

Oregon's Children with Special Health Care Needs
Five Year Needs Assessment Findings – September 30, 2020

CHAPTER THREE

Health Care Needs, Access to Care, and Experiences of Racism for Black Children and Youth with Special Health Care Needs and Their Families

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Executive Summary

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) and the Sickle Cell Anemia Foundation of Oregon (SCAFO) collaborated to collect data about the needs and experiences of families of Black children and youth with special health care needs (CYSHCN). Specifically, we sought to describe the following: health and other support needs; access to needed care and support; availability of culturally and linguistically appropriate care and support; and support for the transition from pediatric to adult health care. To collect these descriptive data, SCAFO conducted 11 focus groups around the state with 45 adults who are parents or guardians of Black CYSHCN. Of those, 37 were parents or guardians of children younger than 18 years old and eight were parents or guardians of young adults age 18 through 25 years old.

In 10 of the 11 focus groups, family members described experiences of racism. They reported feeling disrespected and judged by their child's providers, and described health care providers lacking the cultural context to understand health care conditions that primarily affect Black children. Race played a key role in determining the quality of care that Black CYSHCN received. Additionally, in almost all focus groups, at least one family member indicated that they had personally experienced one or more traumatic events when receiving health care. These collective experiences contributed to families' distrust in the healthcare system. They also had low expectations of finding a Black health care provider.

When asked about their CYSHCN's needs, family members in nearly all 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 emergency department services, and difficult to access behavioral/mental health care and medical specialists. They described a provider shortage and difficulty in getting appointments. They said they had to advocate persistently to access services. Family members discussed needing to stay involved in their young adult's health care after they turned age 18, and reported a lack of health care system support for the transition to adult health care. Family members in more than one-third of the focus groups described that their child experienced at least one type of adverse childhood experience (ACE), most frequently abuse and neglect.

Although our report findings cannot generalize to all families of Black CYSHCN in 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, it is imperative to ensure that Black CYSHCN and other CYSHCN of Color 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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About Sickle Cell Anemia Foundation of Oregon

The Sickle Cell Anemia Foundation of Oregon (SCAFO), formerly the Portland Sickle Cell Anemia Foundation, was established in 1981 by Pastor Marcia L. Taylor, BA, CEO and Executive Director. Its mission is to improve the quality of life of those suffering with sickle cell disorders and to inform and educate the general population. The goal is to promote awareness of the genetic causes and health effects of sickle cell anemia and related conditions; to promote improved access to care through raising the number of sickle cell educated clinicians; to remove the stigma that sickle cell clients are drug seekers which impede the ability to provide sensitive and quality care. It has culturally specific and multi-cultural staff who implement programs and outreach to low-income individuals with sickle cell disease living in Alaska, Idaho, Washington and Montana in addition to Oregon. SCAFO programs include a wide variety of services ranging from patient advocacy, support groups, parent workshops, ongoing education and treatment to assist with physical needs (e.g., heating during winter months, free diagnostic testing through our partnership with Legacy Emanuel Medical Center, food, new coats and toys, and often first and last month's rent through community partnerships), and to keep the sickle cell community informed of new medical treatments and clinical trials. Because of the work of Pastor Taylor and the SCAFO Board, the state of Oregon began testing for sickle cell trait and disease. Her current staff is Michael Aiello, BA, Data Manager, Charles Smith, MA, Program Manager, and Lisa McConnell, BA, Social Worker.

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

Our team provides the following definitions and expanded discussion to facilitate reader understanding and interpretation of our findings.

Racism: We use the following definitions.

- “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 resources” (Jones, 2003, p.10).
- “A variety of practices, beliefs, social relations, and phenomena that work to reproduce a racial hierarchy and social structure that yield superiority, power, and privilege for some, and discrimination and oppression for others. Racism exists when ideas and assumptions about racial categories are used to justify and reproduce a racial hierarchy and racially structured society that unjustly limits access to resources, rights, and privileges on the basis of race. Racism also occurs when this kind of unjust social structure is produced by the failure to account for race and its historical and contemporary roles in society” (Cole, 2020).

Institutionalized or institutional racism: Racism that is structured into political and social institutions and directly or indirectly limits the rights of groups of people – and their access to societal goods, opportunities, and services – based on their race (Jones, 2000).

Examples of limitations in access include access to safe, quality education, employment, environments, and health care, in addition to limiting access to information, resources, and voice (Jones, 2000). Institutionalized racism also identifies the cultural assumptions and practices of the dominant group as the norm to which all other cultural practices should conform. The individuals who lead and manage our institutions may not be racist individuals, but in carrying out their jobs they may perpetuate discrimination without the awareness that their institution is contributing to a discriminatory outcome.

It is important to understand and identify institutionalized racism because it has resulted in racial stratification and disparities in education, employment, government, health care, and housing. Although many laws were passed in the mid-20th century to make discrimination illegal, the impact of the original policies and practices continues to affect non-dominant racial communities (e.g., mortgage loan redlining, alumni legacy preference in university admissions criteria).

“We live in a society where race is one of the biggest indicators of your success in life... We cannot look at a society where racial inequity is so universal and longstanding and say, ‘This is all the doing of a few individuals with hate in their hearts.’ It just doesn’t make sense... if our systems aren’t acknowledged and changed, it will bring negligible benefit to the lives of people of color...” (Oluo, 2019, p.31).

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). In considering personally mediated racism, it is important to understand implicit (or unconscious) bias. Implicit Bias, also known as implicit social cognition, refers to the attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner. These biases, which encompass both favorable and unfavorable assessments, are activated involuntarily and without an individual’s awareness or intentional control. Residing in the subconscious, these biases are different

from known biases that individuals may choose to conceal for the purposes of social and/or political correctness.

The implicit associations we harbor in our subconscious cause us to have feelings and attitudes about other people based on characteristics such as race, ethnicity, age, and appearance. These associations develop over the course of a lifetime beginning at an early age through exposure to direct and indirect messages. In addition to early life experiences, the media and news programming are often-cited origins of implicit associations. The experiences of personally mediated racism reported by families participating in this study may have resulted from explicit or implicit biases.

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). Internalized racism is detrimental to People of Color because acceptance of negative messages about their ethnicity or race may result in individuals feeling shame about this facet of their identity. They may hate their skin color, hair, or other physical characteristics and may result in low self-esteem and discomfort with themselves because they believe that their race makes them inferior.

The stories and experiences conveyed by the family participants provide illustrations of how parents experience racism when dealing with the health care system; particularly in how power is exerted, privilege is misused, and superiority is conveyed in their dealings with different people within the health care system.

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 of data describing the population of Oregon children and youth with special health care needs (CYSHCN).¹ NSCH results provide a wealth of information, yet results that generalize to CYSHCN – particularly Black CYSHCN – often do not exist due to inadequate sample size. OCCYSHN routinely collects input from families when conducting its legislatively-required Title V five-year needs assessments; however, these results do not adequately describe the experiences of families of Black CYSHCN, again because of small sample sizes. Therefore, the Sickle Cell Anemia Foundation of Oregon (SCAFO) partnered with OCCYSHN to inform Oregon’s 2020 Title V needs assessment with answers to the following questions:

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

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

Methods

The SCAFO-OCCYSHN team (we) developed a focus groups data collection method to gather data to answer these questions. SCAFO team members recruited, screened for study eligibility, organized, and conducted the focus groups. SCAFO worked with partner organizations (see Exhibit 3.1) to recruit potential families to participate. 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 race/ethnicity was African American, African [Black], Caribbean [Black], or Other Black,² and (c) their child’s age was younger than 26 years. Because we sought to learn about the experiences of families of Black 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).

