

## Oregon's Children with Special Health Care Needs

*Five Year Needs Assessment Findings – August 20, 2020*

# CHAPTER FOUR

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

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## Executive Summary

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) and the Latino Community Association (LCA) collaborated to collect data about the needs and experiences of immigrant families of Latino children and youth with special health care needs (CYSHCN). Specifically, we sought to learn about families' health and other support needs and their ability to access them; availability of care and supports that are responsive to the family's culture and language needs; and preparation for and experience with transitioning to adult health care. To meet these objectives, LCA conducted six focus groups with 22 parents or guardians of Latino CYSHCN. Of those, 15 were parents or guardians of children younger than 18 years old, and seven were parents or guardians of young adults ages 18 through 25. All focus groups occurred in the three counties that compose Central Oregon: Crook, Deschutes, and Jefferson. This region is primarily rural, although Deschutes County is home to Bend, Oregon's seventh most populous city (Portland State University Population Research Center, 2020)

In all focus groups, family members described experiences of racism. Family members described culturally-insensitive and discriminatory comments directed to them by health care providers. Family members described challenges they faced interacting with the health system because their primary language is Spanish, or because they belonged to a non-White culture. Family members reported challenges obtaining interpreter services. Requests for interpreters delayed appointments, and families reported frustration with interpretation quality. Race and language played a key role in determining the quality of care that Latino CYSHCN received.

When asked about their CYSHCN's needs, family members in all focus groups reported that their child needs or uses behavioral or mental health care. Family members reported that it was easy to access primary care and obtain health insurance coverage, and difficult to access medical specialists and allied therapy. They described access to care challenges such as a lack of providers and quality care locally, and long wait times for appointments. They said they had to advocate persistently to access services. Family members described a range of experiences with their child's healthcare when their child turned 18; they reported not being given warning that their child would need to transition to an adult provider and they expressed concerns about consistency of health insurance and care for their young adult.

Although our findings do not generalize to all immigrant families of Latino CYSHCN in Central Oregon, our needs assessment found that these families experience racism in Oregon's health care systems. To ensure that all CYSHCN in Oregon receive care in a patient-centered medical home, Latino CYSHCN and other CYSHCN of Color must have access to family-centered and culturally responsive care. Our report concludes with a set of recommendations that identify opportunities for Oregon Title V CYSHCN to collaborate with culturally-specific service organizations to promote culturally responsive care in Title V Block Grant strategies.

## Acknowledgements

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## Statement from Latino Community Association

Desde el año 2000, la Asociación de la Comunidad Latina ha sido un punto de encuentro esencial para nuestras familias inmigrantes latinas en Oregón Central. Nuestros programas incluyen: Capacitación laboral, Desarrollo familiar, Familias sanas, Desarrollo juvenil y Enriquecimiento cultural. Nuestra misión es capacitar a nuestras familias Latinas para prosperar creando oportunidades para progresar y construyendo puentes que nos unan y fortalezcan a todos. Tenemos nuestras sucursales en las comunidades de Bend, Redmond, Madras y Prineville en el estado de Oregon.

Since 2000, the Latino Community Association has been an essential connecting point for our immigrant Latino families in Central Oregon. Our mission is to empower our Latino families to thrive, creating opportunities for advancement and building bridges that unite and strengthen us all. Our programs include Workforce Education & Training, Family Empowerment, Healthy Families, Youth Rising and Cultural Enrichment. We have offices in Bend, Redmond, Madras and Prineville, Oregon.

## About Oregon Center for Children and Youth with Special Health Needs

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) is Oregon's public health agency for children and youth with special health care needs. OCCYSHN partners with the Oregon Health Authority Public Health Division to implement Oregon's Title V Maternal and Child Health Services Block Grant. OCCYSHN's mission is to improve the health, development and well-being of all Oregon's child and youth with special health care needs.

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## Foundational Terminology

The terms used in this report are defined as follows:

**Racism** – “A system of structuring opportunity and assigning value based on race that unfairly disadvantages some individuals and communities, unfairly advantages other individuals and communities, and undermines realization of the full potential of the whole society through the waste of human sources” (Jones, 2003, p.10).

**Institutionalized racism** – “Differential access to the goods, services, and opportunities of society by race” (Jones, 2000, p. 1212). Differential access is shown through “material conditions and in access to power” (Jones, 2000, p.1212). The former is seen in access to safe, quality education, employment, environment, housing, and medical care; the latter includes information, resources, and voice (Jones, 2000).

**Personally mediated racism** – “Prejudice and discrimination, where prejudice means differential assumptions about the abilities, motives, and intentions of others according to their race, and discrimination means differential actions toward others according to their race” (Jones, 2000, pp. 1212-1213).

**Internalized Racism** – “Acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth, and is characterized by their not believing in others who look like them, and not believing in themselves” (Jones, 2000, p. 1213).

## Introduction

The National Survey of Children’s Health (NSCH), administered by the U.S. Maternal and Child Health and the U.S. Census Bureaus, and OCCYSHN’s five-year needs assessments are the primary sources describing the population of Oregon children and youth with special health care needs (CYSHCN).<sup>1</sup> NSCH results provide a wealth of information, yet results that generalize to CYSHCN often do not exist due to inadequate sample size. Results are further limited for CYSHCN who are Latino.<sup>2</sup> The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) routinely collects input from families when conducting its Title V legislatively-required five-year needs assessments; however, these results do not adequately describe the experiences of families of Latino CYSHCN, again because of small sample sizes. Therefore, to inform Oregon’s 2020 Title V needs assessment, the Latino Community Association (LCA) partnered with OCCYSHN to collect data to answer the following questions:

1. What health (behavioral, oral, physical) and other care services do immigrant families of Latino CYSHCN need to care for their child?
2. What has been the experience of immigrant families of Latino CYSHCN attempting to access needed care?
3. What has been the experience of immigrant families of Latino CYSHCN in accessing culturally responsive care?

