OREGON CENTER FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

Accessing Allied Therapies

Challenges for Oregon's Children and Youth with Special Health Needs

2021

Allied therapy is an essential element of the system of care for Oregon's children and youth with special health care needs (CYSHCN).[1] The American Medical Association defines allied health professionals as, "*a large cluster of health-related professions and personnel whose functions include assisting, facilitating, or complementing the work of physicians and other specialists*."[2] Three types of allied therapists commonly required by CYSHCN are physical therapists (PTs), occupational therapists (OTs), and speech language pathologists (SLPs).

Allied therapy can be rehabilitative (*restoring* lost skills and function) or habilitative (*maintaining or improving* existing function).[3,4] Children with new-onset disabilities and those with chronic health conditions often need ongoing allied therapies.[4] The duration and frequency of these habilitative therapies vary, and they can be extensive and expensive.[5] This brief focuses on habilitative therapy, because it is difficult to determine health insurance coverage for an unfixed amount of therapy for CYSHCN due to their ongoing needs.[3,4] Thus, CYSHCN experience more difficulty accessing habilitative, rather than rehabilitative, care.[3]

The National Standards for Systems of Care for CYSHCN call for "*reasonable access requirements and wait times for…habilitative services*."[1] Oregon CYSHCN do not consistently have reasonable access to these therapies. In OCCYSHN's 2015 needs assessment, about half of family survey participants reported that their CYSHCN had an unmet need for one or more allied therapies.[6] In OCCYSHN's 2020 needs assessment focus groups, some families reported that the first available appointment for their CYSHCN to see an OT, PT, or SLP was often months away.[10,11] Workforce shortages, insurance challenges, and education system shortfalls make it difficult for families to access allied therapy for their child.

Thirty-nine percent of Oregon counties have a shortage of allied therapists.[7] CYSHCN in rural areas face particular difficulty accessing these services, as some counties lack specific kinds of allied therapists altogether (see table).

Rural and Frontier Oregon Counties Lacking Allied Therapists

● = No providers practicing in the county

County	Physical Therapists	Occupational Therapists	Speech-Language Pathologists
Crook		●	
Gilliam	●	●	●
Harney		●	
Sherman	●	●	●
Wheeler	●	●	●

Source: Oregon Health Authority 2016-17

Speech-Language Therapy (SLT): Prevents, assesses, diagnoses, and treats speech, language, social communication, cognitive-communication, and swallowing disorders.[16]

Occupational Therapy (OT): Maintains or rebuilds skills in order to support or maximize independence through personalized interventions.[17]

Physical Therapy (PT): Strengthens, reduces pain, restores function, and prevents disability through therapeutic exercise and functional training.[18]

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

OHSU

In facilitated discussions with OCCYSHN, public health nurses also reported that CYSHCN lack access to therapists in rural areas generally.[6] Additionally, there are few Black and Hispanic/Latino allied therapists in Oregon, compared to the state's Black and Hispanic/Latino population,[8] making it more difficult for CYSHCN of color to get "racially concordant"[9] services.

Insurance system challenges make it difficult for families to maintain continuity in allied therapy care for their child. Insurance typically covers a specific number of allied therapy appointments per year. Family members of CYSHCN often report that the number of visits covered is insufficient to meet their child's needs. In OCCYSHN's 2015 and 2020 needs assessments, family members reported that CYSHCN experienced detrimental gaps in therapy when they had to wait for insurance to approve additional visits or after they exhausted their annual insurance benefit. Families reported that interruptions to their therapy care make it difficult for their children to retain the skills that they were building in treatment.[10,11]

> *" … If your [occupational and sensory therapy] appointments are three months apart, I feel like to be an advocate for our children, we need something to do in the meantime until they can get to that next appointment. Because it's so far out … Everything that they've learned, if you have to wait three months to get to the next appointment it's like they're starting all over again."*
>
> – Parent of CYSHCN
> OCCYSHN 2020
> Needs Assessment Focus Group

Findings from OCCYSHN's 2020 needs assessment showed that CYSHCN often face inadequate insurance coverage; allied therapies were one of the types of care about which families described insurance inadequacy.[10,11] One research report shows that insurance companies decline to pay for clinic-based allied therapies when a child is getting school-based allied therapies, even though school-based therapies are limited to addressing learning objectives.[3] Some children may require clinic-based therapies to perform functional tasks that cannot be accomplished solely with school-based therapies.[4] For example, a school-employed OT can help a child with handwriting, but cannot help them with tooth brushing because this functional task does not achieve school learning outcomes.[4]

An additional barrier for CYSHCN, who require allied therapy to pursue learning outcomes, is that some education systems do not have sufficient resources to provide all of the child's required therapy.[12] For example, the majority of Oregon CYSHCN receiving special education have a speech or language impairment.[13] In facilitated discussions with OCCYSHN, public health nurses reported that some school districts in their area stopped providing speech-language therapy because they lacked qualified staff.[6] Further, a 2020 audit by the Oregon Secretary of State reported that physical and occupational therapy were generally not available through Oregon's public school systems.[12] Occupational therapy interventions in educational settings are often implemented by people who are not licensed practitioners.[7,14] Oregon Administrative Rules allow occupational therapists to delegate therapeutic activities to educational or daycare staff. Those staff members have varying skill levels for implementing such interventions.[14]

Telehealth may address some allied therapy access barriers. The COVID-19 pandemic resulted in a sudden and substantial increase in telehealth services. Leveraging telehealth may improve access to allied therapies for rural Oregon CYSHCN with insufficient access to local providers.[15] However, for telehealth services to be equitable, families need access to broadband internet, digital literacy education, and skilled translation services. For telehealth services to be sustainable for providers, insurers must pay the same rate for virtual services as they would for in-person services.

Allied therapies are important to supporting the health and development of CYSHCN. Workforce shortages and insurance inadequacies exacerbate the unmet allied therapy needs of Oregon CYSHCN. In addition, Oregon's education system lacks resources to adequately address allied therapy care for CYSHCN. Addressing the barriers CYSHCN face to accessing allied therapies requires a focused cross-sector collaboration between health, education, insurance, and policy systems. Such efforts would maintain or improve the health and functioning of Oregon CYSHCN, and would advance a more integrated statewide system of care.

