It's frustrating because, let's say the appointments or the meetings are set like a week ago, they'll come in like ten minutes before, and they're like, 'can you translate?' First off, it's not translating, it's interpreting. Secondly, no, because I'm not

prepared. You cannot say IEP/504 plans and just translate or interpret them right into Spanish. That's not how this works. You put me in this position. I look unprofessional.” – CHW

Parents, providers, and educators did not identify improving interpretation services as a high priority during the voting. However, poor-quality interpretation, especially literal translation of complex and high-level language without additional context or information, was a common complaint heard in interviews and group discussions at the Provider and Educator and Family Events.



COMMUNICATION AND COLLABORATION BETWEEN AND WITHIN ORGANIZATIONS AND WITH FAMILIES. We clearly heard that communication and collaboration can be improved. CHWs, providers, and educators would like to strengthen partnerships *between* their organizations. Many partners, especially CHWs, also mentioned the need for improved communication *within* organizations so that all staff know about their organization’s programs and services. Latino families of CYSCHN also talked about their desire to be more involved in their child’s care and education, especially partnering with professionals to better support their children’s learning and development at home. All professionals highlighted the importance of partnering with families to better meet the needs of CYSCHN and families.

¹⁰ [Families of Latino CYSCHN in Central Oregon also experience interpretation challenges.](#)

“Even personally within [my organization], there's programs that I'm not even familiar with... just like setting the tone within each organization of 'we should all understand all of the resources that are within our organization'... making sure that everybody within the organization is familiar and able to work and provide the services, you know, because if someone calls in and they're like 'Hey, I need something for this or that. How can I access this?' If you're unfamiliar with it, you could totally miss an opportunity to help someone...” – CHW

“[There's] a lot to work on in supporting good communication and coordination between organizations...” – Pediatric nurse

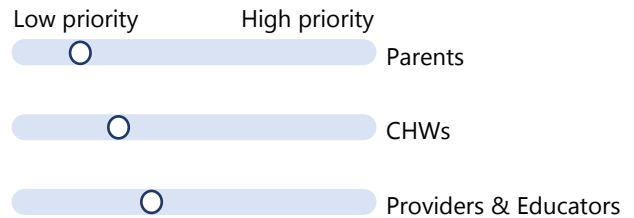
“Yo diría que a lo mejor tener el apoyo de [profesionales] ya tan siquiera enseñar a los padres, como ayudar a nuestros hijos tener el soporte... o sea que nos respalden y digan, '...eso es lo que ustedes, como padres, pueden hacer en su casa' o pueden guiarnos cómo tratar de darles una mejor vida a nuestros hijos.” – Parent

Translation: *“I would say maybe having [professionals'] support and even teaching the parents, how to help our children have support... so that they can support us and tell us, '...This is what you, as parents, can do at home,' or they can guide us on how to try to give our children a better life.” – Parent*

Voting results showed that a good portion of professionals want to prioritize improving collaboration and communication. When Latino families spoke about improving communication and collaboration, they mostly focused on improvements between providers and families, not between services and programs. Some, however, said that strengthening communication and collaboration between services and programs would be helpful.

Additionally, Latino families talked about relying on a resource navigator or someone in a care coordination role to make connections between services. With programs and services short-staffed, however, many families do not have someone to

support communication and collaboration between services and programs.



ADVOCACY & PERSISTENCE. Latino families of CYSHCN and Latino CHWs noted that it takes self-advocacy and persistence to get needed services and programs. When one resource is unhelpful or no longer available, the family often must find a new one. CHWs do this by researching all community services and by finding loopholes and back channels to accessing services and programs. When families are responsible for researching services and finding loopholes and back channels, CYSHCN and their families often don't get what they need because service systems are hard to navigate. Families also mentioned that it takes a lot of time to get their CYSHCN's needs met, which leaves them with little time to attend to other important family needs. Latino families' experiences with racism, immigration challenges, language barriers, and stigma all affect their ability to advocate for their child. Rather than asking families to advocate for themselves, Latino families have asked for help from professionals to advocate for their children.