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<sup>1</sup> 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).

<sup>2</sup> LCA team members determined that we should use the term “Latino” for our project as that is the term that the community uses to describe itself.

4. What has been the experience of immigrant families of Latino CYSHCN in transitioning their child from pediatric to adult health care?

## Methods

The LCA-OCCYSHN team (we) developed a focus groups data collection method to gather data to answer these questions. We co-developed the focus group discussion guide, which was translated into Spanish by an LCA team member. LCA team members recruited, screened for study eligibility, and arranged and conducted the focus groups in Spanish. Families were eligible to participate in the focus groups if (a) their 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), (b) their child's ethnicity was Latino, and (c) their child's age was younger than 26 years. Because we sought to learn about the experiences of immigrant families of Latino CYSHCN with transition from pediatric to adult health care, we organized focus groups according to child age (younger than 18 years, or 18 through 25 years). However, recruiting family members of young adults in the older age group proved challenging, so the age groups were combined.

LCA conducted six focus groups in Central Oregon with 22 adults who were parents or guardians of Latino CYSHCN. Of those, 15 were parents or guardians of children younger than 18 years old and seven were parents or guardians of young adults age 18 up to 26. In five focus groups, the seven parents or guardians of young adults were asked about their young adult's experience transitioning from pediatric to adult health care. An average of four family members participated in the focus groups, with a range of two to seven participants in each group. Three counties compose Central Oregon: Crook, Deschutes, and Jefferson. This region is primarily rural, although Deschutes County is home to Bend, Oregon's seventh most populous city (Portland State University Population Research Center, 2020)

LCA collected demographic questionnaires from all focus group participants. Ninety-five percent of family members were Latino/a (includes Hispanic or Latino Central American; Hispanic or Latino Mexican; Hispanic or Latino South American; Other Hispanic or Latino). The average age was 40 years, and 91% were the mother or father. Seventy-two percent reported having health insurance. On average, respondents completed 11 years of school, with a range of 5 to 17 years. The average number of people in the family member's household was five, and 63% reported having an annual household income of less than \$34,999.

## Results

We used a thematic approach to analyzing the data. Because the data that result from focus groups are the product of interaction among participants, the focus group is the unit of analysis by which we report results (e.g., seven focus groups described theme x). We identified a theme if an idea or experience was reported in at least half of the focus groups. When analyzing the data, we first identified overarching themes, or content that aligned with our four research questions: (1) types of health-related care needs, (2) access to care, (3) culturally responsive care, and (4) experiences transitioning from pediatric to adult health care. We then identified second tier themes within each of the four overarching themes; in some cases we also identified third tier themes within second tier themes. Discussion of these results follows.

## Health-Related Care Needs

During each focus group, LCA asked family participants to describe the types of health-related care needs and supports that their CYSHCN currently or previously used or needed (see Exhibit 4.1). Family members in all groups (n=6) reported that their child needs or uses behavioral or mental health care. Similarly, in all groups (n=6), family members described their child needing or using primary care and specialty care services. In addition, family members frequently discussed need for or use of occupational, physical, sensory, or speech therapy (n=5). Exhibit 4.1 includes quotations that illustrate the most common care needs.

Exhibit 4.1. Health-related Care Need Types By Number of Focus Groups

Number of Focus Groups	Health-related Care Need Sub-themes
6	<p>Behavioral/Mental Health Care: Need or use of behavioral, mental, psychiatric health services, such as behavioral therapy, assessments, psychologist, etc.</p> <p><i>“... My daughter, who has all the diseases, is becoming very aggressive and began to develop aggressiveness. I try to talk to her, but she does not reason, she is a special girl so sometimes she does not reason and it is difficult ... I am seeing that my daughter is developing aggressiveness. I have to talk to her specialist and tell her and that I do not understand why. Is there anything that uncovers aggressiveness in children? Because I am trying to understand, my daughter was a very sweet girl, she was very kind. The teachers tell me that she was a very sweet girl but lately not anymore, and I would like to know what takes the children to that level?” (Focus Group 4)</i></p>
6	<p>Primary Care Providers (General Provider, Gynecology, Pediatrician): Need or use of primary care, including regular check-ups.</p> <p><i>“... My one and a half year old boy was diagnosed with autism, but it is not such severe autism, so the services he receives right now is with the doctor, [the PCP] has been a very good doctor for us because he is the one that has put him in speech therapy, sensory therapy, years ago, like 8 years he was very active in these therapies. There were not as many services as we would have liked, because the therapies only lasted about 15 min, but those services that they have given him.” (Focus Group 6)</i></p>
6	<p>Specialists: Need or use of pediatric specialty or subspecialty care such as burn care specialist, cardiologist, ENT, geneticist, neurologist including seizure assessment and monitoring, specialists who work with Glass syndrome, eye surgeon, sleep apnea center, etc.</p> <p><i>“My child is going to be four years old and his condition is a very rare condition, it is Glass Syndrome and his learning level is very slow, very, very low. He also does not eat through his mouth, does not speak, I give him food through a tube in his stomach.” (Focus Group 1)</i></p>
5	<p>Allied therapy: Need or use of occupational therapy, physical, sensory, or speech.</p> <p><i>“I have a daughter who is now 10 years old, she is a burn survivor and she also receives services. She needs surgeries. She had an accident when she was two years old and had many skin graft surgeries and was in the hospital for several weeks. She was in and out of the hospital for several weeks and even now she still has surgeries for that situation. She received physical therapy, occupational therapy, and the services of a burn specialist surgeon” (Focus Group 3)</i></p>
4	<p>Developmental specialists: Need or use of pediatric specialists or subspecialists to assess and care for Autism Spectrum Disorders, developmental and intellectual disabilities.</p>