Citations

[1] Association for Maternal and Child Health Programs and National Academy for State Health Policy. (2017). *Standards for Systems of Care for Children and Youth with Special Health Care Needs v. 2*. Retrieved from http:/www.amchp.org/programsandtopics/CYSHCN/Documents/

[2] Committee to Study the Role of Allied Health Personnel Institute of Medicine (1987). *Allied health services: Avoiding crises*. Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK218850/

[3] Rosenbaum, S.J. (2013). *Habilitative services coverage for children under the essential health benefit provisions of the Affordable Care Act*. Retrieved from: https://hsrc.himmelfarb.gwu.edu

[4] Houtrow, A. & Murphy, N. (2019). *Prescribing physical, occupational, and speech therapy services for children with disabilities. Pediatrics, 143(4). Retrieved from* https://pediatrics.aappublications.org

[5] Lucile Packard Foundation for Children's Health (2013). *Habilitative services under the ACA: What states should consider*. Retrieved from https://www.lpfch.org/habilitative_services_fact_sheet

[6] Martin, A.J., et al. (2015). *Oregon's children and youth with special health care needs: Title V Maternal and Child Health Block Grant five-year needs assessment findings.* Retrieved from https://www.ohsu.edu/occyshn/assessment-and-evaluation

[7] Oregon Health Authority (2017). Health Care Workforce Reporting. Retrieved from https://www.oregon.gov/oha/hpa/analytics/Pages/Health-Care-Workforce-Reporting.aspx

[8] Oregon Health Authority, Office of Health Analytics. (2018b). *The diversity of Oregon's licensed health care workforce based on data collected during 2016 and 2017.* Retrieved from: https://www.oregon.gov/oha/hpa/analytics/Pages/Health-Care-Workforce-Reporting.aspx

[9] Shen, M.J., et al. (2018). *The effects of race and racial concordance on patient-physician communication: A systemic review of the literature. Journal of Racial and Ethnic Health Disparities*, 5(1). doi:10.1007/s40615-017-0350-

[10] Gallarde-Kim, S., et al. (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. July 15, 2020.* Portland, OR: Oregon Center for Children and Youth with Special Health Needs.

[11] Gallarde-Kim, S., et al. (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.* Portland, OR: Oregon Center for Children and Youth with Special Health Needs.

[12] Oregon Secretary of State Audits Division (2020*). ODE can better support students experiencing disabilities through improved coordination and monitoring of services*. Retrieved from https://sos.oregon.gov/audits/Documents/2020-24.pdf

[13] Oregon Department of Education (2018). *Oregon IDEA federal data reports*. Retrieved from https://www.oregon.gov/ode/reports-and-data/SpEdReports/Pages/IDEA-Federal-Data-Reports.aspx

[14] Oregon Public Law (n.d.). *Occupational therapy services for children and youth in education and early childhood programs regulated by federal laws*. Retrieved from https://oregon.public.law/rules/oar_339-010-0050

[15] Oregon Health Authority (2021). *Oregon's health care workforce.* Retrieved from https://www.oregon.gov/oha/HPA

[16] American Speech-Language Hearing Association (n.d.) *About speech-language pathology*. Retrieved from https://www.asha.org/Students/Speech-Language-Pathologists/

[17] American Occupational Therapy Association (n.d.). *What is occupational therapy?* Retrieved from https://www.aota.org/About-Occupational-Therapy.aspx

[18] Oregon Board of Physical Therapy (n.d.). *About the practice of physical therapy.* Retrieved from https://www.oregon.gov/pt/Pages/career.aspx

OREGON CENTER FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

Accessing Mental and Behavioral Health Care

Challenges for Oregon's Children and Youth with Special Health 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

Oregon's children and youth with special health care needs (CYSHCN) need mental and behavioral health (M/BH) care. In 2016, 40% of the state's CYSHCN population (ages 3-17 years) received mental health treatment or services, compared to 5% of their peers without special health care needs.[1]

Oregon CYSHCN often have trouble getting the M/BH care they require. OCCYSHN's last three needs assessments (conducted in 2010, 2015, and 2020) found persistent access issues for CYSHCN who require M/BH care.[2,4,5] In 2015, 24% of family survey participants reported that M/BH care was one of three things that their child or family most needed but had difficulty accessing. In 2020, M/BH care was *the* most frequently report health care need cited in focus groups conducted with Black and immigrant Latino families of CYSHCN.

A 2020 audit by Oregon's Secretary of State found that the state's "behavioral health system for children is in crisis and is failing to serve children, youth and families who are involved with multiple systems and have complex needs." The same audit reported that in the last biennium, the Oregon Health Authority budgeted about ten times more money to adult programs at Local Mental Health Authorities than it did to programs serving children and families.[3]

Widespread workforce shortages limit access to appropriate M/BH care for Oregon CYSCHN. The demand for M/BH care exceeds the state's supply of qualified providers.[8] A dearth of providers can lead to detrimental wait times for appointments, and/or costly travel for care. In OCCYSHN's 2020 needs assessment, families of Black and Latino CYSHCN reported long wait times to get M/BH appointments for their CYSHCN.[6,7] One parent reported a year-long waitlist for the Applied Behavior Analysis therapy their child urgently needed.[6] Provider shortages are especially acute in Oregon's rural counties.[8] Two Eastern Oregon counties (Gilliam and Sherman) have no licensed M/BH providers whatsoever, meaning CYSHCN who live there must travel to other counties to get M/BH care.[8]

> Children and youth with special health care needs (CYSCHN) are those who require more health care and related services than their peers. [14] 18.7% (160,752) of Oregon's children meet that definition. [1]

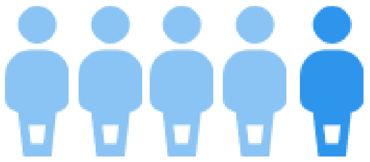
A shortage of culturally appropriate providers exacerbates the impact of workforce shortages on CYSHCN of color. There are not enough providers of color to meet the needs of Oregon CYSHCN. [9] In OCCYSHN's 2020 needs assessment focus groups, families of Black and Latino CYSHCN reported preferring health care providers who understand their culture.[6,7] Although these families wanted racially concordant providers (meaning they share racial identity),[10] a shortage of providers of color made that preference difficult or impossible to accommodate.[6,7]

Insurance issues present another barrier to accessing appropriate M/BH care for CYSHCN. Seventeen percent of families of Oregon CYSHCN reported that their insurance "sometimes or never" offered benefits or services for M/BH needs.[1] Needs assessment respondents reported to OCCYSHN that insurance plans sometimes did not provide adequate coverage for M/BH care (by limiting numbers of visits covered per year, for example).[6,7] Moreover, both publicly and privately insured families reported that they had trouble finding providers who took their insurance, or who would continue treatment if their insurance changed.[6,7] Combined with the statewide shortage of M/BH providers, limited insurance coverage for M/BH can make it difficult for CYSHCN to get the care they need.