Exhibit 3.1. SCAFO Partner Organizations

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| • African Family Holistic Health Organization (AFHHO) | • Family and Community Together (FACT) Oregon |
| • Autism Society of Oregon | • Head Start Programs- Klamath Falls, Redmond |
| • Black Community of Portland | • National Association for the Advancement of Colored People (NAACP) Eugene/Springfield Chapter |
| • Black Educational Achievement Movement (BEAM) | • N.W. Down Syndrome Association |
| • Bridging Communities- Medford | • Oregon Family Support Network- OFSN |
| • County Developmental Disabilities services departments | • Pauline Memorial AME Zion Church- Salem |
| • Easter Seals | • Portland Parents Union |
| | • United Cerebral Palsy |
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SCAFO conducted 11 focus groups around the state with 45 adults who were parents or guardians (family members) of Black CYSHCN. Of those, 37 were family members of children younger than 18 years old and eight were family members of young adults ages 18 through 25 years. In five focus groups, the eight family members of young adults discussed their experience transitioning from pediatric to adult health care. Due to recruitment challenges, two scheduled focus groups had just one family member participate. An average of four family members participated in each focus group, with a range of one to 10 family members participating per group. SCAFO conducted focus groups in six cities across the state. Four were in urban areas, and two were in urban clusters in rural counties (Oregon Office of Rural Health, 2018).

SCAFO collected 30 demographic questionnaires, completion of which was optional for family members. Eighty-seven percent of questionnaire respondents were African American/Black (includes African American, African [Black], Caribbean [Black], or Other Black). Sixty percent of respondents reported being the mother or father of the child. Respondents’ average age was 49 years old, and 37% completed some college or received a 2-year degree, and 30% completed high school or received a GED. The average number of people in the respondents’ household was four, and 50% reported having an annual household income of less than \$24,999.

² SCAFO team members approved use of this definition based on Oregon Health Authority’s REAL-D project (OHA Office of Equity and Inclusion, 2020).

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 five of the 11 focus groups. For transition, we identified a theme if an idea or experience was reported in at least three of the five 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, (2) access to care, (3) culturally responsive care, and (4) experiences transitioning between pediatric and 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 the second tier. Discussion of these results follows.

Health-related Care Needs

During each focus group, SCAFO asked family participants to describe the health-related care and services their child has needed (see Exhibit 3.2). The care needs identified by family members are not a comprehensive accounting of all care needs; rather, they represent the needs the family chose to discuss in response to the discussion question. Family members in nearly all groups (n=9) reported that their child needs or uses behavioral or mental health care. Family members in more than two-thirds of the groups (n=7) described their child needing or using supports in an educational setting. Family members also frequently discussed their child's need for occupational, physical, or speech therapy (n=5) and medical specialists (n=5). Exhibit 3.2 includes quotations that illustrate the most common care needs.

Exhibit 3.2. Health-related Care Need Types By Number of Focus Groups

Number of Focus Groups	Health-related Care Need Sub-themes
9	Behavioral/Mental Health Care: Counseling, therapy, behavior therapy, "someone to talk to" <i>"My decision to have the Black psychologist and why I had him going was he just needs a place to be able to talk because he knows he's different. I've been teaching him that since he was little. It's okay, we all learn different, we're all different, but that didn't stop the bullying, the teasing, the kids that noticed his work was different than theirs even though I made sure he stayed in the classroom and was not pulled out so that he is singled out."</i> (Focus Group 11)
7	Educational Supports: Early Intervention (EI) or Early Childhood Special Education (ECSE), preschool supports, IEP, 504, classroom support, or school staff trained to support special conditions <i>"My daughter has two trained support staff at her school for her diabetes who have been trained by the nurse, and everybody in the school has been trained to be able to properly... support her. Like if she was somewhere and something happened, they would know...everybody had to be trained to know what diabetes looks like."</i> (Focus Group 3)
5	Allied Therapies: Occupational, physical, or speech therapy <i>"... as a baby and as a toddler it was physical therapy, occupational therapy, speech therapy, and then when she got into school, she has a neurologist because of the seizures, and endocrinologist because she has precocious puberty... she has a medication to stop</i>

Number of Focus Groups	Health-related Care Need Sub-themes
	<i>that. She has the vision services for the classes, the hearing aid. We see the services for that, and also braces for her feet. It's been a lot of doctors."</i> (Focus Group 2)
5	Medical Specialists: Pediatric specialty or subspecialty care (e.g., cardiologist, endocrinologist, neurologist, ophthalmologist, etc.) <i>"When he was born... I didn't know if it was a birthmark or a dirt patch... it wouldn't go away.... I was concerned and I took it to his doctor. And he wasn't too concerned about it at first... it didn't really show up till he was a year and a half. And then when I brought him in for his checkup [the doctor is] like, 'this is getting more pronounced. I want him to go see a specialist...' [The specialists] checked him out and they said it was pigmentary mosaicism and it is seen a lot in mixed children."</i> (Focus Group 8)
4	Care Coordination: Communication and coordination among providers or team-based care.
4	Primary or General Health Care
4	Vision Supports: Eye doctor, optometrist, eye exams, and eyeglasses or other devices to support vision.
3	Durable Medical Equipment (DME): Braces for feet or legs, nebulizers, wheelchairs, hospital beds, traction equipment, canes, crutches, walkers, kidney machines, ventilators, monitors, etc.
3	Emergency Department, emergency room, hospital
3	Prescription Medication
2	Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD) Supports
2	Developmental or Intellectual Disability Care or Supports: Someone to help with daily living activities (e.g., personal support worker), vocational and job supports
2	Oral Health Care: Preventive, orthodontic, or other specialty dental care, surgery, or treatment
1	Augmentative Communication: Devices to supplement or replace speech or writing
1	Clothing or Food Needs
1	Feeding Therapy or Specialized Nutrition Care.
1	Hearing Supports: Hearing aids, audiologists, sign language interpreter, etc.
1	Ambulance Transport
1	Phlebotomist able to draw blood from children with Autism Spectrum Disorder

Access to Care

We asked family members to describe the ease of accessing health-related care for their child. We summarize the types of care that family members needed, and how hard it was for them to access it. The challenges that emerged across most focus groups were health insurance authorization and coverage, the need to persistently advocate to get their child's care, difficulty in getting appointments, and provider shortages in their communities.

Health-related care services that are easy to access

Family members in most focus groups reported that primary care (n=8) and emergency department services (n=6) were easy to access. They described using the emergency department because they could

not access non-emergency services in a timely manner. Family members in seven focus groups reported that their child was covered by health insurance. Quotations illustrating these experiences follow. Appendix A lists services discussed in all focus groups.

"... primary care is easy, accessible. But you get a new doctor every time you go take them." (Focus Group 8)

"When he go to the hospital for the treatment, he's covered [by insurance]. Emergency through the ambulance has been covered. The dentist been covered. He just had a tooth pulled that was covered. I was there for that. Follow-up appointments, it was covered... [The coverage has been pretty good]." (Focus Group 9)

"The ER is the only person that's gonna be in there and check everything. They're gonna check everything before they let you go. You're only in there a few hours, but at least you're fitting to get the utmost primary care. Don't matter if you got insurance or not... when you got health care and go to a regular hospital for a checkup or whatever, they look at you like, 'I'll see you later. Come back six months later.'" (Focus Group 11)

"Take [your child] to emergency, they don't mind. They just do it. You know? Don't try to take 'em to the doctor. Go to emergency. You get help. I think you get help quicker. You might be there all night but you can get some help." (Focus Group 6)

Health-related care services that are difficult to access

Behavioral/mental health care (n=6) and medical specialists (n=5) were the types of care that family members in most focus groups described as difficult to access. The following quotations illustrate family members' experiences. Appendix A contains the expanded list of health-related care services that family members in fewer than five focus groups identified as difficult to access.

