

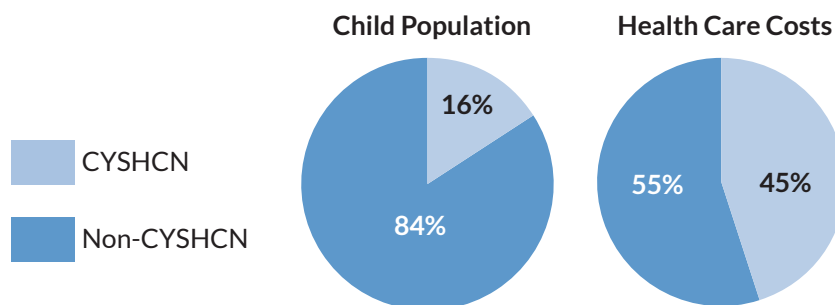
Oregon's Children and Youth with Special Health Care Needs: An Overview



February 2016

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.² Caring for CYSHCN affects families, schools, communities, and Oregon as a whole. This overview describes some challenges faced by Oregon CYSHCN and their families.

Caring for CYSHCN is expensive. Nationally, CYSHCN make up 16.2% of the child population, yet they account for 45% of the total health care costs for children (excluding dental care, long term care, education services, and institutional care costs).



Newacheck, P.W., & Kim, S.E. (2005). A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatric and Adolescent Medicine*, 159, 10-17.

Nearly one in five Oregon children has a special health care need.¹

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.

There are many conditions that might qualify as a special health need. A few examples are asthma, autism, deafness, cerebral palsy, depression, diabetes, and muscular dystrophy.

Even though most Oregon CYSHCN have health insurance, 21% of their families reported having problems paying for their child's medical bills.¹ Their out-of-pocket expenses averaged twice those of other families.²

Healthcare can be hard to access. Most medical specialists in Oregon are located in cities or large towns. Families living outside those areas can not always get the care their CYSHCN need close to home. Public health nurses reported to OCCYSHN that dental care, mental health services, primary care, and specialty care are harder to access for CYSHCN in rural Oregon communities. Families who are able to travel to distant specialty care providers face additional expenses such

as transportation, lodging, and child care for their other children.

Youth with special health care needs need support to transition to adult health care. While over 90% of American CYSHCN live to adulthood, they are less likely than non-CYSHCN to finish high school, attend college, or be employed.³ Health and health care are two of the key challenges to moving into a successful adulthood.⁵

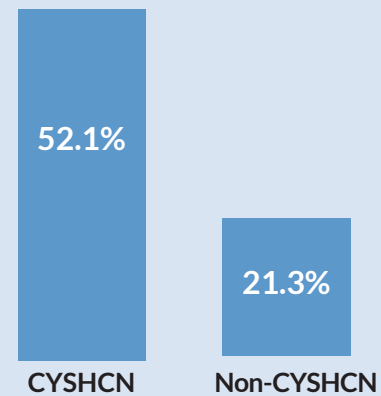
There are standards for transition services in medical practices. Those standards include helping patients make a plan for getting appropriate adult health care, and tracking progress on that plan.⁶ 65% of youth with special health care needs did not receive the services necessary to transition to adult healthcare in 2009/10.³

CYSHCN come from diverse families and cultures. Thirty-two percent of Oregon CYSHCN are identified by their families as being non-Caucasian.⁷ To be effective for everyone, services for CYSHCN must be sensitive to differences in culture, language, and literacy. Even English speakers sometimes have trouble understanding health care and insurance terminology.

CYSHCN need their care coordinated. Most CYSHCN require a variety of professionals to address their care and services. Forty-nine percent of CYSHCN in Oregon have two or more chronic health conditions,¹ which increases the number of people involved in their care. Getting the right information into the right hands at the right time is not easy when there are different programs, schools, agencies, and health care providers involved.

Families of CYSHCN don't always have the tools they need to coordinate their children's care. Parents of Oregon CYSHCN were three times as likely as other parents to report that they could have used extra help coordinating their child's care.¹

Percentage of Oregon Children with Two or More Adverse Childhood Experiences (ACEs)



Oregon CYSHCN are twice as likely to have two or more Adverse Childhood Experiences (ACEs) than non-CYSHCN.¹ ACEs (including violence, substance abuse, divorce, and deprivation) increase the risk for additional health and social challenges.⁸

The full report of the 2015 Needs Assessment findings from the Oregon Center for Children and Youth with Special Health Needs is available online at www.occyshn.org/publications. This publication is available in alternate formats.

¹ National Survey of Children's Health. (2011-2012). Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12-20-2015 from www.childhealthdata.org.

² Newacheck, P.W., & Kim, S.E. (2005). A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatric and Adolescent Medicine*, 159, 10-17

³ U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2013). *The National Survey of Children with Special Health Care Needs Chartbook 2009-2010*. Rockville, MD: Author.

⁴ U.S. Department of Health & Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (2015) "Title V maternal and child health services block grant to state program. Guidance and forms for the Title V application/annual report. Rockville, MD: Author.

⁵ 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.

⁶ VanLandeghem, K., Sloyer, P., Gabor, V., & Helms, V. (2014). *Standards for systems of care for children and youth with special health care needs*. A product of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs project. Washington, DC: Association of Maternal & Child Health Programs

⁷ National Survey of Children's Health. (2009-2010). Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12-20-2015 from www.childhealthdata.org.

⁸ Felitti, V. J., & Anda, R. F. (2009). The Relationship of Adverse Childhood Experiences to Adult Medical Disease, Psychiatric Disorders, and Sexual Behavior: Implications for Healthcare. In R. Lanius, E. Vermetten, & C. Pain (Eds.), *The Hidden Epidemic: The Impact of Early Life Trauma on Health and Disease* (pp. 77-87). Cambridge University Press.