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

OHSU

Another challenge facing Oregon's young adults with M/BH care needs is inadequate support for the transition from pediatric to adult M/BH care. Without guidance, young adults with special health care needs and their families are frequently not prepared for the legal, financial and logistical changes that can happen overnight when someone turns 18. Some families of youth with medically complex conditions reported to OCCYSHN that their young adults' M/BH care providers gave little or no notice that their services would end when the youth turned 18.[11] OCCYSHN's 2020 statewide needs assessment results showed that families of Black and Latino CYSHCN were not adequately prepared for their child's transition to adult health care, and they expressed concern that their young adults were not equipped to manage their own health care.[6,7]



Four out of five Oregon youth with emotional, developmental, or behavioral conditions did ***not*** get transition services.

2016-17 National Survey of Children's Health

Our findings demonstrate that Oregon CYSHCN have persistent unmet M/BH care needs, and that challenges accessing appropriate care may be exacerbated for CYSHCN of color.[6,7] In addition to culturally competent care, the components of a quality system of care outlined in the *National Standards for Systems of Care for CYSHCN* include geographic and timely access to mental health services.[12] The *Standards* call for sufficient insurance coverage, and systems that support youth with special health care needs as they transition to adult health care.[12] Unmet M/BH needs can impact a young person's health, education, vocation, and family function. Oregon's failure to meet M/BH care standards for CYSHCN risks exacerbating their conditions and increasing stress on their families.

---

[1] Child and Adolescent Health Measurement Initiative [CAHMI]. (2020). *2016-2017 National survey of children's health data query.*

[2] Aiello, M. et al. (2020). *How are Oregon children and youth with special health care needs faring? Oregon Title V needs assessment chapter 1: Summary of findings. July 15, 2020.* Portland, OR: Oregon Center for Children and Youth with Special Health Needs.

[3] Oregon Secretary of State Audits Division (2020). *Chronic and systemic issues in Oregon's mental health treatment system leave children and their families in crisis.* Retrieved from: www.oregon.gov/newsroom/Pages/NewsDetail.aspx?newsid=37271.

[4] Office of Family Health, Oregon Health Authority, Oregon Center for Children and Youth with Special Health Needs, and Oregon Health and Science University. (2010). *Oregon five-year MCH needs assessment. July 15, 2010.*

[5] Martin, A. et al. (2015). *Oregon's children and youth with special health care needs: Title V Maternal and Child Health Block Grant five-year needs assessment findings. June 22, 2015.* Portland, OR: Oregon Center for Children and Youth with Special Health Needs.

[6] Gallarde-Kim, S. et al. (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. July 15, 2020.* Portland, OR: Oregon Center for Children and Youth with Special Health Needs.

[7] Gallarde-Kim, S. et al. (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.* Portland, OR: Oregon Center for Children and Youth with Special Health Needs.

[8] Hemeida, S., et al. (2019). *An analysis of Oregon's behavioral health workforce: Assessing capacity of licensed and unlicensed providers to meet population needs.* Retrieved from: www.oregon.gov/oha/hpa/analytics/Pages/Health-Care-Workforce-Reporting.aspx.

[9] Oregon Health Authority, Office of Health Analytics. (2018b). *The diversity of Oregon's licensed health care workforce based on data collected during 2016 and 2017.* Retrieved from: www.oregon.gov/oha/hpa/analytics/Pages/Health-Care-Workforce-Reporting.aspx.

[10] Shen, M.J., et al. (2018). The effects of race and racial concordance on patient-physician communication: A systemic review of the literature. *Journal of Racial and Ethnic Health Disparities, 5*(1). doi:10.1007/s40615-017-0350-4

[11] Roy, S., et al. (2020). *Compilation of findings from secondary data sources. Oregon Title V needs assessment chapter 2. Children and youth with special health care needs.* Portland, OR: Oregon Center for Children and Youth with Special Health Needs.

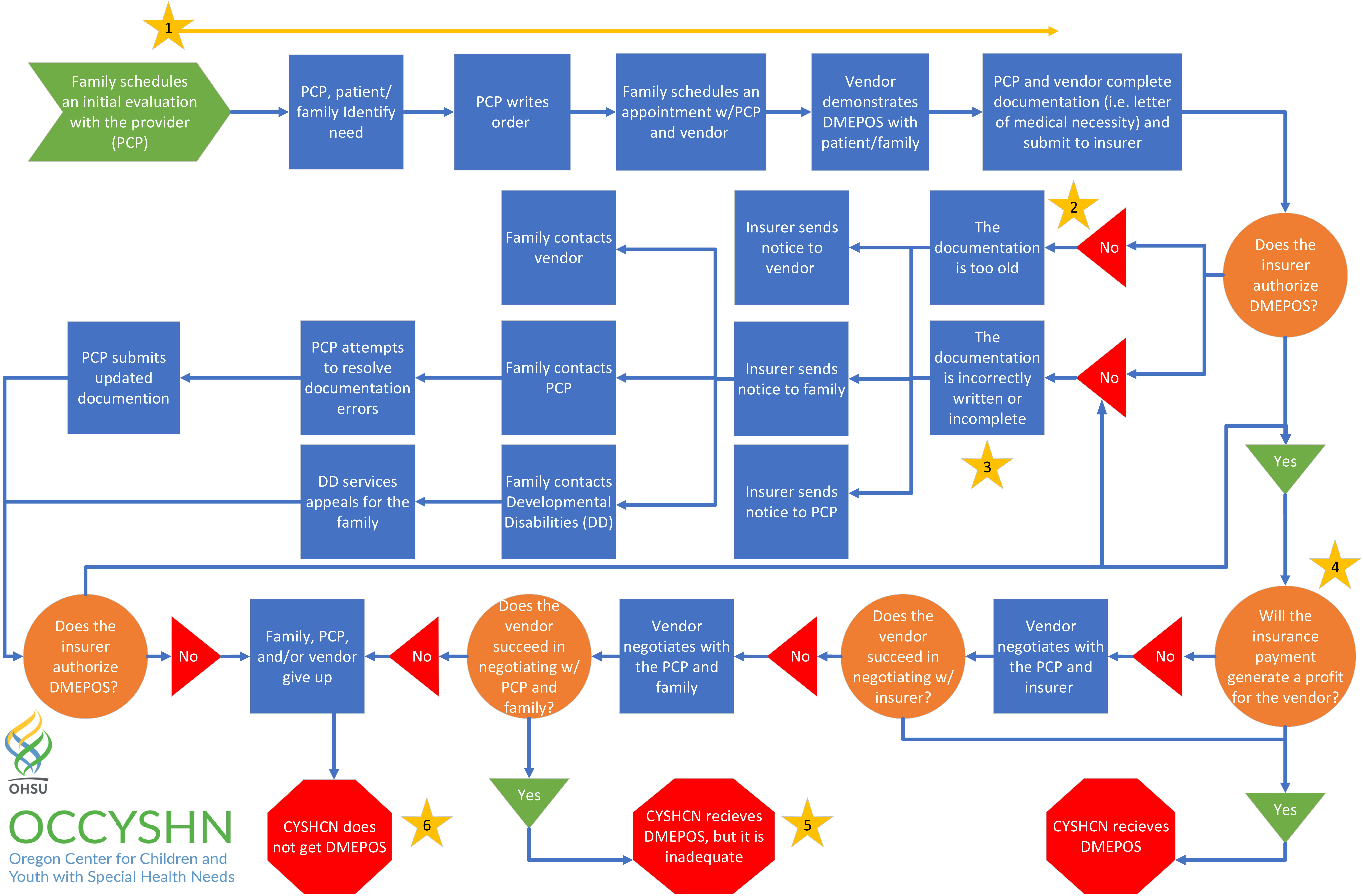
[12] Association of Maternal & Child Health Programs and National Academy for State Health Policy. (2017). *Standards for systems of care for children and youth with special health care needs version 2.0*. Retrieved from www.amchp.org/programsandtopics/CYSHCN/projects/NationalStandards/