"And I just want someone to come maybe help him out. Behavioral therapy. That way he would be able to... maybe use other coping skills that he can use. 'Til now it's been like four months, no behavioral therapy. You'll call this place, leave a voicemail... You can't find someone. And I don't know if it [is] because [of] OHP? They will automatically say, 'We aren't available.'" (Focus Group 1)

"Specialty care is difficult. There is ways to get on lists and stuff with the pediatrician, but we would've had to change from [Hospital 1] to [Hospital 2] doctors. And then there's only certain days of the month that you'd be able to get this specialty person. And there's usually long wait-lists." (Focus Group 7)

Health-related care services experienced as both easy and difficult to access

Family members' experiences accessing care varied. For example, family members described both positive and negative experiences getting (a) pharmacy services, and (b) educational supports for their child. Family members in four focus groups discussed experiences with pharmacy services. Two groups reported positive experiences, and the other two reported negative experiences. Those that reported negative experiences accessing pharmacy services had trouble refilling medications and getting insurance re-authorizations. The following quotes illustrate families' pharmacy experiences.

"We have a great pharmacy staff here that go to bat for us all the time as far as fighting the insurance for everything..." (Focus Group 3)

"...Pharmacy. We do mail-order pharmacy for the most part... Pharmacy is not a big deal." (Focus Group 7)

"The only issues I've had with the insurance is – because my child is a twin – [the insurer gets] them confused... [OHP] kept merging them into one person... It was ...a battle doing the prescriptions... And I guess 'cause they have the same birth date it's confusing when you're trying to do the prescription and stuff at the pharmacy. That's the only hiccup I've always had with them. And it's still happening today. Like they can't figure it out. And I don't know why... But other than that, the OHP, the insurance people, are pretty good. It's just the pharmaceutical side that I'm having issues with." (Focus Group 8)

Family members in seven focus groups discussed their ability to access educational services. Three focus groups described ease of access, and four described challenges. Some families reported that they had easy access to Early Intervention, Individual Education Plans (IEP), and other school supports. Other family members in four focus groups reported delays getting Individualized Education Plans (IEPs) and school supports appropriate for their child's needs. The following quotes illustrate family experiences.

"Why does it take our kids so long to get an IEP when they're in school? ...with my ten-year-old, I asked for one last year and he was supposed to get it. They needed to wait for something-or-other and he didn't [get an IEP]. I asked at the beginning of this year, 'Can we get this done now?' Like I called our counsel group so we can come up with a full five plan for him to help him in school. No IEP yet. Why does it take so long?" (Focus Group 2)

"My daughter has two trained support staff at her school for her diabetes who have been trained by the nurse, and everybody in the school has been trained to be able to properly ... support her. [They are] more aware if something was to happen [to my daughter]." (Focus Group 3)

Access to care challenges

Family members described challenges they encounter getting the care their child needs. Exhibit 3.3 presents the number of focus groups in which the challenge theme emerged.

Exhibit 3.3. Access Challenge Type by Number of Focus Groups

Number	Type of Challenge
10	Health care insurance challenges
7	Difficulty in getting appointments
7	Persistent family advocacy to access needed services
4	Provider shortage

Challenges with health insurance

Although most family members reported that their child had health insurance, in ten focus groups they described experiencing insurance challenges. They reported issues with service re-authorization, some services not being covered, and difficulty finding a provider within their child's insurance network. The following quotations illustrate family experiences.

"And the counseling was very hard for me... to get him in because of the fact that he has Medicaid. He's not OHP. So I had to go through a whole other list of doctors to try and find him the proper counseling."
(Focus Group 5)

"My kids get state insurance because of their disabilities, and they need sedatives a lot... We have a fast metabolizing enzyme that runs in our family, so if you give them one [sedative] for bloodwork, they're gonna be sitting there screaming...I have to pay for that 'cause their insurance doesn't cover it... Sometimes if it doesn't work that time then we gotta wait a couple weeks, pay for a whole other prescription, go in again. It's not only time-consuming, but it should be covered by insurance. I shouldn't have to pay for something that they need in order for them to get their shots that are mandatory by the state just to go to school."
(Focus Group 11)

Difficulty in getting appointments

Family members in seven focus groups described difficulties in getting appointments for their child. In all seven focus groups, family members reported experiencing long waits between calling for an appointment and the date of the scheduled appointment. Family members experienced long waits for services, such as developmental assessments and allied therapies. Families also experienced long waits due to overbooked providers, which resulted in having to schedule an appointment months in advance. Having to schedule an appointment so far in advance can result in missing the appointment due to unforeseen circumstances or attempting to balance health care with other quality of life priorities. Family members in four focus groups also described additional types of difficulties getting appointments. Examples of these difficulties included providers scheduling an appointment without confirming the date with the family and not giving a reminder call, finding an appointment time that aligned with the family member's work schedule, and experiencing getting appointments quicker when the child was privately insured compared to when the child was publicly insured. The following quotations illustrate family experiences.

"But it took them at least three to six months to find the speech therapy... You'll call this place, leave a voicemail... You can't find someone. And I don't know if it [is] because [of] OHP? They will automatically say, 'We aren't available.'"
(Focus Group 1)

"... you still have to call sometimes before you take your child or you have to get a referral and be like, 'I don't need a referral. I need to get him in right now'... that can get frustrating, and then having to take time off for appointments, because for a while it was like every week..." (Focus Group 2)

"...when you're considered for appointments... they're gonna see people with commercial insurance first because I've been there and I've been able to get into an appointment so quick. But now that the OHP is in play it's a completely different ballgame... They're not allowed to do that, but they do it." (Focus Group 3)

"The dentist – our past experience with the dentist has been a challenge. [The appointment] was way far out. But myself – I had missed an appointment. And so then that brings more challenges 'cause they are so booked out and they have so many people and then they kick you out and stuff like that. So with my own fault of, appointments was a challenge. But even if I hadn't missed an appointment, I felt like the dentists I took him to were poor, poor, poor." (Focus Group 8)

Persistent family advocacy to access needed services

Family members in seven focus groups reported needing to advocate persistently to get the services their child needed. They used various strategies to get their child's needs met. Family members described waiting in a provider's office to get the referral they needed, researching information on their

own, and repeatedly contacting a provider’s office to try to schedule an appointment. The following quotations illustrate family experiences.

"I ended up calling and calling trying to get into the doctor, and they kept telling me to wait. One day I decided I'm gonna pack a lunch, I'm gonna go down, I'm gonna sit in this doctor's office, and I have all day until they give me a referral to go get the services. We ended up getting that referral..." (Focus Group 3)

"The services are out there, but you gotta do a lot of advocating and asking a lot of questions and the resources. You better do the homework if your child has special needs. Do the homework. It's a lot." (Focus Group 10)

Provider shortage

Related to long waits for appointments, family members in four focus groups described an overall shortage of providers and services in their local community. The following quotations illustrate family experiences.

"...Maybe it's because the type of provider he needs... [is] so backed up... The demand for it is great, but there's not enough suppliers to meet it, so that there [are] backs up and that's another issue." (Focus Group 2)

"...I just think they need more health care providers in this town. Maybe hiring more people. Because as far as making and scheduling appointments, [there are] a lot of people that need to be seen but not enough providers... they need more health care providers in town so it won't be far booked out. That's the stressor." (Focus Group 8)

Culturally Responsive Health Care

During each focus group, we asked family participants to describe their experiences accessing culturally responsive care for their child. Three second-tier themes, which illustrate a lack of culturally responsive care for Black CYSHCN, emerged from the data (see Exhibit 3.4). A description of each of the themes follows.

