

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) is Oregon's public health agency for children and youth special health needs (CYSHCN). OCCYSHN partners with families, health and service providers, and policy-makers across the state to improve health systems to meet the needs of this large and vulnerable population.

CYSHCN need more care and services than other children. Their chronic conditions might be physical, developmental, behavioral, or emotional. CYSHCN make up 16.2% of the U.S. child population, and account for 45% of the total health care costs for children.<sup>1</sup> Serving these children better can lead to more efficient and effective health systems for everyone.

OCCYSHN is housed at Oregon's only academic medical center, Oregon Health & Science University. This setting lends the benefits of research, education, and clinical expertise to OCCYSHN's public health work.



One in five Oregon children has a special health need.

## Transforming Systems of Care for Children with Special Health Needs

### Assessment and Evaluation

OCCYSHN monitors the needs and status of Oregon CYSHCN with population-based assessment and surveillance. Data is used to identify needs, and analysis is shared widely to guide informed policy and program decisions.

### Family Involvement

Serving CYSHCN effectively depends on including their family members at every level of systems improvement. OCCYSHN partners with families to identify problems and to implement practical solutions.

### Systems and Workforce Development

OCCYSHN provides resources and technical assistance to partners across Oregon, helping them leverage local resources and build better systems of care for CYSHCN in their communities.

<sup>1</sup> 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.

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# Challenges for Oregon CYSHCN

Data sources available in the full report of OCCYSHN's 2015 Needs Assessment: [www.occyshn.org/publications](http://www.occyshn.org/publications).

## Medical Home

- A quarter of Oregon's CYSHCN live in rural or frontier areas, often far from specialty care and services.
- More than half of Oregon CYSHCN did not receive coordinated, ongoing comprehensive care within a medical home.
- Two thirds of parents said their CYSHCN had no care plan in place. Of those that did, half said the care plan was not shared with all the child's providers.

## Transition to Adult Health Care

- Two thirds of Oregon's youth with special health needs did not get necessary services to transition to adult health care.
- Only 12% of youth surveyed by OCCYSHN reported that their doctor talked to them about finding an adult-focused health care provider when they turned 18.

## Culturally and Linguistically Appropriate Services

- 6% of Oregon's population speaks English "less than very well."
- In more than 15% of Oregon households, English is not the primary language spoken in the home.
- One in five parents reported their child's health care providers were not always sensitive to their family values and customs.

## Solutions for Oregon CYSHCN

### CACOON (CAre COordination) Nurses

OCCYSHN supports home-visiting public health nurses in most Oregon counties. These nurses are care coordination experts who inform and empower families to manage complex care and services for their CYSHCN.

### Family Involvement Program

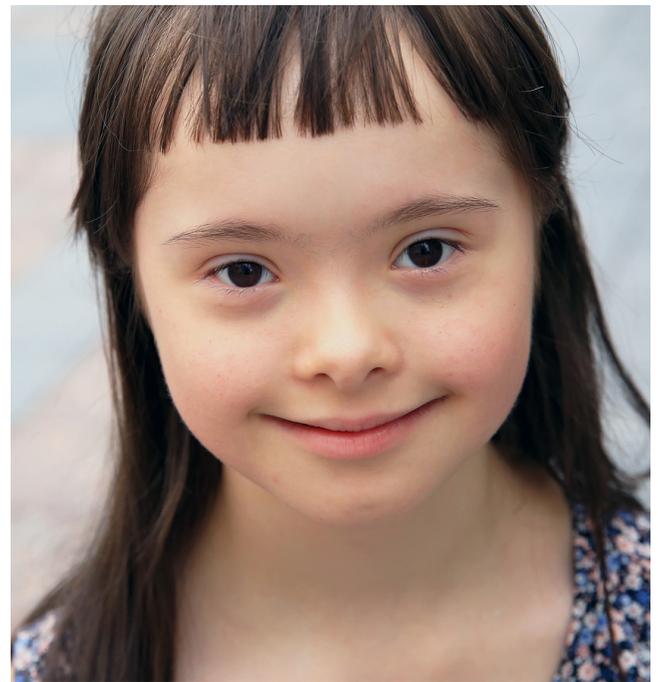
Family members of CYSHCN work with OCCYSHN as staff and advisors. A statewide network of parents is trained and coordinated to provide support, information, and resources to other parents of CYSHCN, and to advocate for CYSHCN in their communities.

### Shared Care Planning

OCCYSHN contracts with public health departments across Oregon, and supports them to develop shared care plans for CYSHCN. The plans are formed by convening local teams that include families and providers of health care, education, mental health, insurance, and community services. Cross-system connections are strengthened while individual families are served.

### Innovation

OCCYSHN develops and supports innovative projects that strengthen systems of care for CYSHCN. These projects foster cross-systems collaboration, workforce development, and family-informed care.



[more information](#)

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