[13] Martin, A.J., & Vega-Juarez, R. (2020). *Oregon systems of care for children and youth with special health care needs. Oregon Title V needs assessment chapter 5: Children and youth with special health care needs.* Portland, OR: Oregon Center for Children and Youth with Special Health Needs.

[14] McPherson, M., et al. (1998). A new definition of children with special health care needs. *Pediatrics*, *102*(1 Pt 1), 137–140.

Improvement Opportunities for Oregon CYSHCN Access to Durable Medical Equipment, Prosthetic, Orthotic, and Medical Supplies (DMEPOS)

When families have a child or youth with a special health care need (CYSHCN), they may need access to durable medical equipment, prosthetic, orthotic, and/or medical supplies (DMEPOS). This graphic depicts the experience of Oregon families of CYSHCN attempting to access DMEPOS beginning at the initial evaluation. Three outcomes are possible: DMEPOS receipt, receipt of inadequate DMEPOS, or no receipt. The complexity of the roadmap increases when a greater DMEPOS need exists and more providers are involved.



1

Family schedules an initial evaluation with the provider (PCP)

PCP, patient/ family Identify need

PCP writes order

Family schedules an appointment w/PCP and vendor

Vendor demonstrates DMEPOS with patient/family

PCP and vendor complete documentation (i.e. letter of medical necessity) and submit to insurer

Does the insurer authorize DMEPOS?

No

2

The documentation is too old

No

The documentation is incorrectly written or incomplete

3

Insurer sends notice to vendor

Insurer sends notice to family

Insurer sends notice to PCP

Family contacts vendor

Family contacts PCP

Family contacts Developmental Disabilities (DD)

PCP attempts to resolve documentation errors

DD services appeals for the family

PCP submits updated documention

Yes

4

Will the insurance payment generate a profit for the vendor?

No

Vendor negotiates with the PCP and insurer

Does the vendor succeed in negotiating w/ insurer?

No

Vendor negotiates with the PCP and family

Does the vendor succeed in negotiating w/ PCP and family?

No

Family, PCP, and/or vendor give up

No

Does the insurer authorize DMEPOS?

Yes

CYSHCN recieves DMEPOS

Yes

CYSHCN recieves DMEPOS, but it is inadequate

5

CYSHCN does not get DMEPOS

6

OHSU

OCCYSHN

Oregon Center for Children and Youth with Special Health Needs

Summary of DMEPOS need among OR CYSHCN

Children and youth with special health care needs (CYSHCN) can require different types of durable medical equipment, prosthetic and orthotic devices, and medical supplies (DMEPOS) to maintain their health and quality of life (see Exhibit 1). Oregon families of CYSHCN reported that they experience difficulties accessing DMEPOS, such as long wait times for, and lack of full insurance coverage of, these items. To better understand the difficulties reported by families, OCCYSHN gathered information from Family Leaders and professionals who work with CYSHCN and their families (see Exhibit 2) to develop the roadmap on the previous page. We intend the graphic to provide a general representation of the experiences that families of Oregon CYSHCN encounter; experiences may vary slightly depending on the specific type of DMEPOS needed, provider experience ordering DME, and insurer. The following starred points present examples of unintended, challenging consequences for families and health care providers in this process.

Unintended Consequences of DMEPOS Process Barriers:

1 A family must request a face-to-face appointment with their primary care provider (PCP) to discuss why the child needs DMEPOS. Afterwards, the family schedules and meets with an allied therapist (often a physical therapist) and a DMEPOS vendor at the same time to determine the appropriate equipment fit. Coordinating an appointment where the allied therapist, vendor, and family are present can be challenging. This responsibility falls to the family with little or no support from the health care system.

2 Insurance requires PCPs, allied therapists, and vendors to meet with the patient and family, and submit documentation, within specific timeframes. These timeframes often challenge providers given the coordination involved in #1. If meetings occur, or documentation is submitted, after the insurer's required timeframe, the insurer will deny the request and the family, providers, and vendor must repeat the steps in #1.

Some timeframes are so difficult that a child's basic needs can go unmet if a mistake occurs. For example, one Family Advocate described a food security challenge with 30-day timeframes for submitting enteral feeding supply requests. CYSHCN with conditions requiring feeding supports need to be able to ingest their nourishment requirements daily. When families miss the timeframe to submit the request, they must find workarounds (e.g., blending, thinning out remaining feeding supplies) to keep their child from going completely hungry.

3 Incorrect documentation can result from providers having varying degrees of understanding the order process. Health care professionals, especially new professionals, may lack knowledge of existing documentation standards, or Oregon Administrative Rules (OARs), for DMEPOS prescriptions. Documentation corrections require clinic resources to revise and resubmit. Providers must use non-billable time between patients to make corrections and update documentation. In some instances, vendors may require additional documentation from the provider. If the family has multiple providers, the referring primary care provider who initiated the DMEPOS process must submit the documentation on behalf of the child's care team. Revising and resubmitting documentation contributes to longer wait times for the child.

4 The child's insurer determines the costs covered for DMEPOS, and Medicaid coverage can be too low to pay for the exact DMEPOS needed. For example, an Assistive Technology Professional (ATP) noted that Medicaid sets a $1500 allowable for gait trainers and walkers, which does not allow for all manufacture parts to be included. Additionally, the ATP reported that medically complex children need equipment beyond what Medicaid allows, and the family and provider have to compromise with alternative equipment.

