

Access to Care for Oregon's Children and Youth with Special Health Needs

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Children and youth with special health care needs (CYSHCN) require more and different services and supports than other children. Getting these services and supports can be challenging. Nearly one third of Oregon families report that their CYSHCN have unmet service or equipment needs.¹

Insurance. Most Oregon CYSHCN have health insurance.² However, health and service providers across the state reported to OCCYSHN that insurance does not always cover the services CYSHCN need. They reported that private insurance plans don't provide adequate coverage for mental health services for CYSHCN, and that it does not cover the cost of transportation.

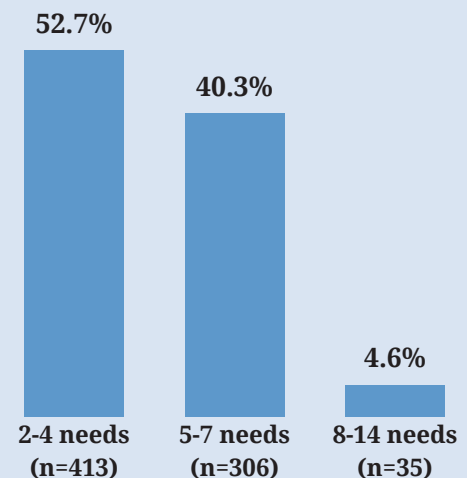
For people insured by Medicaid, the Oregon Health Plan (OHP) is implemented by Coordinated Care Organizations (CCOs). Providers reported to OCCYSHN that coverage varies by CCO. Examples they cited of services and supports which may or may not be covered included: mobility aids (like wheelchairs), genetic testing, and mental health care.

Health and service providers also reported that OHP does not always cover the cost of care received across state lines, which is sometimes the closest care available for families living near Oregon's borders. While health care providers could consult with families remotely using phone or video technology, insurance will not reimburse them for that time, which makes them less likely to use those resources to serve rural CYSHCN.

Another challenge reported is that some health care providers don't accept OHP. Since there are already relatively few doctors and dentists practicing in rural and semi-rural Oregon, the fact that some of them don't accept OHP can result in a months-long wait for an appointment.



Percent of Families of Oregon CYSHCN with Numbers of Specific Health Care Service or Equipment Needs in the Past Twelve Months



Data source: National Survey of Children with Special Health Needs, 2009/2010. The survey asked about the following needs: preventive medical, specialty care, preventive dental, other dental, prescription medications, physical/occupational/speech therapy, mental health, substance abuse treatment or counseling, home health care, eyeglasses/vision care, hearing aids/hearing care, mobility aids/devices, communication aids/devices, and durable medical equipment.

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Information & Communication. Some families have trouble getting their CYSHCN's needs met because they aren't sure what care is needed, or where to look for services in their area. There are sometimes language, literacy, or cultural barriers to getting care for CYSHCN. Also, qualifying for services can be difficult for children with health conditions that don't fit neatly into one system of services (like mental illness and developmental disabilities).

Geography & Transportation. Oregon is a large state (nearly 100,000 square miles). The specialized care and services CYSHCN need are easier to find in the cities and large towns of the Willamette Valley than in the rest of the state. Families living in rural Oregon might have to travel some distance to get care, which takes time and money. OHP offers help with transportation costs in some cases, but families and providers report that the service can be unreliable and hard to arrange. Transportation costs are not typically covered for children with private insurance.

Twenty percent of families of Oregon CYSHCN report that paying for transportation to get their child to health care providers is "always" or "usually" hard. In addition to gas costs, they may face lodging costs, and childcare costs for siblings. Rural health care providers report that families who live far from specialty care and services sometimes end up relying on the emergency room for their children's care.

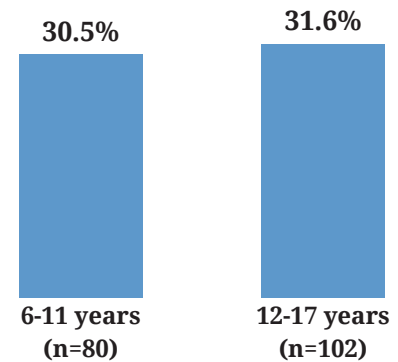
Mental/Behavioral Health. Nationally, the most commonly reported unmet need for CYSHCN is mental health care or counseling.³ A 2009 study found that 38% of families of CYSHCN enrolled in Medicaid had a child with a mental health problem in need of treatment.⁴ Of CYSHCN who needed mental health care in Oregon at that time, 7.5% did not get the care they needed.¹

A quarter of the families responding to OCCYSHN's 2015 Needs Assessment survey said that mental or behavioral health services were one of the top three services they had difficulty getting for their child. There are various reasons this care might be hard to get. Sometimes insurance did not cover the services. Sometimes insurance coverage is limited to just a few sessions, when more are needed. Additionally, health care providers and care coordinators reported that many areas of the state don't have enough mental health providers to meet the demand.

Care and services that families of CYSHCN report are hard to get:

- Allied health care (physical therapy, occupational therapy, speech/language therapy)
- Behavioral and mental health services (including autism-specific therapies)
- Health supports (e.g., durable medical equipment, mobility aids, home health care, palliative care)
- Respite care
- Specialty dental care
- Specialty medical care

Percent of Oregon CYSHCN (age 6-17 years) needing mental health care in the past twelve months.



Data source: National Survey of Children with Special Health Needs, 2009/2010

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.

¹National Survey of Children with Special Health Care Needs. (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.

²National Survey of Children's Health, NSCH 2011/2012. Data query from the Child and Adolescent Health Measurement Initiative. Data retrieved 12/23/2015 from www.childhealth.org

³U.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.

⁴Agency for Healthcare Research and Quality. (2009). Mental health needs of low-income children with special health care needs. Issue brief no. 9. Retrieved on December 16, 2014, from <http://www.ahrq.gov/cpi/initiatives/chiri/Briefs/brief9/brief9.pdf>.