Number of Focus Groups	Health-related Care Need Sub-themes
4	Educational Support: Need or use of educational supports such as Early Intervention (EI) assessments and services or supports in primary or secondary schools.
4	Prescriptions: Need or use of prescription medication or transfusions.
3	Durable Medical Equipment (DME): Need or use of feeding tubes, crutches, machines, wheelchairs, etc.
3	Hospital / Emergency Department Visits: Need or use of hospital or Emergency Department services.
3	Nutrition services: Need or use of nutrition services such as a nutritionist.
2	Audiology and hearing care: Need or use of audiology assessments and hearing supports and services.
2	Family Support: Need or use of supports for the family, including parents/guardians or siblings
2	Vision supports: Need or use of vision supports such as an eye doctor.
1	Care Coordination: Need or use of communication and coordination among providers or team-based care.
1	Other Health Care Support: Need or use of other health care support and staff.

## Access to Care

We asked family members to describe the ease or difficulty of getting the health care their child needed. The challenges that emerged across most focus groups were health insurance challenges, lack of local providers, poor care quality, long wait times to get services, and the need to advocate persistently to get care.

### *Health-related care services that are easy to access*

In five focus groups, family members described the types of health-related services that they found easy to access. Family members in almost all of the focus groups (n=5) reported that their child was covered by health care insurance. Family members in nearly all groups (n=4) also reported that primary care was easy to access. Appendix A contains the list of services discussed in three or fewer focus groups.

*"My daughter was born in Medford, and the legal guardian processed everything. My daughter in five days already had [health insurance coverage]." (Focus Group 1)*

*"For me it has been good to apply for OHP without a problem and I have tried to be a little disciplined when I should renew or when I should send the information they are requesting so they can continue to have coverage. So far I have not experienced any difference between my children having OHP coverage from the state than if they had private coverage." (Focus Group 3)*

*"My [child's] doctor is another pediatrician... she cares about children. She does call me as soon as they refer me to Portland. She takes care of calling them and gives me the references I have to have." (Focus Group 1)*

*"As they say here, the easiest [to access] is the pediatrician but for others it is very difficult." (Focus Group 4)*

### *Health-related care services that are difficult to access*

In all focus groups, family members described the types of health-related care services that they found difficult to access. Family members most often reported difficulty accessing medical specialists (n=6) and

allied therapies (n=5). Allied therapies consist of occupational, physical, and speech therapy. Appendix A contains the expanded list of health care and other service types, which were discussed in fewer than three focus groups.

<p><i>“So the other services that are difficult to access are the services for which you have to go to Portland. They are like the most specialized services; for example, because of sleep apnea (which is something very new for parents) we all have to be going to Portland.”</i> (Focus Group 1)</p>	<p><i>“...it has been very difficult despite the fact that the doctor has supported us, because the doctor started helping us about 3 years ago, but from then on it did make it difficult for us to find therapies, because... they lasted very little, they were every 8 days, there were not so many services.”</i> (Focus Group 6)</p>
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*Access to care challenges*

Family members described challenges they encounter getting health-related services for their child. The challenges consist of health insurance challenges, a lack of local providers, lack of quality care, long wait times for services, and the need to advocate to get their child needed care. Some family members described traveling outside of their community to access needed services, because their local community lacked providers and quality care. Exhibit 4.2 presents the number of focus groups in which the challenge theme emerged.

Exhibit 4.2. Access Challenge Type By Number of Focus Groups

Number	Type of Challenge
5	Health insurance challenges
4	Lack of providers locally
3	Lack of quality care locally
3	Long wait times to obtain needed services
3	Persistent family advocacy to access needed services

*Health insurance challenges*

Although family members frequently reported that their child was covered by health care insurance, they described experiencing challenges in five focus groups. They reported experiencing difficulty finding a provider within their child’s insurance network, issues with certain services not covered by insurance, and challenges with health insurance representatives. The following quotations illustrate experiences described by families.

*“...The dentist has been a bit complicated because they have a contract with certain dentists and sometimes you can't take them wherever you want because they don't have a contract with the state [insurance]...” (Focus Group 3)*

*“... Sometimes there are medicines that are expensive. The medical [insurance] cannot cover certain medicines, so they should provide the amount that does not matter what the medicine costs that they give it to all parents, not only for her... There are medicines that cost a lot of money and they don't want to give them to you.” (Focus Group 6)*

*“Sometimes [the health insurance representatives] are mean. I don't think they are motivated to help people like us. There are a few people willing to help from the bottom of their hearts... Because sometimes they think they are superior because they have that job, and they think they have the right to treat us like that, and I get upset...” (Focus Group 7)*

Additionally, one parent described experiences with providers preferring private insurance over public insurance, *“... I feel they look at what kind of insurance you have, if you have a good one or private one, the one you pay out of your pocket, then the first appointment available is for you. But since we have the state insurance, I could pay more for my girl to have both, but unfortunately I can't”* (Focus Group 1). This discrimination on the basis of insurance type illustrates how Latino families of CYSHCN can face intersectional discrimination (e.g., ethnicity and socioeconomic status) when accessing care.

#### Lack of providers locally

Family members in four focus groups discussed the lack of local providers and services. They described traveling outside of their community to access a needed provider. The following quotations illustrate experiences described by families.