5 Families also encounter challenges with commercial insurers, and in some cases the challenges seem illogical. For example, one Family Leader shared that their commercial insurance plan covered a $7,000 wheelchair that did not meet their child's health needs, but was unwilling to cover a $3,000 wheelchair that did.

Exhibit 1. Definitions.

Durable medical equipment: Devices that can withstand repeated use, and can be reusable and be removable. Some examples include wheelchairs, crutches, and hospital beds.

Prosthetic and orthotic devices: Medical devices that replace all or part of an internal body organ. Some examples include ostomy bags and supplies, or leg, arm, back, and neck braces and artificial replacements.

Medical supplies: Health care related items that are disposable and cannot withstand repeated use. Some examples include diapers, syringes, gauze bandages, and tubing.

Exhibit 2. Information sources.

- Experiences of allied therapists providing DMEPOS services to Oregon CYSHCN.
- Experiences of Family Leaders participating on OCCYSHN's Children with Medical Complexity Collaborative for Improvement and Innovation Network team.
- Experiences of OCCYSHN staff who support the CaCoon public health nurse home visiting and shared care planning programs
- Experiences of Oregon Family to Family Health Information Center staff working with Oregon families of CYSHCN.
- Gallarde-Kim, S., et al. (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. July 15, 2020. Retrieved from https://www.ohsu.edu/occyshn/assessment-and-evaluation
- Gallarde-Kim, S., et al. (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
- Martin, A.J., et al. (2015). Oregon's children and youth with special health care needs: Title V Maternal and Child Health Block Grant five-year needs assessment findings
- Oregon Secretary of State (n.d). Durable medical equipment, prosthetic orthotics and supplies (DMEPOS): Definitions.
- Regional listening sessions conducted in 2014 with professionals who serve Oregon CYSHCN and their families.

6 A public health nurse reported they struggled to get their client incontinent supplies despite having access to public health insurance. The public health nurse explained:

> *"The child has issues with incontinence. They don't qualify for diapers, even if the child has [Oregon Health Plan]. She uses a walker and has [cerebral palsy] They don't qualify for [Developmental Disability] services and don't qualify for any services really, even respite care. And they can't get diapers. This child has qualifying conditions, so how can [Oregon Health Plan and Developmental Disabilities] say no with these issues?"*

OREGON CENTER FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

Oregon's Children & Youth with Special Health Care Needs

An Overview

2022

Special health care needs can affect any child. Nationally, children and youth with special health care needs (CYSHCN) do not enjoy the same levels of health care, education, family health, and healthy lifestyles as other children.[1] Caring for CYSHCN affects families, schools, communities, and Oregon as a whole. This overview describes some of the challenges faced by Oregon CYSHCN and their families.

Health care costs impact families of CYSHCN

CYSHCN require more health care services than other children. Their families spend more than others on medical bills, and related expenses like transportation to appointments and child care.[2] These additional costs can result in financial hardship for families.

Even though most Oregon CYSHCN have health insurance, families of CYSHCN are twice as likely as others to have problems paying their child's medical bills.[3] Twenty percent of Oregon families with CYSHCN reported that they stopped working or cut down on work hours because of their child's health conditions, compared with four percent of other families.[4] A 2021 national study estimated that the average lost earnings from forgone family employment due to a child's special health care needs was about $18,000 per year.[5]

Health care for CYSHCN can be hard to access in less populous parts of Oregon

Families living in rural and frontier areas cannot always get the care their CYSHCN need close to home. These areas experience more shortages of primary care, dental, and mental health providers.[6] Most medical specialists in Oregon are located in cities or large towns People in rural and frontier areas are one and a half times more likely to have unmet health care needs than those in urban areas.[6] In focus groups with families of Latino CYSHCN in Central Oregon, family members often described needing to travel to Portland to get quality care.[7]

One in five Oregon children under age 18 has a special health care need.

Children and youth with special health care needs (CYSHCN) either have chronic health conditions, or they are at risk for having them. The conditions can be physical, developmental, behavioral, or emotional. CYSHCN need more health and related services than other children.[13]

Many conditions qualify as special health needs. Examples include asthma, autism, cerebral palsy, deafness, depression, diabetes, intellectual and developmental disability, muscular dystrophy, obsessive-compulsive disorder, and sickle cell disease.

Youth with special health care needs need support for the transition to adult health care

Good health and health care are important foundations for moving into successful adulthood.[8] A structured process for transitioning youth with special health care needs (YSHCN) from pediatric to adult health care can help prevent negative outcomes like gaps in care, dissatisfaction with care, and preventable hospital visits.[9] About 73% of Oregon YSHCN (age 12 through 17) did not receive the services they needed to help them transition from pediatric to adult health care.[4] In interviews with Oregon families of young adults with medical complexity, most family members reported inadequate or absent guidance for health care transition.[10]

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

OHSU

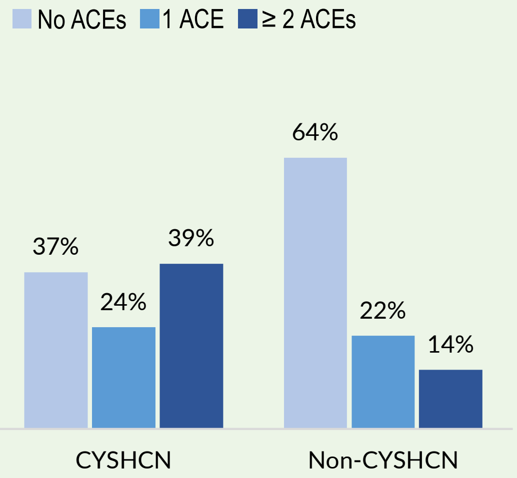
CYSHCN of color do not receive culturally responsive care

Services for CYSHCN must be sensitive to differences in culture, language, and literacy to be equitable. In focus groups with Oregon families of Black and Latino CYSHCN, families reported experiencing racism in health care settings.[11] They reported being subject to racist, stereotypical comments and behavior. They also reported that health care systems failed to provide quality interpretation services, racially concordant providers, and/or providers with knowledge about health conditions affecting their racial communities.[11] Findings from the focus groups show that Oregon CYSHCN of color have unequal access to health care, and that Oregon's health care systems fail to provide families of Black and Latino CYSHCN with culturally responsive and family-centered care.[11]

CYSHCN continue to need coordinated care

Many CYSHCN require a variety of professionals to meet their health care and service needs. Sixty-four percent of CYSHCN in Oregon have two or more chronic health conditions.[4] These CYSHCN are likely to have a number of professionals involved in their care. Integrating care and services is difficult when there are various programs, schools, agencies, and health care providers involved in a child's life. Only 36% of families of CYSHCN in Oregon reported that their child got effective care coordination when they needed it.[4] Parents of CYSHCN were three times as likely as other parents to report needing help with care coordination.[4] About one-third of families of children with developmental disabilities reported that health and service providers did not collaborate effectively for their child.[12]

Percent of Oregon Children by Number of Adverse Childhood Experiences (ACEs)



Oregon CYSHCN are nearly three times more likely to have two or more Adverse Childhood Experiences (ACEs) than non-CYSHCN.[4] ACEs (including violence, substance abuse, divorce, and deprivation) increase risk for health and social challenges.