Exhibit 3.4. Culturally Responsive Health Care Second Tier Themes, by Number of Focus Groups

Number	Second Tier Themes
7	Lack of Black health care providers
10	Experiences of racism
9	Experience-based perceptions about the health care system

Lack of Black health care providers

In seven of the 11 focus groups, family members described challenges finding a Black health care provider, because there are so few of them. For example, one family member stated *"They're rare. So, that answer that you heard was our laugh. Now you know"* (Focus Group 2). Another family member responded, *"I just know there's nobody in [town]. It's our fault for where we live pretty much. But even my daughter now lives in the western part of the state, and sometimes you can find people of color but not necessarily African American"* (Focus Group 7).

In addition to a shortage of mental health providers (see Exhibit 3.2), family members said it was especially hard to access Black (culturally specific) mental health providers. Although families reported preferring that their children see a Black mental health provider, they had trouble finding them. For

example, one family member stated, *“I just recently got my son into therapy through [health system]. It took a long time because I wanted an African American counselor”* (Focus Group 10).

Experiences of racism

Family members described experiencing racism in 10 of 11 focus groups. Three third tier themes emerged in the experiences of racism category: lack of cultural understanding, lack of respect, and assumptions made about Black people. Descriptions of these themes follow.

Lack of Cultural Understanding

In nine of 11 focus groups, family members described how health care providers did not have the cultural context to understand the health care needs of Black children and their families. One family member expressed feeling frustration when a health care provider commented on her child’s strength and size. She felt like these comments minimized her child’s legitimate need for care and treatment. In other examples, family members expressed their dissatisfaction with health care providers not knowing enough about health conditions that are prevalent among Black people. Because of this, health care providers misdiagnosed conditions, or failed to appropriately treat them.

“They are 12 years old – they’re 5’7” tall and strong. When they go to the doctor, ‘You’re bigger than me. You’re strong.’ And I say, ‘It doesn’t matter. They’re sick. They need help. They need medicine. Give them medicine. Don’t look their height. Don’t look their body. That’s none of your business. I came here to treat them. Treat them.’”
(Focus Group 1)

“I just remember going to take my son to one of his checkups when he was a baby... but them not knowing that the Mongolian mark, and the nurse and them... making it seem like [it] was a bruise instead of what it was. I’m like, ‘No, he’s had that since he was born.’ I remember my actual primary doctor apologized to me later and him being like, ‘I’m gonna make sure there’s a note in your chart this time so that doesn’t happen again.’ But just having that experience, being like, ‘This is something he was born with. If you knew anything about biracial or people of color then you would know this is natural.’ Just the experience; it was not a cool experience. It was really negative.” (Focus Group 3)

“That’s one of the major problems that we have. We go to the doctor, which is usually somebody white who has no idea... about African American culture or values, morals, anything like that, and they just kind of give you a rough version of what they think you need or should do.”
(Focus Group 11)

Lack of respect

In eight of 11 focus groups, family members described health care experiences where they felt disrespected or discriminated against. They reported that health care providers discounted or ignored family member input, and did not respond to family members’ specific requests for services or resources. The following quotations illustrate these dynamics.

“I really don’t like going to the doctor’s. Even if it’s for me or even taking my kids. That’s one thing I dread doing is going to the doctor’s office. I’m so serious. I just don’t even like going to appointments because of the disrespect. I just don’t. And the discrimination.” (Focus Group 8)

“For me what happened was he was complaining about having abdominal pain. So, I felt on him, his stomach, his abdomen. I’m like, okay, something doesn’t feel right. So I did this, that, and the other, and I’m like, ‘No, there’s something there that needs to be addressed.’ They would say, ‘Oh no, he’s just backed up. He just needs to do this.’ No, he doesn’t need to do that. He’s been doing this the whole time. That’s not the problem. He needs to be seen by a specialist. Can you please hook that up?” (Focus Group 11)

This theme also included examples of advocacy by family members. They reported gathering information about their child’s health conditions, so they could advocate for services or treatments. They did this because they anticipated their requests would be denied (e.g., see the following quotation). Findings related to advocacy are consistent with the second tier theme under Access to Care: Persistent Family Advocacy to Access Needed Services.

“I felt if they push me to doses that I know they’re too high and all, I ask the pharmacist: ‘Is it the right dose for a little kid?’ I go online. I do my own research before I give the medicine to my child. What is the side effect? ‘Cause some of the time I ask the doctors, ‘What are the side effect of this medicine that I’m giving to my child? Is it gonna bring any negative impact on him? What will be the outcome?’ They won’t give you an answer. And I was like, ‘If you don’t tell me then you’re hiding something from me that I need to know. He’s not taking the medicine. I will find other ways, other resources.’ And they were like, ‘Okay.’” (Focus Group 1)

Assumptions made about Black people

In six of 11 focus groups, family members described feeling judged about their marital status, parenting style, or ability to care for their child. Family members felt their health care providers treated them in ways that implied racial stereotyping, like implying that their child was miserable because the parent was unmarried and young, or that money was a primary motivation for them because they were Black. The following quotations illustrate families’ experiences.

“I wanna say he was in second or third grade and I did have him tested and they wanted me to sign off on him [having intellectual disability], and I would not. I just said, ‘No.’ This was at a charter school, and I remember the lady saying, ‘If you sign off on [intellectual disability], you’ll get a check. You’ll get money.’ And I was offended by that because it made me feel like all Black people want a check and that’s what it’s about, and that’s not what I was about.” (Focus Group 10)

“That’s why the parent don’t already wanna access your services: because they feel like they already know that they got something going on and you coming in judging... I don’t need you to come in and beat me more.” (Focus Group 4)

“I got my son’s medical records one time and I was reading it, and the comments that the doctor made – ‘You can tell that she’s a young, single, unwed mother.’ ... – it has absolutely nothing to do with my son, the fact that he has a tumor... He’s miserable. He has seizures. He’s on medication, so yeah, he’s gonna cry for hours. The comment about my parenting ... ‘She doesn’t have control of her kid.’ Those kind of comments; that wouldn’t have been written in there for a wed white mom.” (Focus Group 3)

Family members also reported that health care providers were hypervigilant with Black families. The examples below illustrate instances when family members sought care for their children and were subsequently reported to child protective services.

“When we arrived to the emergency room and I’m like, ‘Hey, my daughter got into the medical cabinet’ the doctor came in and was like, ‘How many did you feed your children? What were you trying to do to your kids? You were trying to kill your kids? You were trying to feed your kids pill bottles?’ And I was clearly devastated, hysterical.... Child Protective Services comes in and is like, ‘I’m really sorry that I have to do this, but I have a lot of questions for you. I can tell that you seem like a totally normal parent, but the doctor is requesting.’ For me, it’s hard to go into an emergency room ‘cause you never know who you’re gonna get and what kind of judgment you’re gonna get, and especially in urgent situations you’re not thinking as clear as you probably could be in a normal visit type of thing.” (Focus Group 3)

“In order for him to get a bed he had to wait almost two weeks at the hospital. One of the doctors got tired of it and decided he wanted to discharge him. My husband was told by the counselors if they did that to say, ‘No, we can't keep him safe.’ ‘Cause we were afraid he was gonna kill himself. And so then that doctor.....reported us to DHS. So I was down figuring out the plan for him and they said, "Oh, by the way, we need to let you know that you've been reported to DHS'” (Focus Group 7)

Experience-based perceptions about the health care system

Our findings indicate that experiences of racism create conditions such that members of a racial or cultural group distrust the health care system and have low expectations of finding health care providers that represent their race or culture. These perceptions were described by family members in nine of 11 focus groups.

