

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

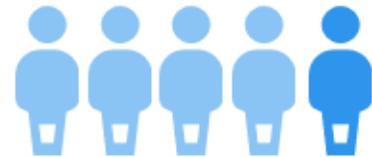
Widespread workforce shortages limit access to appropriate M/BH care for Oregon CYSHCN. The demand for M/BH care exceeds the state's supply of qualified providers.⁸ A dearth of providers can lead to detrimental wait times for appointments, and/or costly travel for care. In OCCYSHN's 2020 needs assessment, 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 (CYSHCN) 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.

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.

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- 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.