---

[1] Abdi F.M., Seok D., Murphey D. (2020). *Children with special health care needs face challenges accessing information, support and services.* Child Trends. https://www.childtrends.org/wp-content/uploads/2020/02/CYSHCN-Brief_ChildTrends_February2020.pdf

[2] Catalyst Center. (2017). *Breaking the link between special health care needs and financial hardship: Second edition.* Center for Innovation in Social Work & Health. https://ciswh.org/wp-content/uploads/2017/05/Catalyst_Center_Breaking_The_Link-2nd-ed.pdf

[3] OCCYSHN analysis of NSCH 2016 - 2017 data using multivariate logistic regression.

[4] Child and Adolescent Health Measurement Initiative [CAHMI]. (2020). *2019 - 2020 National Survey of Children's Health (NSCH) data query*. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). www.childhealthdata.org

[5] Foster, C. C., Chorniy, A., Kwon, S., Kan, K., Heard-Garris, N., & Davis, M. M. (2021). Children with special health care needs and forgone family employment. *Pediatrics, 148*(3). https://doi.org/10.1542/peds.2020-035378

[6] Oregon Office of Rural Health (OORH). (2019). *Oregon areas of unmet health care need report.* Rural Health Information Hub. https://www.ruralhealthinfo.org/states/oregon/resources

[7] 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. https://www.ohsu.edu/occyshn/assessment-and-evaluation

[8] Park, M. J., Adams, S. H., & Irwin, C. E., Jr. (2011). Health care services and the transition to young adulthood: challenges and opportunities. *Academic Pediatrics, 11* (2), 115-122. https://doi.org/10.1016/j.acap.2010.11.010

[9] Schmidt, A., Ilango, S.M., McManus, M.A., Rogers, K.K., & White, P.H. (2020). Outcomes of pediatric to adult health care transition interventions: An updated systematic review. *Journal of Pediatric Nursing, 51,* 92-107. https://doi.org/10.1016/j.pedn.2020.01.002

[10] Roy, S., Valdez, M.D., A., Trejo, B., Bakewell, T., Gallarde-Kim, S., & Martin, J., A. (2021). "All circuits ended": Family experiences of transitioning from pediatric to adult healthcare for young adults with medical complexity in Oregon. *Journal of Pediatric Nursing, 1-6.* https://doi.org/10.1016/j.pedn.2021.06.008

[11] Oregon Center for Children and Youth with Special Health Needs. (2020). *Racism in Oregon's health care system: Experiences of families of Black and immigrant Latino children and youth with special health needs.* Oregon Health & Science University. https://www.ohsu.edu/occyshn/assessment-and-evaluation.

[12] National Core Indicators. (2018*). Child Family Survey 2016-17 Final Report.* https://www.nationalcoreindicators.org/upload/core-indicators/CFS_2016-17_final_for_compliance.pdf

[13] McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., Perrin, J. M., Shonkoff, J. P., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics, 102*(1 Pt 1), 137–140. https://doi.org/10.1542/peds.102.1.137

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.

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

OHSU

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.

---

[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.

Oregon Center for Children and Youth with Special Health Needs
occyshn@ohsu.edu www.occyshn.org

Sickle Cell Anemia Foundation of Oregon
info@sicklecelloregon.org www.sicklecelloregon.org

Latino Community Association of Central Oregon
info@latinocommunityassociation.org www.latinocommunityassociation.org

OREGON CENTER FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

Supporting Economic Stability for Families of Children with Special Health Care Needs

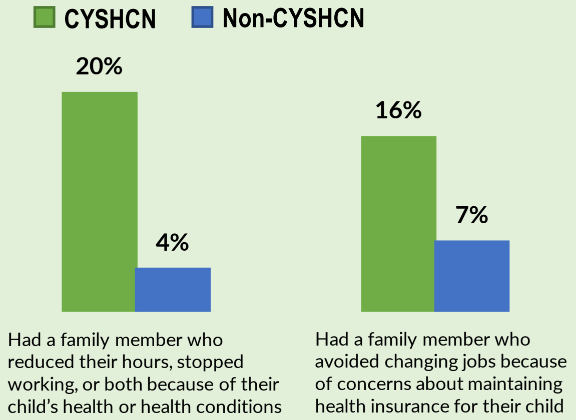
2022

Children and youth with special health care needs (CYSHCN) require more health care services than other children. As a result, their families spend more than others on medical bills and related expenses like child care, transportation to appointments,[1] or housing that can accommodate their child's needs.

These additional costs can result in financial difficulties. In 2019-2020, 22% of CYSHCN lived in families with annual incomes below 100% of the federal poverty level, as compared to 18% of non-CYSHCN.[2] Families of CYSHCN are twice as likely as other families to have problems paying their child's medical bills.[3,4]

In addition, family members of CYSHCN, including those in Oregon, face potential impacts on their employment. Some have to miss work, or even forgo employment altogether to care for their children (see Figure 1). One parent of a medically complex youth (Parent A) reported that for years their spouse could not work because they had to care for their young adult. Currently, their spouse can only work half time from home, which significantly reduces their family's income in the short-term. Additionally, this parent explained that their spouse's social security income will be negatively affected by years of lost wages, thus reducing their long-term retirement income.

Figure 1. Oregon families of CYSHCN experience greater financial challenges than families without CYSHCN



Data source: *National Survey of Children's Health 2019-2020*

The expenses associated with having CYSHCN with very complicated health conditions affect every aspect of family life. Three parents described their families' experiences for this brief, to contextualize quantitative survey results. Decisions about families' geographic locations, homes, vehicles, and jobs were governed by their children's complex needs. These decisions had significant financial ramifications. For example, one family reported spending all their savings on a vehicle that could accommodate a wheelchair.