*“Everyone has to go to Portland, there's nothing here.” (Focus Group 1)*

*“It has not been easy, but we tried to look for help... for her therapies... the doctors told me, ‘you have to take her to Portland, are you going to go or not?’... you just tell me where and I'll take them.” (Focus Group 7)*

*“...what they always say is that the state is a small state...there are not many doctors. Here what is needed in the state of Oregon is specialist doctors, who have the capacity to care, no matter where someone comes from, towns or counties... it was difficult for us when we arrived here in 2005... we were in [City, Out of State] and there that state did have enough. We realized that many things are missing here... When we started looking for help as we already knew my son had Autism... we regretted coming here... everything is very limited, and we would like to ask the government...for Oregon to support us. That they give more support, that they give more funds... because we do not know how many more children and more diseases are being found today, so that is what I would like more doctors, more medicine, I would like them to set up a workshop....” (Focus Group 6)*

#### Lack of quality care locally

In three focus group, family members described a lack of quality care in their community. Family members reported providers not following up after an appointment, providers not coordinating with each other, feeling that providers did not attend to child's needs, and local providers misdiagnosing their child. Additionally, some family members reported traveling outside of their community to access quality care. When family members described traveling outside of their community to access quality care, they most often referenced traveling to Portland. The following quotations illustrate experiences described by families.

*“My daughter has down syndrome...as for all her doctors in Portland I am very happy to take her to Portland. I have had small details here with some providers... they are talking a lot about the sleep apnea... They sent her for evaluations here with a provider in Bend, but this provider told me that my daughter supposedly did not hear that she had apnea and that they had to operate and... put tubes because she could not hear. I said: ‘Do you know what? You are wrong, my daughter does hear and they just had her evaluated in Portland. I do not know why you said she can’t hear...’ So I worried a lot, my husband and I decided to take her to Portland. They did the sleep studies again... she has sleep apnea, but my daughter hears well. Then we decided that they would better treat her in Portland not here in Bend.” (Focus Group 1)*

*“For my son, my experience right now is being the best, because I took action. In Portland they have been helping me a lot, and everything I ask to be done they do everything. And I am happy to take it to Portland, although it is a little difficult to drive there, and more so in this time because of the snow. But the truth is I don’t think I would go back to see the doctors here and leave [the doctors in Portland].” (Focus Group 5)*

*“It has been hard for me to take my daughter to her appointments, she needs a lot of services and some of them are here in Madras. For 2 years I took her 3 days a week to Bend and then to Portland. [Clinic] is in Portland. She needed therapy and I took her to Redmond but [Clinic in Portland] was better, I took her there just once a week. I’m pretty sure she would be more advanced if I would have had something like that here.” (Focus Group 7)*

#### Long wait times to obtain services

Family members in three focus groups reported experiencing long wait times for services. They described long wait times for a neurological evaluation, therapies, and specialists. One family member described a delayed diagnosis for their child. The following quotations illustrate experiences described by families.

*“Since August, four months ago... the doctor there said that in about three weeks he had to have the [brain] evaluation done. He was going to talk to the pediatrician here and until now they have not called, I have asked, but they have not told us anything.” (Focus Group 1)*

*“... They take a long time to give you appointments where children need some therapy. Because it is from [the] government (the OHP) then you go and ask for an evaluation and they tell you it takes six months, but instead if you have private insurance they do attend [to] you quickly. But with OHP it takes six months to a year to [get] an appointment...” (Focus Group 4)*

*“Everything is complicated due to his blood, he suffers from nosebleeds. He just had surgery on his nose last week, we hope it will be the solution to stop bleeding. I already decided to take him to Portland because as I said, I did not like how [the local provider] treated me. If my son needed the quick service, it took three years for him to be diagnosed. When I took him to Portland... the doctor said: ‘Why did it take so long, a little longer and his red and white blood cells would no longer serve him anymore, and if it had taken longer, he could have had leukemia,’ just because I was here looking for the doctors and for them to tell me that they couldn’t do anything for what my son doesn’t have. And back in Portland they quickly detected the problem he had.” (Focus Group 5)*

#### Persistent family advocacy to access needed services

In three focus groups, family members reported that they had to advocate persistently to get their child needed services. They reported a variety of ways they had to assert themselves within the health care system, including repeatedly calling their child’s school to access Early Intervention, having to “yell” or “be rude” to the provider to get an appointment for their child, or talking to their child’s principal about

the lack of school support for her child’s special needs. The following quotations illustrate experiences described by families.

*“[My daughter] has seizures, and when she lacks of medicine she starts having small episodes and starts to wake up a lot at night. I called the doctor about four times to see if they could give me more medicine or if the doctor wanted to see her or call the pharmacy to give me more medicine to get through the month. They passed me from message to message and person to person. Until one day I called and said ‘I want to know if the doctor wants to see her or [if he is going to] give me the medicine’ and she said ‘yes, I can give you an appointment in May’ I said ‘no, I already I have an appointment in February why would I need one in May?, I need you to fix this now’... I feel bad because sometimes I have to yell at them and be rude to the people who are working there...it is difficult especially with a child in special needs.” (Focus Group 1)*

*“... I think [my daughter] needs another surgery... and [the doctors] say ‘no, that she is fine.’ I've been fighting with doctors; I need power because they ignore me...” (Focus Group 4)*

*“I had to go to 4 appointments, and take letters to the psychologist, psychiatrist, occupational, and speech therapists. They told me it wasn’t good for her to take external therapies if at school they wouldn’t help her... Early Intervention, the school district, and the state people had a meeting and all of them told me the same. I was alone with a blindfold over my eyes because I didn’t know anything about my daughter’s condition. I had to do my own research through the internet... I told myself, this is not ok and you have to look for help and assistance. I was with the pediatrician insisting and insisting, letter after letter. Every year when my daughter started [school], they never had anything about her condition, so I had to collect all the information from the psychiatrist and send everything again. For me, dealing with the school has been the worst part of the process. You basically need to be alert and fight for the assistance...” (Focus Group 7)*

## Culturally Responsive Health Care

During each focus group, LCA asked family participants to describe their experiences accessing culturally responsive care for their child. Two second tier themes emerged from the data: Experiences of Racism (n=6) and Interpretation Issues (n=5). A description of each theme follows.

