OREGON CENTER FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

Racism in Oregon's Health Care System

Experiences of Families of Black and Immigrant Latino Children and Youth with Special Health Care Needs

This brief is based on information from the *Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) Title V CYSHCN Five-Year Needs Assessment Findings, October 2020*

> **RACISM** – "a system of structuring opportunity and assigning value based on the social interpretation of how one looks (which is what we call 'race') that unfairly disadvantages some individuals and communities, unfairly advantages other individuals and communities, and saps the strength of the whole society through the waste of human resources." [11] - *Camara Phyllis Jones*

INTRODUCTION

In 1985, the Department of Health and Human Services Task Force on Black and Minority Health released the first report to document health disparities for people of color in the United States, calling such disparities "an affront both to our ideals and to the ongoing genius of American medicine."[1] This report significantly raised awareness of the disparate health of the country's people of color compared to the white population.[2] More than 30 years later, research shows that unjust health disparities persist.[3] Racism is a social determinant of health, and a force that drives unequal health disparities and health care disparities for children.[4] Disparities in health care quality affect health outcomes.[5] Families of Black and Latino children and youth with special health care needs (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 (compared to families of White CYSHCN).[6]

To better understand the health care experiences of families of CYSHCN of color, the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) contracted with the Sickle Cell Anemia Foundation of Oregon (SCAFO) and the Latino Community Association (LCA). SCAFO conducted focus groups with families of Black CYSHCN, and LCA conducted them with immigrant families of Latino CYSHCN. The purpose of this brief is to share findings from those focus groups, particularly family reports of experiencing racism in Oregon's health care systems.[7,8] Dr. Camara Phyllis Jones' "Levels of Racism" framework[9] provides a useful structure for understanding those experiences. (See green box.)

LEVELS OF RACISM

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

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."

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, C. (2000). Levels of racism: A theoretical framework and a gardener's tale. American Journal of Public Health, 90(8), 1212-1215.

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OCCYSHN's PARTICIPATORY NEEDS ASSESSMENT

OCCYSHN conducted a participatory needs assessment with SCAFO and LCA as part of the 2020 Needs Assessment. OCCYSHN developed the questions guiding this research, and SCAFO and LCA co-developed the data collection methods and Institutional Review Board protocol, collected and co-own the data, and participated in analysis and dissemination efforts.

SCAFO conducted 11 focus groups, with 45 families of Black CYSHCN in six cities across the state. An average of four family members participated in each discussion. LCA conducted focus groups with immigrant families of Latino CYSHCN in Central Oregon. They conducted six focus groups with 22 immigrant families of Latino CYSHCN in the Central Oregon area. An average of four family members participated in each discussion.

To the best of our knowledge, this is the first study in the United States that used a large, statewide sample to explore whether families of Black CYSHCN get culturally responsive care. No studies have examined access to culturally responsive care for families of immigrant Latino CYSHCN. Certainly, in Oregon, access to culturally responsive care for families of Black and Latino CYSHCN has not been studied. Our findings show that families of Black and Latino CYSHCN experience racism in Oregon health care settings. Families described experiencing both personally mediated and institutionalized racism.[9]

EXPERIENCES OF RACISM FOR FAMILIES OF BLACK CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

In 10 out of 11 focus groups, family members of Black CYSHCN described experiencing racism in the health care system.[7] Families experienced personally mediated racism when health care providers made comments or acted according to racial stereotypes. Examples include allegations of child neglect and abuse, references to marital status, and reports to child protective services. They recounted experiencing disrespect or discrimination from health care providers. Family members described feeling judged about their marital status, parenting style, or ability to care for their child.

"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)

Families experienced institutionalized racism when providers did not know how to care for their child's condition because their child was Black. Family members described consistently encountering health care providers with little to no understanding of the care needed to respond to conditions that affect, or as they manifest, in Black CYSHCN, or Black culture, as illustrated by the following quotes.

"That's one of the major problems that we have. We go to the doctor, which is usually somebody White who has no idea anything 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)

"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)

They felt disrespected when their child's health care provider did not appear to value their concerns and thoughts about their child's care and discounted or ignored family member requests for specific services or information. Information is a form of power,[9] and barring access to power keeps institutionalized racism alive. The inherent power differential between the family and their child's health care provider enabled institutionalized racism.

Families of Black CYSHCN described burdens that included assuming responsibility for researching their child's treatments, advocating to ensure their CYSHCN's health care needs were met, defending themselves against unwarranted allegations, and providing cultural context for their CYSHCN's health care needs. Our findings point to a need for more education for health care professionals about conditions and needs specific to the Black community.

EXPERIENCES OF RACISM FOR IMMIGRANT FAMILIES OF LATINO CYSHCN

In all six focus groups, immigrant family members of Latino CYSHCN described experiencing racism in the health care system.[8] Families experienced personally mediated racism when health care providers made blatantly insensitive and discriminatory comments, as illustrated in the following quotes. This created an unsafe, hostile environment for Latino family members. They described feeling nervous, discouraged, and uncomfortable in medical settings. Family members anticipated that their concerns would not be understood or respected by health care providers.