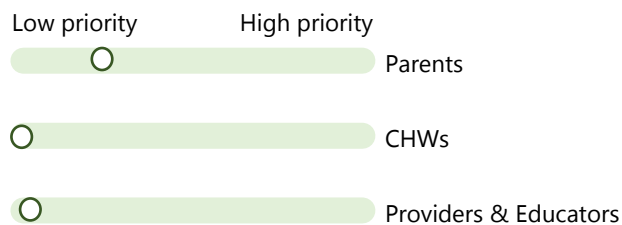
“Llevo 3 a 4 años batallando por lo que son las cámaras, un pequeño brincolín, su caminadora, sus plásticos para la cama. Lo único que [mi hijo] recibe son los pull-ups y guantes y el medical pues. Siento que nos ha cerrado las puertas.” – Parent

Translation: *“I've been fighting for 3 to 4 years about the cameras, a small trampoline, his treadmill, his plastic bed covers. The only thing [my son] gets are the pull-ups and gloves and, well, medical insurance. I feel like the doors have closed on us.” – Parent*

“Pero siento que hay [padres] que no tienen esa misma capacidad de decidir, o sea, si [los profesionales] te dicen ‘no,’ como que [los padres] se quedan ahí [y no toman acción]. Pero yo no. Yo soy de las personas que busca y busca y trato de buscar y hablar a donde pueda, para que [los profesionales] miren que no nomás es uno lo que acepto, sino le sigo dando y dando porque al final de cuentas, ella necesita esa ayuda, el bien para ella, no es para mí.” – Parent

Translation: *“But I feel that there are [parents] who don’t have that same ability to decide, like, if [professionals] tell you ‘no,’ [parents] kind of stay put [and don’t take action]. But not me. I am one of those people who seeks and searches and I try to look and talk wherever I can, so that [people working with my child] see that it is not the only thing I accept [don’t take no for an answer], but I keep going and going because at the end of the day, she needs that help, the benefits are for her, not for me.” – Parent*

Advocacy help to access services and programs was identified as a higher priority for Latino families than for the professionals. Advocacy did not rise to the top of CHW priorities because it is already a primary aspect of their daily work.



COMMUNITY HEALTH WORKERS. CHWs address many of the needs that surfaced during our conversations with communities. Thus, they are at the center of the graphic on page six. In interviews and in our group discussion, CHWs talked about helping families navigate separate services and programs. They also talked about collaborating

with other CHWs, providers, and educators as they are able,¹¹ and persistently advocating for their clients. Every CHW we spoke with noted that they inevitably provide some form of support for interpretation and translation, even though it is explicitly not their job. CHWs can make requests for interpretation services as well as help families learn to advocate for an interpreter themselves. When lack of high-quality interpretation services causes confusion, CHWs said they step in to support their clients. CHWs also emphasized their role in providing social and emotional support to Latino families, including immediately following a child’s diagnosis, which can be a difficult time for families. The ability to listen and provide empathetic support are exactly the skills that Latino families said that they want to see in the navigator or care coordinator role. With the exception of providing interpretation services, these roles align with Oregon Community Health Worker Association’s CHW [scope of practice](#).

SUPPORTS FOR CHWS. It is clear that CHWs can fill service gaps for Latino CYSCHN, and for some families they already do. However, in interviews and the group discussion, CHWs noted a number of ways that employers and partners can better support their work. Most notably, CHWs are underpaid¹² and feel undervalued and unrecognized by community partners, especially in medical and educational settings. Their role in supporting families is often misunderstood, and they are often expected to do things that fall outside of their job description (like interpretation and translation). CHWs said they want role recognition and appropriate compensation, more training and certification opportunities, more financial support to pay for professional development, clear career pathways, and training for partners on how to work with CHWs and interpreters. Improvements in these areas could support CHWs in better filling service gaps for Latino CYSCHN and their families.