### *Experiences of Racism*

In all six focus groups, family members reported experiencing racism in the health care system. For example, family members and children were subjected to culturally-insensitive and discriminatory comments. These comments made families feel that the environment was hostile, and that their concerns for their child were not taken seriously. One family member described that they did not receive family-centered care; the provider did not take into consideration that they were members of a non-dominant culture, and may not be familiar with therapies like speech and occupational therapy.

*“I have noticed certain things; for example, when I had my daughter in speech therapy, occupational, at first it was something new for me. I had never needed that before nor had it been such an open topic for me because I was not familiar. So sometimes I needed more information because it was different because of my culture and what I was used to... although the language was no problem, I felt that there was something else. They assumed that I already had to know.” (Focus Group 3)*

*“...when my daughter had surgery on the arteries that had clots, the doctor said it ‘is that you are Hispanic and Hispanics invent diseases.’<sup>3</sup> And my daughter was dying because of the clot she had, and they sent her home.” (Focus Group 4)*

*“...A few years ago when he was at school, he wore diapers... he’s chubby, one of the nurses was changing his diaper... told him ‘I’m pretty sure you eat just Mexican food, that’s why you are the way you are.’ I was like ‘in what world could she even say that to my son?’ She was American, and I think is discrimination.” (Focus Group 7)*

### Experience of family members facing language and cultural barriers with care providers

Family members described facing challenges interacting in health systems because they did not speak English, or because they belonged to a non-dominant culture. Family members described feeling nervous and discouraged that they did not have an opportunity to express themselves in the language they felt most comfortable speaking. Some family members described that their children or other family members who spoke English helped them with interpretation. One family member felt uncomfortable asking for interpreters because they anticipated they would face discrimination as a result of the request. These instances contributed to the racism experienced by immigrant Latino families in Central Oregon.

*“For me it’s very, very difficult because I don’t speak any English. Call to a place where they do not speak Spanish and I do not speak English it has been difficult. As I said, my husband is the one who calls everywhere because he is the one who speaks a little English. I almost always ask my friend Carolina, and she tells me where to call to talk to someone in Spanish.” (Focus Group 3)*

*“It has always been difficult to get help for my children because I always depend on a person to do something. I cannot fight for my daughter because if she is going to be my interpreter she will not translate as if I am angry, and she always tells me that she is going to say how she can but it does not convey that I am angry and frustrated and that they need to listen to me!” (Focus Group 4)*

*“There have been other occasions, such as when we go to a blood test, and we see that there is no interpreter, and sometimes we get discouraged, we better not ask because we already know that they are going to answer us ugly.” (Focus Group 7)*

### Issues with interpretation

Five of the six focus groups discussed this second-tier theme. Family members talked about challenges getting interpretation services. Requests for interpretation services delayed the availability of appointments. Family members also expressed dissatisfaction about the quality of interpretation. They felt that interpreters left out important information and did not convey nuances such as the tone of the conversation. This interfered with the development of a productive provider-family relationship.

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<sup>3</sup> Latino community members in Central Oregon would not use the term “Hispanic” to describe themselves. In this example, the term “Hispanic” was used by a health care provider and, given the term’s origins, contributed to personally mediated racism.

*“My neurologist does not have an interpreter either, and if you ask for an interpreter they take longer to [schedule] the appointments. If you don’t need an interpreter, they give it to you faster.”* (Focus Group 1)

*“....It has been harder for me because of the language... I do not speak English to understand all my children's illnesses because I am depending on a person who speaks English or translates it and sometimes they do not say what one is saying. They say things that one didn't say or they don't tell you what the doctor says.”* (Focus Group 4)

*“.... I asked a doctor if he could do an evaluation for my son... I told him in Spanish, ‘please doctor, would it be possible to do an analysis of the liver for my son, because he says it hurts?’ But then the interpreter told [the doctor] as an order, not as something I was asking him for, so the doctor got angry because he said that I couldn't know more than him [and was] sure it wasn't the liver.”* (Focus Group 6)

### Family-centered care

In all six focus groups, family members described positive, family-centered experiences with specific health care and educational providers. However, these experiences of family-centered care were not the typical experiences of immigrant Latino families.

*“For me, I have a good relationship with my son's doctor. Dr. [name] is a very good doctor, very patient. Dr. [name] is the psychologist who speaks pure English, but he has also had a lot of patience, he has given us a lot of opportunity to go and talk to him. For me they have been good experiences.”* (Focus Group 4)

*“The teacher she had was a good disability specialist teacher. The teacher paid a lot of attention to her. My daughter was happy even with the assistant, my daughter was very happy. And I know they welcomed her well, and she understood in English.”* (Focus Group 5)

*“He is a very great, good doctor, he supports everything. Sometimes when my son needs an appointment, he says I have many patients but I will do my best, bring him to me in the afternoon I will do my best, no matter.”* (Focus Group 6)

### Transition from Pediatric to Adult Health Care

Of the six focus groups conducted by LCA, five groups included a total of seven family members of young adults with special health care needs ages 18 through 25 years. These family members described a range of experiences with their child’s healthcare when their child turned 18, but we did not achieve saturation, or the point where analysts gain no further new insights, to enable us to identify themes in responses (Krueger & Casey, 2009). The results do, however, provide initial understanding of the experience of transition to adult health care for Latino CYSHCN living in Central Oregon.