Distrust in health care system

In six of 11 focus groups, family members’ responses reflected a distrust of the health care system. For example, one family member described struggling with overcoming the perception in the Black community that if she asked health care providers to help her child, the system will separate her from her child. This family member appealed to the health care system to assure Black families that asking for help will not disadvantage her or her family.

“That's something very much...that I see in the...African American community, ...like I said: don't talk. Let people know it's okay: ‘You're not gonna get in trouble. DHS ain't coming after your kid because of you asking for help.’And that would be something for me because that's the struggle; it's real.” (Focus Group 6)

Another family member described how it took her a lot of time and research to overcome the stigma associated with Individualized Education Plans (IEP). The stigma led to the perception that IEPs will prevent her child from succeeding in school. These examples suggest that the distrust results from past instances in which institutions acted unjustly towards members of the Black community.

“I think there’s a stigma with IEPs. I think people of color automatically think of pulling them – they’re in a class with kids that are really severely disabled, and it took me to do some research to understand that IEP actually is a safety net for your child that helps them. It’s not a bad thing. It’s not gonna follow them... But it took a while for me to get to that place.” (Focus Group 10)

Low expectations of finding Black health care providers

In seven of 11 focus groups, family members described that it was not realistic to envision having a Black health care provider for their child. Responses from family members reflected low expectations for finding a Black health care provider. These low expectations arose from family experiences. Family

members faced barriers when they requested a Black health care provider, and they rarely encountered Black providers in the health care system. The following quotations illustrate this theme.

“...if I were to even ask for a black doctor, I would have to fill out a paper. I would have to sign it and say why and how come I want to switch the provider, and why in this and that. It’s like it’s not worth it.” (Focus Group 5)

“...I know living in [city], growing up in [city], we’re not gonna see very many African American doctors, ‘cause it’s not important and that’s just not the profession, unfortunately.” (Focus Group 11)

Some family members described that medicine was not a traditional profession for Black people, in part because of lack of funding, and in part because there are few Black role models in health care. In one example, a family member revealed doubts in the competence of Black providers they had encountered. These responses reflect both institutionalized and internalized levels of racism (Jones, 2000). The following quotations illustrate this theme.

“There are not very many scholarships for black people unless you go to a historically black university, which are all in the South... and that has to have a lot to do with the lack of providers, you know? As far as doctors and all of that. Like the feedback loop. So if I can’t find a doctor for my kids who’s black and there’s no scholarships... So, yeah, I think that’s part of the problem. If people aren’t able to get funding to go to college and if they’re already having difficulty – all the institutionalized racism. And I think from the kids that I’ve met that my daughter hangs around with at school...they don’t wanna be in that system that is – if all your professors are white.....It’s a domino effect.” (Focus Group 7)

“I’d rather base my information and how I’m choosing off of what is right in front of me, and as much as I’d love to have a Black doctor at some point sometimes, I’m kinda torn ‘cause I’ve heard plenty of bad experiences about it. It’s not even the doctor. It’s just like you say, they miss something and we kind of get mad at them and just don’t want to go back to them.” (Focus Group 11)

Family-centered care experiences

Family members in nine of 11 focus groups described positive, family-centered experiences with specific providers (health and education) or hospitals. Family members felt supported when health care providers heard their concerns regarding their child’s health, shared treatment decision-making with families, made referrals, helped them coordinate care, and considered the entire family in their CYSHCN’s care. Families who experienced family-centered care often wished such care was the normative standard of care.

“He's a [specialist]. Asian. And I didn't mean to pick him but out of the blue they assigned him, and I sit with him and I say, ‘If you gonna rush into surgery and other stuff, give me options. Let me know what the problem is. Don't say, oh, he has this; I have to rush him to surgery.’ And he say, ‘No, you have the choice.’ And I was able to sit with him and work with him.” (Focus Group 1)

“I guess just listen. I'm the mom and I'm with my kid all the time. So, if they're behaving differently and I think they have something wrong, I know what I'm talking about. My son's doctor..., he actually says that to me. He's like, ‘You know better than I. I'm new to his file. His chart is admittedly too thick to read, so what do you need [from] me?’” (Focus Group 3)

“I think up at [Hospital 1], [Hospital 2], and then also [Hospital 3], it's a different world of pediatrics up there. I feel like the population that they serve is much different than the population that pediatric serves here. They're more experienced with disabilities. When you're in an inpatient environment, they look at the whole family. They care that you're okay. They care that you get to sleep for an hour. They'll send a nurse in to do the hands-on stuff, because for me, everything I've experienced with my daughter I've been alone, so I'm coordinating for my other child here and making sure her routine is staying in place as well as doing everything I need to do there. Inpatient experiences at [Hospital 2] have been amazing. I couldn't ask for better. And then here, early intervention services, they pretty much will help advocate for me and they will do and support whatever I need. Those are some positives. Typically, with primary care too they're really good now at dishing out referrals...” (Focus Group 3)

Transition from Pediatric to Adult Health Care

This overarching theme describes the experiences of families transitioning their young adult from pediatric to adult health care providers. SCAFO held five focus groups with family members of young adults with special health care needs (YSCHN) aged 18 through 25 years. Two second tier themes emerged: (1) Family experiences staying involved in their young adult's health care after age 18, which was described in all focus groups; and (2) A lack of support from the health care system during the transition process, which was reported in four of five focus groups. A description of each theme and examples follow.

Family experiences staying involved in young adult's health care after age 18

In all five focus groups, family members described staying involved in their young adult's health care after age 18. Family members explained their reasons for why they stayed involved, and what helped or hindered them.

Reasons family members stayed involved in young adult's health care

In four of five focus groups, family members described their reasons for staying involved in their young adult's health care, even after their child reached legal adulthood. Family members indicated that their young adult was not prepared to manage their own health care. Additionally, some family members said they did not trust health care providers to provide proper care without family member involvement. Family members stayed involved in their young adult's care by researching ways to manage conditions, finding health care providers in the young adult's new residence, making appointments, ordering medications, managing insurance-related issues, and accompanying their young adult to medical appointments.

“...With my daughter... when she was seeing the doctor from 16....we found that she was prediabetic.....But there was never a follow up. So I was trying to find out what do you normally do for teenagers who’s prediabetic... other than eat right and exercise. I already know [that], so I knew then that the doctor wasn’t worth a hoot. Okay, so once she turned 18 they moved her upstairs to this other doctor who was a female. She seemed more concerned, because she was telling [my daughter] about her weight. Because she lost a lot of weight. They was telling her about her weight and then she was not prediabetic... See what I’m saying? They don’t always check. They just call things out because they don’t want to check.” (Focus Group 4)

“Like I pretty much still order all her insulin...I order all of her pump supplies and her Dexcom and then I deal with all the – there’s just unbelievable nightmares of insurance. So I deal with all of that. And trying to teach her a little bit of it. But it’s just a lot for her to handle as a college student.” (Focus Group 7)

Barriers to family members staying involved in young adult’s health care

In three out of five focus groups, family members described that they felt the need to stay involved in their young adult’s health care, but were prevented from doing so by patient privacy rules. Some family members said this was a problem because their young adult relied on their support with health care. Family members in two of the five transition-aged focus groups described that a medical power of attorney or a release of information helped them participate in their young adult’s health care. One family member said they were fortunate to be told about power of attorney when their young adult was 17. Examples follow.

