

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

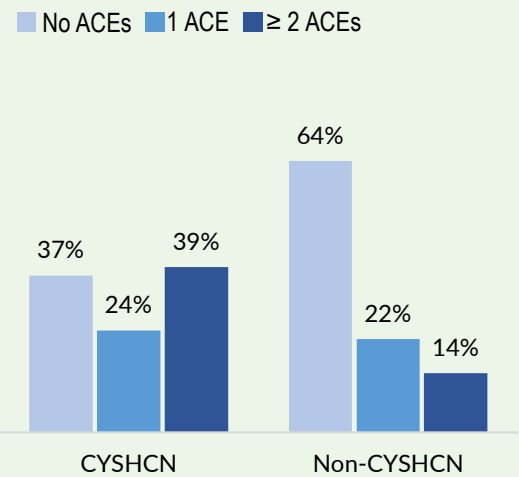
CYSHCN of color do not receive culturally responsive care

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>