Family members reported not being given warning that their child would need to transition to an adult provider. Family members expressed concerns about consistency of health insurance and care. Family members also described difficulties engaging with their child as a young adult. Exhibit 4.3 presents a full summary of family concerns and experiences.

Exhibit 4.3. Transition to Adult Health Care Concerns and Experiences by Focus Group

Focus Group	Type of Experience
1	<ul style="list-style-type: none"> <li>Parent experienced difficulty answering adolescent questions of why the health condition happened to the adolescent.</li> </ul>

Focus Group	Type of Experience
3	<ul style="list-style-type: none"> <li>• Parent was not given referrals for insurance for their child after public insurance ended when their young adult turned 18.</li> <li>• Parent has concern about young adult losing their health insurance and paying for \$5,000/month medications; young adult previously insured through Cover All Kids.</li> </ul>
4	<ul style="list-style-type: none"> <li>• The young adult's physical size combined with their conditions presents threat to parent's physical safety.</li> <li>• Young adult's behavior has resulted in neighbors calling the police; parent has to share information about the young adult's condition with neighbors so that they do not call the police.</li> </ul>
5	<ul style="list-style-type: none"> <li>• Parent found it difficult to accept that their child is an adult.</li> <li>• Parent found it difficult to accept that they would have to "start over from scratch" in identifying and working with new adult providers.</li> <li>• Parent experienced no changes. The same provider who worked with child as a pediatric patient will work with young adult as an adult patient.</li> <li>• Parents were given no, or one month's, notice about pediatric care stopping.</li> </ul>
7	<ul style="list-style-type: none"> <li>• Parents have inconsistent information about whether they can get paid for caring for their over 18 year old young adult and other available supports.</li> <li>• Parent has concern about young adult losing their specialists when turn 21. Parent was given advance notice.</li> <li>• Parent expressed concern about state law that allows 14 year old children to decide that they do not want to work with a psychologist, even if the child needs mental health care.</li> <li>• Parents heard through word of mouth with other parents that they should do all they can to obtain services for their child [before 18], because "when they're older, [health care providers] will forget about them." Young adults will lose support, and providers will not listen to families.</li> <li>• Parents were given no, or one month's, notice about pediatric care stopping.</li> </ul>

## Discussion

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) collaborated with the Latino Community Association (LCA) to better understand the care needs and experiences of immigrant families of Latino CYSHCN in Central Oregon. We sought to answer four research questions: (1) What health-related care (behavioral, oral, physical) services do immigrant families of Latino CYSHCN need to care for their child, (2) What has been the experience of immigrant families of Latino CYSHCN attempting to access needed care, (3) What has been the experience of immigrant families of Latino CYSHCN in accessing culturally responsive care, and (4) What has been the experience of immigrant families of Latino CYSHCN in transitioning their child from pediatric to adult health care? Discussion of findings for each of these questions follows.

### Health-Related Care Needs

The types of health-related care needs reported by immigrant families of Latino CYSHCN is consistent with those reported by families of Oregon CYSHCN generally. Most notably, all six focus groups reported that behavioral/mental health care, primary care, and specialty care and support were needed for their CYSHCN. In addition, allied therapies (i.e., occupational, physical, sensory, or speech therapy) were noted to be an important need among Latino CYSHCN. The behavioral/mental health findings align with quantitative NSCH results describing the population of Oregon CYSHCN. For example, 45% of Oregon CYSHCN had ongoing emotional, developmental, and behavioral conditions, which is similar to national

results (44%; CAHMI, 2020). In addition, 40% of CYSHCN received counseling from a mental health professional (CAHMI, 2020). We lack current quantitative data describing the needs of the population of Oregon CYSHCN for allied therapies. However, OCCYSHN’s 2015 needs assessment family results showed that CYSHCN very commonly need these services: 65% of respondents reported that their child needed occupational therapy, 38% reported physical therapy, and 65% reported speech therapy (Martin, 2014).

### Care Access Experiences

Family members reported that primary care and health insurance coverage were easy to access, although medical specialists and allied therapies were not. Although this study’s results do not describe the extent of this difficulty for all families of Latino CYSHCN – or the disparity in access between families of Latino versus White CYSHCN – the current study’s findings align with those of OCCYSHN’s 2015 needs assessment. The 2015 results showed that 39% of family survey respondents identified specialty medical care as one of the top three health care needs they had difficulty meeting for their child (Martin et al., 2015).

Additionally, we found that immigrant families of Latino CYSHCN often experienced challenges with inadequate health insurance coverage, long wait times for services, lack of local quality care, and a lack of needed providers. Similarly, Zuckerman (2015) found that Latino parents of children with Autism Spectrum Disorder (ASD) described the ASD diagnostic process as complex, slow, and disjointed. They experienced long waits for care, and a lack of communication among providers involved in the child’s care. Family members’ descriptions of a lack of quality care locally included providers who failed to coordinate with each other. The current study’s findings also align with findings from our 2015 needs assessment in that a majority of family survey respondents reported that it is at least sometimes difficult to obtain appointments as quickly as needed, and 47% of family survey respondents reported “rarely” or “never” receiving as much help as they wanted arranging or coordinating their child’s care. (Martin et al., 2015).