A recent study estimated the average lost earnings from forgone family employment due to a child's special health care needs at approximately $18,000 per year.[5] In addition to reduced household income, missing work or forgoing employment results in missed professional opportunities.[2,6] For example, a second parent of a medically complex youth (Parent B) said *"I had to let go of my dream job because insurance at the new job was not adequate for [my child]'s health care needs."* Both Parents A and B reported that they can only take jobs that provide health insurance for their children. Although even with insurance, health care costs affect their family finances.

Parent B reported that their child has private insurance and Medicaid, but the family still pays $400 each month in co-pays for specialty medications. Parents A and B both reported finding workarounds to secure necessities for their child that insurance does not cover. For example, Parent B reported using thrift stores to buy lower-cost adult-sized diapers for their growing youth. They asked thrift store staff to contact them when the correct size is donated by the Veterans' Administration or local nursing homes.

OCCYSHN
Oregon Center for Children and Youth with Special Health Needs

OHSU

Care Coordination and Financial Well-Being

Receipt of effective care coordination is a standard of care for CYSHCN; that is, all CYSHCN should “*have access to patient- and-family-centered care coordination that integrates physical, oral, mental health and community-based services*.”[7] Coordinating care for their children is one of many caregiving responsibilities that families of CYSHCN have. When care is not coordinated by professionals, family members must do their best to ensure that their child’s multiple care and service providers have accurate and timely information, and that the providers’ decisions align. Only 35% of families of CYSHCN in Oregon reported that they got effective care coordination when they needed it.[1,8]

Parents A, B, and C all reported that they didn’t get help coordinating their child’s care. They coordinate care on their own, while juggling work and caring for their family. Parent B described coordinating eight providers to get their child’s bloodwork done. Parent A described needing to contact their child’s pediatrician and all their specialists to coordinate lab work every time the child’s feeding tube is changed.

> *“My daughter has seven different health care providers. I pretty much coordinate them all. Caring for my daughter, and organizing her care, is a full-time job. I spend about 30 - 40 hours a week on it. In reality I couldn’t work.”*
>
> – Parent C

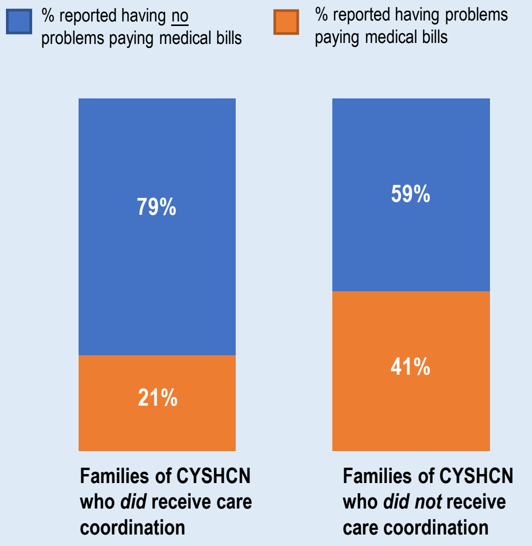
Serving as a care coordinator takes significant time and has financial implications, like lost income. Parents A and B said that access to professional care coordinators for their CYSHCN would free up their time to focus on family and work.

Parents of CYSHCN who received care coordination reported missing less work than parents who did not.[9] Additionally, our analysis of National Survey of Children’s Health data showed that families of CYSHCN who received needed care coordination were significantly less likely to report problems paying their child’s medical bills, compared to those who did not (Figure 2).[3,10]

> *“Whenever my child needs a feeding tube change, I have to contact my child’s pediatrician and every single specialist to ask who needs labs. They message me back about what labs to get. It is time-consuming. Why isn’t there someone who automatically says ‘This child needs lab work done.’? All of these things take time away from my kids, family members, and work.”* – Parent A

In 2020, Oregon’s Governor directed Oregon’s Coordinated Care Organizations, which administer Medicaid to more than one-third of Oregon CYSHCN,[3] to include a focus on social determinants of health and health equity.[11,12] A major emphasis of this work is on economic stability and financial well-being, which is associated with improved overall health.[13,14] Care coordination may be an effective strategy for addressing the disparate health care cost burden faced by the families of Oregon’s estimated 179,228 CYSHCN.[2]

Figure 2. Nationwide, families of CYSHCN who did not receive care coordination were more likely to report problems paying their child’s medical bills than families who received care coordination



Data source: OCCYSHN analysis of National Survey of Children’s Health 2016-2017 data

Citations

[1] Catalyst Center. (2017). Breaking the link between special health care needs and financial hardship: Second edition. Retrieved from https://ciswh.org/wp-content/uploads/2017/05/Catalyst_Center_Breaking_The_Link-2nd-ed.pdf.

[2] Child and Adolescent Health Measurement Initiative. (2022). *2019 - 2020 National Survey of Children's Health (NSCH) data query*. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved from www.childhealthdata.org.

[3] Child and Adolescent Health Measurement Initiative. (2021). *2016 - 2017 National Survey of Children's Health (NSCH) data quer*y. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved from www.childhealthdata.org.

[4] OCCYSHN analysis of NSCH 2016 - 2017 data using multivariate logistic regression.

[5] Foster, C. C., Chorniy, A., Kwon, S., Kan, K., Heard-Garris, N., & Davis, M. M. (2021). Children with special health care needs and forgone family employment. *Pediatrics*, *148*(3).

[6] Ghandour, R.M., Hirai, A.S., Blumberg, S.J., Strickland, B.B., Kogan, M.D. (2014). Financial and nonfinancial burden among families of CSHCN: Changes between 2001 and 2009-2010. *Academic Pediatrics*, *14*(1), 92-100.

[7] Association for Maternal and Child Health Programs [AMCHP] and National Academy for State Health Policy [NASHP]. (2017). *Standards for systems of care for children and youth with special health care needs version 2.0*. Retrieved from https://amchp.org/resources/standards-for-systems-of-care-for-children-and-youth-with-special-health-care-needs-version-2-0/

[8] In the National Survey of Children's Health, the Child and Adolescent Health Measurement Initiative (2021) defines effective care coordination as satisfaction with communication between doctors when needed, satisfaction with communication between doctors and schools when needed, and getting needed help coordinating care.

[9] Palfrey, J.S. et al. (2004). The pediatric alliance for coordinated care: Evaluation of a medical home model. *Pediatrics, 113*(5), 1507 - 1516.

[10] National findings are included in the brief because Oregon data on CYSHCN is limited in sample size and meaningful findings on financial hardship cannot be obtained.

[11] Oregon Health Authority. (2020). *CCO 2.0: The future of coordinated care.* Retrieved from https://www.oregon.gov/oha/OHPB/Pages/CCO-2-0.aspx.

[12] CCOs focus on prevention and helping people manage chronic conditions. Managing chronic conditions entails coordinating care for patients.