“So since the girls get certain age, you can’t get no information about them. But guess what? If they get pregnant, guess who they gotta come to? They mom. If they wanna get abortion, they gotta come to the mom. But we don’t know [whether they have those issues]. Why? Like the boys – my son turned 12. Well, they took his MyChart off my thing because he turned 12. Yeah. So then I tried to get it put back on my thing. They didn’t know how to do it. They still haven’t called me about that yet. So I gotta get their permission... And that’s how I kept up – it tells you what’s going on.” (Focus Group 6)

“Well, I have to lie sometimes and say I’m them [laughs]....To call and get their refills or this or that. So that’s been a little bit uncomfortable. But as I can I’ve tried to get the permissions signed from them. But my daughter’s in California. So if they’re putting up a barrier – but when she turned 15, they wouldn’t let us see stuff. They said, “Oh, you can’t.” At the diabetic place. And that upset me ‘cause I said, “I understand if it’s related to her sexual health and I’m fine with that. But if it’s related to her diabetes, I’m helping her. I’m the one doing the 2:00 AM checks. I’m the one paying for the medical bill.” So that was really upsetting, the laws and stuff related to that. But we just worked around it. But, yeah, it’s been hard.” (Focus Group 7)

“My son has actually had some pretty significant crises, and luckily, we were told when he was 17 that there was this medical power of attorney packet to have him fill out, so we filled that out. We were given some good advice prior to him being an adult about how I can stay connected and involved, so I know he fills it out and he tells all the doctors, ‘Ask my mom.’ He doesn’t know the answers to most of his medical care. It’s gone surprisingly smooth having that one little piece of paper with the power of attorney thing saying that I can help him and stuff...” (Focus Group 3)

“He [advocates with the medical provider] but only with my consent. He sees another doctor, but even when I set it up for him to see the Black psychiatrist they said, ‘Well, he’s over 18, so you can’t make the appointment for him.’ What I do is I get [my child], I put him on speaker... Even with him getting social security or disability, I had to sign something to say that I can speak to him, that they can release that information to me.” (Focus Group 10)

Lack of health care system support during the transition process

Family members in four of the five focus groups described not receiving support from the health care system for the transition process. For example, one family member said that their child's health care provider did not provide requested help to meet their child's needs. Another family member encountered problems maintaining the young adult's health insurance, which interfered with getting a referral to an adult provider. Yet another family member described challenges working with their young adult's specialists.

"...Because she had reached 18... and they are supposed to send you to another doctor, which is no longer a pediatrician doctor, but she didn't get to that level. My insurance was gone before she could get to there."
(Focus Group 4)

"If I asked a health care provider, when I would ask for help, things on the outside, what can I do to help support him, if they did know, they didn't tell me. It was more or less like, "Well, you can Google this and you can see this" but it was never, "Go to this person. I know this doctor is good. I know this program is good." Anything that I put him in, like I said, has been...me doing homework." (Focus Group 10)

Family Traumatic Health Care Experience

At least one family member in nine of 11 focus groups described having traumatic or disturbing health care experiences of their own. Family members described feeling uneasy because they had personally experienced intimidation or coercion from health care providers or staff. Additionally, family members recounted experiences of feeling pressured by health care providers or staff to use unwanted services or medications. In some focus groups, family members recounted harmful or painful health care experiences. The following quotations illustrate family traumatic health care experiences.

"I had an African American doctor and all he wanted to do was keep me medicated. And I was like I'm done with that... I said 'Something is wrong here. Something is definitely wrong. You telling me this but you're giving me this. I don't buy this. I don't buy this.'" (Focus Group 4)

"... what made me upset with the doctors, with the whole pregnancy, [is that] they kept using scare tactics on me. They kept doing it. They said, 'You're gonna lose her. She can die. She's not gonna make it. She's gonna have this. She's gonna have that. We need to give you a C-section.'" (Focus Group 8)

"Six weeks later... my placenta came out at home, and it put my body through toxic shock. It affected my eyes, my skin. Now I have lupus and sarcoidosis so that I have these flares. I have to take all these medications just for my eyes, my joints, and my body to be okay. It's the same doctors that just put us behind, because if they took the initiative to hear me in the first six weeks I was calling, then maybe this all could've been prevented." (Focus Group 11)

Adverse Childhood Experiences

Adverse Childhood Experiences (ACEs) are potentially traumatic events that occur during childhood (birth through 17 years of age). According to the Centers for Disease Control and Prevention (n.d.), ACEs include experiencing abuse and neglect, growing up in a household with mental health concerns, growing up with parental substance abuse, living in an unsafe environment, experiencing parental separation and/or divorce, and experiencing the death of a parent. Discussion of ACEs occurred in four of the 11 focus groups. Although that did not rise to our threshold of five focus groups for identifying a theme, we present focus groups data on ACEs because CYSHCN are twice as likely as children without

special health care needs to experience two or more ACEs, and Black children are almost twice as likely as White children to experience ACEs (CAHMI, 2020).

The adverse childhood experiences discussed in most focus groups were abuse and neglect. For example, one grandparent described how their daughter’s drug abuse led her to neglect her children, who had to care for themselves at a young age. Exhibit 3.5 presents types of ACEs, the number of focus groups that discussed each, and quotations that illustrate these traumatic events.

Exhibit 3.5. Type of Adverse Childhood Experience (ACE) By Number of Focus Groups

Number	ACE	Quotation
3	Abuse and neglect (includes physical, emotional, and sexual abuse)	<p><i>"...the child that I'm dealing with is a grandchild. And the mother is on drugs, been on drugs for five years.... She neglects the kids. She started abusing the kids, having the oldest child do the things that the mother should be doing... a nine or ten-year-old going to the store, buying food for all the other younger kids, and then coming home and either cooking it or giving them chips..."</i> (Focus group 6)</p> <p><i>"[My grandson] has lashes where his mom did to him and he wakes screaming, 'No, Mom, no' and I have to tear up out of the bed. It's kind of hard because I can't land on my knees because I have blood clots, and he's screaming and scared...and I don't know what's going on."</i> (Focus group 10)</p>
2	Household member with mental health concern	<i>"I have chronic depression. And so there was also times when I cried or didn't feel good. And I also developed RA, severe RA, when my 20-year-old was about 1 [year old]. So a lot of their growing up I was sick."</i> (Focus group 7)
2	Parental substance abuse	<i>"[My grandson's] mom has had some major drug issues... [and] my son [isn't] capable to be the... custodial parent..."</i> (Focus group 5)
2	Unsafe Environment	<i>"[My nephew] grew up [outside the US] where there's a lot of violence and gunshots and racial/ethnic warfare..."</i> (Focus group 7)
1	Parental separation and/or divorce	<i>"... the reason I focus on [my grandson] is because it's a mom and dad situation [who are] not together..."</i> (Focus group 5)
1	Parent death	<i>"... [My nephew's] dad passed. So basically [there is] trauma from that as well."</i> (Focus group 7)
1	ACEs generally	<i>"[The] 24-year-old with... ADHD...anxiety...she also had some traumas... So there're some ACEs that are automatic at birth."</i> (Focus group 7)

Note: The CDC (n.d.) groups ACEs into the six categories outlined in the table.