### Culturally Responsive Care

The most prominent theme that emerged from the focus groups discussions with immigrant Latino families of CYSHCN in Central Oregon was experiences of racism in the health care system. This includes experiences of institutionalized and personally mediated racism (Jones, 2000). Immigrant Latino families in Central Oregon faced barriers to accessing care for their CYSHCN, which suggests that the medical setting was not equipped to provide care responsive to Spanish-speakers and patients/families who did not belong to the dominant culture. Family members described needing more information about their child’s care than was provided by their health care providers. Information, or knowledge, is a form of power (Jones, 2000; Mondros & Wilson, 1994); inhibiting families from accessing information about their child’s health prevents them from accessing power to care for their child and perpetuates *institutionalized* racism. Families also experienced institutionalized racism when inadequate interpretation services gave them unequal access to information. Interpreters

**Institutionalized racism** – “Differential access to the goods, services, and opportunities of society by race” (Jones, 2000, p. 1212). Differential access is shown through “material conditions and in access to power” (Jones, 2000, p.1212). The former is seen in access to safe, quality education, employment, environment, housing, and medical care; the latter includes information, resources, and voice (Jones, 2000).

**Personally mediated racism** – “Prejudice and discrimination, where prejudice means differential assumptions about the abilities, motives, and intentions of others according to their race, and discrimination means differential actions toward others according to their race” (Jones, 2000, pp. 1212-1213).

were not always readily accessible. When they were available, interpreters left important details out of conversations between family members and providers. Families reported dissatisfaction and frustration at being unable to express themselves clearly. Lacking information about the child's health and care needs may result in poorer health outcomes for Latino CYSHCN. For example, Mosquera, Samuels, and Flores (2016) found that when bilingual providers or trained interpreters were unavailable, it decreased the quality of care and parental satisfaction of Non-English Primary Language families and led to serious consequences for the health of CYSHCN.

Family members also experienced *personally mediated* racism through blatant culturally insensitive, discriminatory comments and invalidation of their concerns from health care providers. This created an unsafe, hostile space for Latino family members, who described feeling nervous, discouraged, and uncomfortable in medical settings in anticipation of discriminatory actions from health care providers and lack of support in expressing their needs.

In addition to receiving care from health care systems founded in white supremacy, the overall gap in health care providers who identify as Latino further contributes to an inability to access culturally responsive care. The Oregon Health Authority (2018) found that the ethnic and racial diversity of the health care workforce has not kept pace with the changing ethnic and racial diversity of Oregon's population. The greatest gap between the ethnicity and race of Oregon's population and health care providers in the state is for the Latino community: 12.4% of Oregon's population identifies as Latino, in contrast to only 5.2% of the health care workforce identifying as Latino. In addition, professionals who are Latino are more often represented in health care positions that require fewer licenses (OHA, 2018).

Overall, our findings suggest that Latino CYSHCN and their families in Central Oregon do not receive culturally responsive and family-centered care. These are foundational components of a medical home.

### Transition from Pediatric to Adult Health Care

Oregon CYSHCN do not receive services necessary to transition to adult health care; only 16% of youth with special health care needs ages 12 through 17 years received *at least one* of the three services needed (Roy, Vega-Juárez, Gallarde-Kim, & Martin, 2020). When national NSCH results are disaggregated by ethnicity, about the same percentage (15%) of Latino youth with special health care needs received services necessary to transition. This percentage, however, is lower than that of White youth with special health care needs (21%) (CAHMI, 2020).<sup>4</sup> Reports from family members who participated in our focus groups indicate that they did not receive warning that their child would need to transition to an adult provider. Family members expressed concerns about consistency of health insurance and care when their child turned 18 years old. They also described difficulties they experience as their child develops into a young adult and increases in physical size. These experiences are similar to those described by families of CYSHCN during Oregon Family-to-Family Health Information Center listening sessions.

### Community Reflections

LCA team members exclusively wrote the following section. This section describes their experience conducting the focus groups, emotions observed during the focus groups, and working with immigrant Latino families in their community.

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<sup>4</sup> These results are not available at an Oregon state level due to small sample size.

At the beginning of this collaborative research project with the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), our project team of three at the Latino Community Association (LCA), of course, held a few assumptions. We assumed that our immigrant Latino parents with special needs children would experience many barriers in accessing health care for their kids. We were not surprised that they faced language barriers or that their experiences working with interpreters was mixed – sometimes great and sometimes awful - with their kids or relatives often filling this role. We were not surprised to hear that it was difficult, especially for the parents with children who will never speak and who cannot walk or fend for themselves. And we were not surprised that Central Oregon is void of many of the specialists whose services their children require.

What we did not anticipate was the degree to which parents are exhausted, chronically anxious and oppressed by the isolation they experience and the hopelessness they often feel. We did not expect the parents to shout out for emotional and psychological support, not only for themselves, but for their other kids. We never considered the impact on the siblings, the brothers and sisters, of kids with special needs. Of course they gain invaluable experience that will likely serve them for the rest of their lives, but they inevitably lose the attention the parents have to give to their special needs siblings - and their childhoods, in some cases, are taken from them as they are regularly obligated to fill the roles of caretaker, interpreter and surrogate parent.

We learned that these parents are strong, caring, dedicated and loving people. Their deep love and endurance are legendary. We learned that it is of great benefit to them (and to us) to have opportunities to vent and express their worries, frustrations and dreams. They were grateful for the experience to share and that we care enough to listen. They carry a great burden, and they expressed joy in meeting with other families facing similar challenges and saw hope in the possibility of supporting each other. We learned that our health care providers in Central Oregon, with just a couple extraordinary exceptions, are ill-equipped to serve these families the way they deserve to be served. They are made to feel that they are a burden on the providers who show with their body language, and sometimes their words, that they are not very happy to see them when they arrive.