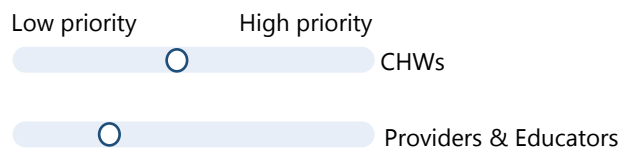
¹¹ CHWs working in clinic or medical settings had direct access to medical providers whereas CHWs working in other settings, like social service organizations, had little to no access to medical providers.

¹² A [needs assessment conducted by ORCHWA](#) in 2018 confirmed CHWs’ perception.

“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

“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 feel like sometimes they unfortunately use that label as ‘I have more power than you and I know more than you.’” – CHW

Understandably, this topic area was important to CHWs. The CHW workforce, like a lot of healthcare and social service workforces right now, has high turnover. In our group discussion, CHWs said that without better incentives to stay, many find better paying jobs or go back to school for a different career path. During the Provider and Educator Event, some providers and educators agreed that improving supports for CHWs should be a priority. Latino families were not asked to vote on this priority for a number of reasons, including the fact that many did not know what a CHW was, and had never worked with one.



MOVING THE WORK FORWARD

We want to thank everyone who participated in conversations, interviews, and meetings. The previous sections summarize the first phase of the pilot project, and we are excited about continuing this work in the Columbia River Gorge. There are many ways to move this pilot project forward, and we at OCCYSHN are looking to local partners, including Latino families of CYSHCN, to help guide the work. We see many areas of opportunity and offer several suggested next steps.

AREAS OF OPPORTUNITY

The following are areas of opportunity for the coordination of care for Latino CYSHCN and their families and CHWs’ role in that work.

- Build connection between parents and providers, and develop and support Latino parents of CYSHCN in leadership opportunities across the community.
- Explore ways to build on the well-functioning B2H Hub model to include more child-serving sectors (e.g., early childhood education, K-12 education) and/or expand to other Traditional Health Worker roles.
- Work toward a shared understanding of CHWs’ role in care coordination for Latino CYSHCN across systems, including health care, education, and social services.
- Collaborate with existing committees and councils serving providers and educators to offer training and education opportunities about:
 - CHW’s role in care coordination
 - Specific needs of Latino CYSHCN and their families
 - Culturally responsive practices that reflect Latino culture and supports a bilingual/bicultural workforce.
- Partner to build formal coordination infrastructure between medical, educational, and social services and programs.

PILOT PROJECT NEXT STEPS

We are working on a plan for the next phase of this pilot project. Our next steps include:

- Partner with The Next Door, Inc. to complete the cultural and linguistic Spanish language adaptation of [OCCYSHN's CHW Course](#) to build capacity for a diverse workforce serving Latino CYSHCN. Several parents who we spoke with in the past year have been invited to join the project's Community Advisory Committee and will inform this process.
- Pursue funding and additional partnerships to increase access to this course by paying for trainings and communities of practice within the Columbia River Gorge and across the state.
- With providers, educators and parents, develop ideas for potential small projects to help address prioritized needs and implement at least one project over the next two years.
- Pursue additional funding and partnerships to scale up one or more of the small projects where we find success.
- Partner with local and/or state agencies to offer trainings and supports for Latino parents of CYSHCN. For example, we are partnering with Oregon Law Center and the Oregon Family-to-Family Health Information Center to hold a series of Spanish-language parent information sessions in the region in early 2024.
- Continue to share OCCYSHCN and Oregon Family-to-Family Health Information Center's CYSHCN-specific resources, tools and state-level connections with partners in the Columbia River Gorge (for example, ACCESS, Shared Care Planning, F2F Parent Partner support).
- Continue to disseminate findings from this pilot project with parents, providers and educators.

If you want to learn more or get involved, please contact Emilie Lamson-Siu at OCCYSHN@ohsu.edu.