"… we got a doctor who spoke little Spanish…and when she saw my son - I don't know if she had already seen in the note that he has autism - she turned to him and said, 'what have you got now?'… she said I'll check your lungs even though you cause an allergy… my son sneezed and she told him… 'You caused me an allergy,' … Well, that was a first and very strong situation… We [did] report it… The [clinic] director came and apologized. I told her that she did not have to apologize, that the one who has to apologize is the one who was offending." (Focus Group 6)

Immigrant families of Latino CYSHCN experienced institutionalized racism with poor interpretation services. Some families had to receive care with no interpreter, and others had to use their child or other family members to receive interpretation. Other families experienced poor quality interpretation; someone in the family knew enough English to know that the translation was incomplete or inaccurate. One family member felt uncomfortable asking for interpreters because they anticipated discrimination as a result of the request. Another felt that such requests would result in a longer wait time for an appointment. These health system inadequacies result in unequal access to information for people of color, and people with limited English. Similar to families of Black CYSHCN, the unequal access to information about their child's health inhibits families from accessing power to care for their child and perpetuates institutionalized racism.

"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)

> *"By acknowledging the role of racism in child and adolescent health, pediatricians and other pediatric health professionals will be able to proactively engage in strategies to optimize clinical care, workforce development, professional education, systems engagement, and research in a manner designed to reduce the health effects of [institutionalized], personally mediated, and internalized racism and improve the health and well-being of all children, adolescents, emerging adults, and their families."* [10]
>
> \- *Pediatrics*, official journal of the AAP

CONCLUSION

Although our report findings cannot generalize to all families of Black and Latino CYSHCN in Oregon, our needs assessment found that these families experience institutionalized and personally mediated racism in health care settings throughout the state. Institutionalized racism – such as not understanding health conditions specific to Black people or not providing appropriate language supports – inhibited CYSHCN from receiving needed, appropriate care. Both institutionalized and personally-mediated racism – disrespectful behavior and comments – negatively influenced family experience working with the health care system. Their subsequent distrust of health care systems and providers ultimately diminished their expectations for culturally responsive care.

These findings demonstrate that Oregon CYSHCN of color have unequal access to health care and further, that Oregon's health care system fails to provide families of Black and Latino CYSHCN with culturally responsive and family-centered care. The latter are foundations of a medical home. Pediatric providers are key members of the health care system for CYSHCN, and have direct influence on the quality of care received by CYSHCN of color. The American Academy of Pediatrics (AAP) asserts that pediatrics should be at the forefront of addressing racism as a core social determinant of health.[10] Oregon's CYSHCN will benefit if racism is acknowledged and addressed in health care. An important starting point is revising pediatric education and training program curriculum and recruitment to be anti-racist.[10] Additionally, establishing learning communities among health care professionals and communities of color to both develop provider self-awareness and to identify and manage power imbalances will benefit the current workforce.[10]

OCCYSHN sincerely thanks the families who participated in the focus groups. We are grateful for their candor, emotion, energy, information, and time.

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[1] Centers for Disease Control and Prevention (CDC). (2018, May 18). Timeline - achievements in minority health - health equity – CDC. Retrieved from: https://www.cdc.gov/healthequity/timeline/index.htm.

[2] Mayberry, R.M., Mili, F., & Ofili, E. (2000). Racial and ethnic differences in access to medical care. *Medical Care Research and Review, 57*(4 suppl), 108-145.

[3] Committee on Improving the Health, Safety, and Well-Being of Young Adults; Board on Children, Youth, and Families; Institute of Medicine; National Research Council. (2015). *Investing in the health and well-being of young adults*. Washington, DC: National Academies Press.

[4] Pachter, L. M., & Garcia Coll, C. (2009). Racism and child health: a review of the literature and future directions. *J Dev Behav Pediatrics, 30*(3), 255-263.

[5] Fiscella, K., Franks, P., Gold, M., & Clancy, C. (2000). Inequality in quality addressing socioeconomic, racial, and ethnic disparities in health care. *JAMA, 283*(19), 2579-2584.

[6] Coker, T. R., Rodriguez, M. A., & Flores, G. (2010). Family-centered care for US children with special health care needs: who gets it and why? *Pediatrics, 125*(6), 1159-1167.

[7] Gallarde-Kim, S., Smith, C., Roy, S., Taylor, M., Vega-Juarez, R., Aiello, M., Hairston, R., and Martin, A.J. (2020). *Health care needs, access to care, and experiences of racism for Black children and youth with special health care needs and their families. Oregon Title V needs assessment chapter 3: Children and youth with special health care needs.* Retrieved from: https://www.ohsu.edu/occyshn/assessment-and-evaluation.

[8] Gallarde-Kim, S. Bisso-Fetzer, C., Roy, S., Porterfield, B., Vega-Juárez, R., Gonzales, O., & Martin, A.J. (2020). *Escúchenos! Immigrant Latino parents of children and youth with special health care needs in Central Oregon share their experiences accessing health care. Oregon Title V needs assessment chapter 4: Children and youth with special health care needs.* Retrieved from: https://www.ohsu.edu/occyshn/assessment-and-evaluation.

[9] Jones, C. (2000). Levels of racism: A theoretical framework and a gardener's tale. *American Journal of Public Health, 90*(8), 1212 1215.

[10] Trent M., Dooley D.G., Dougé J., AAP Section on Adolescent Health, AAP Council on Community Pediatrics, AAP Committee on Adolescence (2019). The impact of racism on child and adolescent health. *Pediatrics, 144*(2).

[11] Jones, C. (2003). Confronting institutionalized racism. *Phylon, 50*(1-2), 7-22.

[12] 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.

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