Some parents spoke of having to be loud and, basically, mean to get the provider's attention. They said it was hard to get the provider to take them seriously – that they often felt ignored and their observations and concerns were not valued. Because of this, they felt doctors often diagnosed their kids much later than they should have, which they believe worsened their child's chances of getting better and living a more normal life. At least half of the parents we spoke with gave the very clear impression that they were made to feel “less than” by the doctor or other medical staff. This was probably the saddest and most unnerving revelation – that not only did they endure the hard work of caring for a special needs child, but they also had to endure a healthcare system that more often than not invalidated their lived experience and their insights about their children. Portland was the exception. Care providers and specialists in Portland were uniformly spoken highly of and with endless gratitude. There they were welcomed with open arms and genuinely friendly gestures.

This community-based research experience has opened our eyes and expanded our awareness. We knew there were immigrant Latino families with special needs children in our region, but we had no idea how many or to what degree they need our community's support. As the focus groups facilitators, we felt privileged to be trusted by the families to hear and to pass on their stories. We felt sadness, joy, pride and anger as they shared the many challenges they face accessing healthcare. We believe that in a region with over 200,000 inhabitants, our health care system ought to be able to provide more of the

services these families need locally to save them the time and expense of having to travel to Portland. We need to make sure our health care providers are aware of their experiences and that they recognize the value and importance of providing culturally responsive healthcare. We need to make sure investments are made to improve services for these families closer to the communities where they live. This report is an important first step in the right direction. ¡Escúchenos! Let's listen to their voices and take action.

### Limitations and Recommendations

To the best of our knowledge, no studies have examined access to culturally responsive care for families of immigrant Latino CYSHCN. Certainly it has not been studied in Oregon. We developed a descriptive study design that aligned with the exploratory nature of our research questions and was responsive to family culture. The primary limitation of our design study is that it does not allow us to generalize findings beyond the immigrant families of Latino CYSHCN who participated in our study. Due to the current political climate and fears of deportation in the community, we experienced challenges recruiting focus group participants, particularly families of young adults with special health care needs. Finally, this study describes the family experience and perspective well, but it does not represent those of health care providers. Further research is needed to obtain their perspective.

Despite these limitations, our findings illuminate the need for improved access to family-centered and culturally responsive care for immigrant Latino CYSHCN and their families. To ensure that all CYSHCN in Oregon receive care in a patient and family-centered medical home, it is imperative that Latino CYSHCN and other CYSHCN of Color have access to family-centered and culturally responsive care. The following recommendations promote this goal.

1. OCCYSHN should work with LCA and other partners to disseminate these findings to state agency, health system, and family partners. For example, OCCYSHN and LCA should share findings with the Oregon Health Authority (OHA) Office of Equity and Inclusion's Health Care Interpreter Training Program to help improve access to highly qualified professional interpreters. OCCYSHN and LCA should schedule presentations with Oregon health systems to present the findings to clinic managers and providers.<sup>5</sup>
2. OCCYSHN should contract with culturally-specific service organizations to review Title V Block Grant cross-systems care coordination strategies to assess cultural responsiveness and sensitivity, and to help modify strategies as needed. OCCYSHN also should contract with culturally-specific service organizations to find examples of culturally responsive care being provided within Oregon, and to promote those practices throughout Oregon's health care systems.
3. OCCYSHN should assess the needs of its local public health authority partners for cultural responsiveness/sensitivity training and technical assistance (TTA). Based on the results of this assessment, OCCYSHN should facilitate high quality TTA to LPHAs.
4. OHA should implement quality measures on health equity for health care providers to improve awareness and practice. Currently, OHA disaggregates Coordinated Care Organization incentive metrics by race and ethnicity to examine how population subgroups fare. The creation and implementation of health care equity quality measures for health care providers may help to improve clinical provider awareness and practice.

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<sup>5</sup>Such presentations should include the Sickle Cell Anemia Foundation of Oregon and findings from its study with OCCYSHN. This study also found that Black CYSHCN and their families experience racism in Oregon health care systems (Gallarde-Kim, Smith, Roy, et al., 2020).

5. OCCYSHN should contract with culturally specific service organizations to ensure that transition to adult health care services are provided in culturally appropriate ways. Strategies should encourage health care providers to (a) initiate transition conversations with their patients with special health care needs beginning at least by 14 years of age, (b) help youth with special health care needs learn skills to manage their own health conditions, and (c) work with families to prepare for changes that accompany their YSCHN turning 18, such as the potential need for supported decision-making or guardianship.

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## Appendix A. Ease or Difficulty of Accessing Health-related Care Types Described in Fewer Than Half of the Focus Groups

Number	Easy to access	Number	Difficult to access
2	Allied therapy	2	Behavioral/mental health care
1	Basic needs	2	Condition-specific support
1	Dental care	2	Developmental assessments (learning disability, autism)
1	Durable Medical Equipment (DME)	2	Educational supports
1	Educational supports	2	Specialized evaluations (sleep study, neurological evaluation)
1	Emergency department	1	Basic needs
1	Local community-based network of health clinics	1	Diagnostic testing (MRI)
1	Mental health care	1	Disability services
1	Nutrition services	1	Durable medical equipment (DME)
1	Specialty care after obtaining health insurance coverage	1	General resources and supports for CYSHCN
1	SSI	1	Habilitative care
1	Visiting specialists from Portland	1	Health care insurance
		1	Health care services in general
		1	Medical transportation
		1	Pharmacy
		1	Primary care (Pediatrician, gynecology)
		1	Recreation
		1	SSI
		1	Supports for parents and family