Discussion

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) collaborated with the Sickle Cell Anemia Foundation of Oregon (SCAFO) to better understand the care needs and experiences of families of Black CYSHCN in Oregon. We sought to answer four research questions: (1) What health-related care (behavioral, oral, physical) services do families of Black CYSHCN need to care for their child, (2) What has been the experience of families of Black CYSHCN attempting to access needed care, (3) What has been the experience of families of Black CYSHCN in accessing culturally responsive care, and (4) What has been the experience of families of Black 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 families is consistent with the types of care needs reported by families of Oregon CYSHCN generally. Families of Black CYSHCN most commonly described need or use of behavioral/mental health care, educational setting supports, allied therapies (i.e., occupational, physical, or speech therapy), and medical specialists. The behavioral/mental health findings align with quantitative data 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, 2020a). In addition, 40% of CYSHCN received treatment or 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 and medical specialists. However, OCCYSHN's 2015 needs assessment family results showed that CYSHCN very commonly needed 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 discussed easily accessing primary care and emergency department services, and commonly reported difficulty accessing behavioral/mental health care and medical specialists. Although the current study's results cannot describe the extent of this difficulty for all families of Black CYSHCN – or the disparity in access between families of Black versus White CYSHCN – the current study's findings align with those of OCCYSHN's 2015 needs assessment. The 2015 results showed that about one-quarter of family survey respondents identified behavioral/mental health care as one of the top three health care needs their child had but had difficulty obtaining (Martin et al., 2015).

Additionally, families of Black CYSHCN often experienced a range of challenges that make accessing care for their child difficult: health care insurance challenges, difficulty in getting appointments, a provider shortage, and a need to advocate persistently for their child to get appropriate care. Similarly, Ngui and Flores (2006) found that Black parents had significantly greater odds, compared with white parents, of reporting that health care services were not easy to use. Again, the current study's results cannot describe the extent to which these experiences are reflective of all families of Black CYSHCN in Oregon, but they do indicate potential differences with families of CYSHCN generally. 2015 needs assessment results showed that few parents of, and care coordinators who work with, CYSHCN reported families experiencing challenges related to insurance. They did, however, report difficulties getting an appointment that aligned with their work schedule, and getting an appointment as quickly as it was needed (Martin et al., 2015).

Culturally Responsive Care

To the best of our knowledge, this is the first study in the United States that uses a large, statewide sample to explore the experiences of families of Black CYSHCN accessing culturally responsive care. The most prominent theme that emerged from our analyses was family members' experiences of racism. Jones' (2000, 2003) levels of racism framework -- institutionalized, personally mediated, and internalized racism -- provides a useful structure for understanding the families' experiences.

The inability to access to power is central to the perpetuation of institutionalized racism. Information is a source of power. In our findings, family members reported that health care providers did not respond to family members' requests for information (i.e., resources and services). Family members described having to independently gather information about their child's health conditions so they could advocate for needed care.

Family members experienced personally mediated racism when health care providers made comments or acted according to racial stereotypes, for example, allegations of child neglect and abuse, references to marital status, and reports to child protective services. They felt disrespected when their child's health care provider did not appear to value their concerns and thoughts about their child's care. These examples also suggest institutionalized racism because a health care system enabled its primary actors to carry out acts of personally-mediated racism. Individuals were enabled due to the differential distribution of power between the patient's family and the healthcare provider.

This power differential extended to the lack of representation of Black people in the healthcare workforce in Oregon.³ Families reported experiencing difficulties trying to find Black healthcare providers because there were so few of them. This reflects institutionalized racism in the inequities in the access to medical or other allied health education for members of the Black community, particularly Black men (e.g., Charles, 2018; Harley, 2006; Laurencin & Murry, 2017). Furthermore, our findings showed that health care providers exhibited little to no understanding of specific health care needs of Black CYSHCN. This finding suggests that medical and other allied health care, as it currently exists, is not necessarily responsive to the care needs of Black people, and thus suggestive of institutionalized racism. That is, the finding suggests that health care trainees are not taught about health care conditions and needs specific to the Black community. Thus, in our study findings, families of Black CYSHCN described that they had to assume the responsibility for researching treatments, advocating in the health care setting to make sure their

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).

³Although analysis by the Oregon Health Authority (2018) shows that the gap between Oregon's Black population and the number of Black providers is relatively small, Black providers may not work in geographic areas that the Black population is able to access. Further, there is an overrepresentation of White providers for the size of Oregon's White population.

CYSHCN's needs are met, in addition to defending themselves against unwarranted allegations, and explaining the cultural background for their CYHSCN's health care needs to health care providers.

Families' descriptions of their experiences made clear that race influenced all of their interactions with the health care establishment. Ultimately, these experiences shaped families' distrust of the health care system, and diminished expectations for culturally responsive care, including finding Black health care providers. Some families expressed disbelief when asked about having encountered Black health care providers. Their explanations for their disbelief reflected both institutionalized and internalized levels of racism (Jones, 2000). Other studies showed similar findings. African American mothers of children with Autism Spectrum Disorder experienced covert and overt acts of racial discrimination, which implicated race as the reason for the differential treatment of themselves and their children by medical and educational professionals and required that the mothers be resilient advocates for their children (Lovelace, Tamayo, & Robertson, 2018). Black families of CYSHCN were less likely to report that they: received culturally-sensitive care; felt like a partner in their child's care; or received needed information from their health care provider (as compared to families of White CYSHCN) (Coker, Rodriguez & Flores, 2010). These racial disparities in health care quality and access were unchanged and persisted over time for children with developmental disabilities and autism spectrum disorders (Magana, Parish & Son, 2015).

Findings from our study contrast sharply with NSCH 2017-2018 results for Oregon CYSHCN younger than 18 years. NSCH results show that families of Oregon CYSHCN "always" or "usually" experience family-centered and culturally responsive care: 92% reported the provider showed sensitivity to family values and customs, 91% reported the provider listened carefully to the family, 90% reported the provider gave information specific to parent concerns, and 89% reported that the provider helped parents feel like a partner in their child's care (CAHMI, 2020). We cannot determine whether these NSCH quantitative findings are representative of the experiences of Black CYSHCN and their families in Oregon because of the small sample size (less than 30). Again, the findings from this qualitative study cannot generalize to all families of Black CYSHCN in Oregon. When juxtaposed with NSCH results, however, our current study's findings validate the importance of culturally-specific studies such as this, and suggest the need for improvements to the NSCH sampling methodology.

[Transition from Pediatric to Adult Health Care](#)

Prior to this study, little to no data existed to describe the needs and experiences of Oregon families of Black CYSHCN regarding the transition to adult health care. The most prominent theme that emerged from families' description of transition experiences for their YSHCN was that they needed to stay involved in their young adult's health care, even after the young adult turned 18. Some family members felt that their young adults were not prepared to handle the complex tasks involved in self-managing their own health conditions. This points to a lack of transition preparation. Some family members also described that they did not trust their child's health care provider to give the correct diagnosis or medication. This finding reflected their general distrust of the health care system. A fundamental barrier to family members' continued involvement in their young adult's health care is the patient privacy law that goes into effect at age 18. A small number of family members reported overcoming this barrier using a medical power of attorney or a release of information form. Thus, it appeared that the lack of transition preparation extended to a lack of information about supported decision-making and guardianship. Families of Black CYSHCN also reported not receiving transition support from the health care system. They did not get the help they asked for finding adult health care providers for their YSCHN.

These results align with those of the NSCH 2017-2018. Sixteen percent of Black CYSHCN ages 12 through 17 years old in the U.S. received services necessary to make transitions to adult health care compared to 21% of White CYSHCN (CAHMI, 2020b).⁴ Although Oregon youth generally, and youth with special health care needs particularly, do not receive services necessary to transition (Roy et al., 2020), it may be that racism experienced by families of Black CYSHCN in health care settings exacerbates the challenges of transition, and the negative outcomes that result when it goes poorly (Gabriel et al., 2017; Schmidt et al., 2020).