[13] Centers for Disease Control and Prevention (CDC). (2020). *About social determinants of health (SDOH).* Retrieved from: https://www.cdc.gov/socialdeterminants/about.html.

[14] Marmot, M. (2002). The influence of income on health: Views of an epidemiologist. *Health Affairs*, *21*(2), 31 - 46.

OREGON CENTER FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

Unmet Expectations

Swahili-speaking immigrants and refugees discuss getting care for their children with special health care needs

2021

Introduction

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) and the Sickle Cell Anemia Foundation of Oregon (SCAFO) collaborated in 2020 to collect data about the needs and experiences of families with Black children and youth with special health care needs (CYSHCN). The aims of this study were to learn about Black CYSHCN's health and support needs, and their family experiences with: access to care and services; cultural and linguistic responsiveness of the care and services; and youth transition from pediatric to adult health care.

After collecting data from English-speaking families of Black CYSHCN across the state, SCAFO partnered with the African Family Holistic Health Organization (AFHHO) to conduct an additional facilitated discussion with Swahili-speaking families of Black CYSHCN (hereafter referred to simply as "families" or "family members"). AFHHO serves the African immigrant and refugee community in the Portland, Oregon metropolitan area.

Methods

In March 2020 (before the COVID 19 pandemic), AFHHO conducted a discussion with ten Swahili-speaking family members of Black CYSHCN. The discussion was held at the AFHHO office in Portland, Oregon. It was facilitated by AFHHO's native Swahili-speaking Community Health Specialist. Families were asked questions about their CYSHCN's needs, accessing care for their CYSHCN, and the cultural and linguistic responsiveness of that care. AFHHO staff translated the transcript into English, and OCCYSHN's research staff analyzed it.

Findings

OCCYSHN's research staff used a thematic approach to analyzing the discussion's transcript. The following six overarching themes were identified from the experiences of immigrant and refugee Swahili-speaking family members of Black CYSHCN.

1. *Language barriers*

Family members described frequently experiencing language barriers with their children's care providers. For example, when they requested interpretation services, they said it was not uncommon to get an interpreter who was fluent in an African language other than Swahili. Families also described interpreters not interpreting what they were saying to the provider correctly, resulting in confusion. One parent said:

> *"…They usually ask what language we speak but yet they still send an interpreter that does not speak my language… The second thing is sometimes you get to your appointment and the interpreter is not there, then they request a virtual interpreter who is far away…"*

Some family members described receiving mail and phone calls in English from providers' offices. They said it was important to use interpreters when calling families. They also said it was important to have the same interpreter at every visit. Family members emphasized that language matters more than the race of the provider when it comes to getting good care for their CYSHCN.

2. *Unmet health care expectations*

Families had expectations about their child getting medical tests and prescription medications that were not realized. Family members perceived that their child's care providers did not adequately test or treat their children's illnesses. They reported that their children were not prescribed medication, even when they were ill.

OCCYSHN
Oregon Center for Children and Youth with Special Health Needs

OHSU

Unmet health care expectations (continued)

> *"... As for us refugees, we are used to, when you are sick, you go to the hospital, get tested and get medications. But here, they will just look at the baby and say, 'the baby is fine.' How will I know if my baby is fine? I am not a doctor. How would you know if your child is sick or not? If I go back home with a sick child, will he be fine without any medication?"*

Some family members reported that it was easier for them to get health care at refugee camps than it is in the United States. Health care was provided at no cost in the refugee camps. One family member said that medications that were free in the refugee camps are expensive here. Another family member reported that refugee health insurance benefits ended after one year. They were still adjusting to life in the U.S., and expected those benefits to last longer.

3. Challenges getting to health care providers

Family members described difficulty getting to hospitals or clinics for their children's care. One family member reported they live far from their child's clinic, and taking public transportation there is time-consuming and expensive. A couple parents described seeking care for their child at a hospital or clinic, only to be redirected to the emergency department. One parent said this was not what they wanted, because getting care at the emergency department is difficult.

4. Financial hardship

Family members reported problems affording basic needs like clothing, housing, rent, and utilities. A couple parents described the difficulty of juggling the employment required to pay bills with the time they need to care for their CYSHCN.

> *"[Housing] is so hard to get; it took me six years to get into affordable housing. I used to pay $1400 in rent by myself as a single parent with sick kids, and I am also sick. I did that for six years. It was so hard."*

5. Parental separation

Family members described the challenges of single parenting CYSHCN. Some parents were separated from their spouses upon establishing refugee status in Oregon. One said she needed help to bring her child's other parent to the US to help care for the child. Family members described difficulty meeting CYSHCN's needs without the support of a spouse.

6. Parent health care experience

Family members shared negative experiences with their own health care. They especially focused on inadequate interpretation services. One parent recalled that when she specifically requested a female interpreter for an appointment focused on women's health issues, the clinic provided a male interpreter.

Conclusion

African immigrants and refugees in Oregon face significant challenges, such as finding employment and affordable housing, having limited English proficiency, and securing health insurance.[1,2] A lack of understanding about the complexities of the U.S. health care system can exacerbate these challenges.

Family members in this discussion expected to have an easier time getting care for their CYSHCN in the U.S. Their experiences also highlight the need for culturally responsive care among *all* immigrant and refugee families of CYSHCN. Better interpretation services are clearly required. Their experiences suggest that Swahili-speaking immigrants and refugee families of CYSHCN need better support navigating health care systems, such as when to make an urgent office care appointment versus going to the emergency department. Family Navigators or Community Health Workers who speak the same language can coach families on navigating the exceedingly complex U.S. health care system.

---

[1] Curry-Stevens, A. & Coalition of Communities of Color (2013). *The African immigrant and refugee community in Multnomah county: An unsettling profile*. Portland, OR: Portland State University. Retrieved from https://www.portlandoregon.gov/oehr/article/713236.

[2] Bikele, F. (2017). *African migrants in Oregon: Healthcare preferences and the importance of worldviews.* [Master's thesis, University of Oregon]. University of Oregon Scholars' Bank. Retrieved from https://scholarsbank.uoregon.edu/xmlui/bitstream/handle/1794/22779/Bikele_oregon_0171N_11776.pdf?sequence=1&isAllowed=y.

Our sincere thanks to the families who participated in this facilitated discussion. We are grateful for their candor, emotion, time, and information.

- **Oregon Center for Children and Youth with Special Health Needs**
  occyshn@ohsu.edu www.occyshn.org
- **African Family Holistic Health Organization**
  info@afhho.org www.afhho.org
- **Sickle Cell Anemia Foundation of Oregon**
  info@sicklecelloregon.org www.sicklecelloregon.org