Themes Relating to Trauma

Black CYSHCN and their families experienced trauma. Family members described their children's Adverse Childhood Experiences (ACE), and their own traumatic health care experiences. The ACEs most commonly discussed in focus groups were child neglect and abuse. Black children experience a disproportionately greater number of ACEs than White children. Sixty percent of Black children in the U.S. have had ACEs, versus 40% of White children. Black children represent 17.4% of all U.S. children who have had ACEs (Bethell et al., 2017), though they constitute only 13% of the population of U.S. children. ACEs can have lasting, negative effects on health, well-being, and opportunity. They can increase the risks of mental illness, substance misuse in adulthood. They are identified as leading causes of death with chronic illness (e.g., cancer, diabetes, heart disease) and suicide (CDC, n.d.).

Family members of Black CYSHCN recounted traumatic health care experiences. Family members described health care providers using coercive tactics to pressure them into using undesirable medical services (see *Parent Traumatic Health Care Experience* above). They expressed discomfort with and frustration towards health care providers as a result of these events. In some instances, family members who did not get appropriate health care had traumatic adverse outcomes, leading them to require more health care services. Traumas experienced by families of Black CYSHCN may contribute to health care disparities. For example, racism, stigma, and systemic inequities lead to disproportionate health outcomes and sustain health and healthcare inequities (The COVID Racial Data Tracker, 2020). The combined racial health disparities and distrust with the health care system may cause racial minority groups to forego care (The COVID Racial Data Tracker, 2020). If the health care system does not acknowledge Black families' traumatic experiences, there is a risk that Black adults will forego needed health care for themselves or their children.

We analyzed, interpreted, and wrote our findings around the time when awareness of health disparities experienced by Black people in the U.S. were reinforced by their higher COVID-19 mortality rates (The COVID Racial Data Tracker, 2020). The higher mortality rate highlights the fact that Black people suffer disproportionately from underlying medical conditions that exacerbate the disease (C.D.C, 2020). Simultaneously, the Black Lives Matter movement gathered momentum in the wake of Black people being killed at the hands of police in the United States. These events resulted in a nationwide call for reformation of the systems that perpetuate racial discrimination. Individuals of all races and ethnicities, and particularly White people, were asked to engage in anti-racism work at the individual, institutional, and societal level. The findings from our study provide evidence that families of Black CYSHCN experience racism within Oregon health care systems. Black CYSCHN are among our most vulnerable citizens. Acknowledging and addressing racism in the health care system is step towards racial justice.

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

Community Reflections

SCAFO team members exclusively wrote the following section. This section describes their observations as they worked to implement the focus groups, and as they participated in the experiences of families sharing their stories and finding connection and support through the process of gathering and engaging in the focus groups.

- **Resilient Parents-** The persistence of parents and grandparents as advocates for their children and families was a powerful theme throughout all the group sessions and individual stories that were shared. The parents' stories provided guidance for others on how to persevere despite multiple barriers, and how to maintain a hopeful spirit when there was little external support for them and their children.
- **Family Stories Illuminated Known Inequities-** The stories of Black families' struggles against racism and bias to get quality health care and support for their children is familiar to those who share the lived experience of being Black in America. The stories shared by the parents were powerful in bringing these inequities to life in a way that makes it possible for those without similar lived experiences "know" and "feel" these inequities more deeply.
- **Sense of Community and Connection among Participants-** The cultural value of shared community and connect was readily observable as the focus groups convened. Focus group participants took the initiative to help one another feel at ease and connected; especially from elders to younger parents. Although parents consistently expressed the challenge of experiencing isolation and not knowing of viable options for finding support, they easily connected with one another in caring and supportive ways; building community even among families who had never met prior to the focus group. Extended family members and other community members also responded to the recruitment efforts. They expressed a shared interest in families from their community who have children with special health needs, and a desire to be supportive and helpful. Many were also personally connected with extended family members or friends who had children with special health needs. Outside of the scope of the formal assessment process, we also convened a community listening session to allow other members of the Black community to share their experiences and perspectives as it relates to focus areas of this study and report. Family and community members clearly conveyed the desire and need for an accessible space and resource to support Black families and children who have special health needs. These views were expressed consistently in every community that we visited throughout the state.
- **Intentional and Persistent Efforts Make A Difference-** In general, families were somewhat reluctant to believe that participating in a focus group would result in their voices being heard in a meaningful way. The combination of history of SCAFO in communities throughout the state, and the relationships and experiences of project team members with a broad cross section of Black families and community-based organizations gave credibility to the overall project in the eyes of Black community members. As outreach continued and more families participated, informal networks of community members began to encourage one another to respond to the focus group opportunities. Focus group participation in the Portland area tripled between the initial session and the final offering one month later.
- **Intergenerational Trauma-** The focus groups ended up also serving as an outlet for parents to voice their personal trauma in dealing with the health care system. People had three stories to tell: the stories of their children, the stories of themselves, and the stories of their parents, ancestors, and community. This study was not designed with an intent to capture these latter two stories, but as

they were being told, we realized the importance and value of allowing them to be voiced and heard by others. This was a healing experience for a number of parents who had not, up to that point, had an opportunity to be fully listened to.

Limitations and Recommendations

Few studies have explored health care access experiences of families of Black CYSHCN. Further, to the best of our knowledge, no studies have examined the experiences of families of Black CYSHCN with culturally responsive care (and certainly not 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 study design is that it does not allow us to generalize findings beyond the families of Black CYSHCN who participated in our study. Secondarily, our study does not reflect health care providers' perspectives. The study design and data collection, however, aligned with our study purpose to understand family experience and perspective.

Despite these limitations, our findings illuminate the need for improved access to family-centered and culturally responsive care for Black CYSHCN and their families. To ensure that all CYSHCN in Oregon receive care in a patient and family-centered medical home, it is imperative to ensure that Black 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 SCAFO and other partners to disseminate these findings to state agency, health system, and family partners. OCCYSHN and SCAFO should schedule presentations with Oregon health systems to present the findings to clinic managers and providers.⁵
2. OCCYSHN should contract with culturally-specific service organizations to review Title V Block Grant cross-systems care coordination strategies to assess whether they are culturally responsive and sensitive, 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 culturally responsive/sensitive training and technical assistance (TTA) needs of LPHAs and their partners. Based on the results of this assessment, OCCYSHN should facilitate high quality TTA to LPHAs.
4. The Oregon Health Authority (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.
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 YSHCN 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.

⁵ Such presentations should include the Latino Community Association and findings from its study with OCCYSHN. This study similarly found that Latino CYSHCN and their families experienced racism in Oregon health care systems (Gallarde-Kim, Bisso-Fetzer, Roy, et al., 2020).

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Appendix A. Additional Health-related Care Types Families Reported As Easy or Difficult to Access By Number of Focus Groups

Number	Easy to access	Number	Difficult to access
3	Medical specialists	4	General resources and supports
2	Dental Care	3	Black providers
2	Durable medical equipment (DME)	3	Diagnostic testing
1	Allied Therapy	3	Durable medical equipment (DME)
1	Development Disabilities (DD) services	2	Basic needs
1	Health care services in general	2	Culturally-specific supports
1	Recreation	2	Health care services in general
1	Telehealth	2	Medical transportation
		2	Primary care
		1	Allied Therapy
		1	Care coordination services
		1	Dental care
		1	Developmental assessment
		1	Egg-free flu vaccination
		1	Financial supports
		1	Health care insurance
		1	Non-faith based hospital
		1	Personal in-home support provider
		1	Respite care