

## OCCYSHN HEADER

### Highlights of Fiscal Year 2012

<p>OCCYSHN promotes the optimal health and functioning of Oregon's children and youth with special health needs.</p>	<p><b>Who are children and youth with special health needs (CYSHN)?</b> CYSHN are young people (from birth to age 21) who require more attention to their health than most. They have chronic conditions or disabilities. This can mean more doctor visits, specialized treatments, prescriptions, or mental health services.</p>
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<b>What Does OCCYSHN Do?</b>
Collects and shares information and data about how Oregon CYSHN are faring and what their needs are.
Tracks legislation and policy that impacts CYSHN. Represents CYSHN in statewide health system and policy efforts.
Empowers families of CYSHN to have a voice in their care.
Trains healthcare providers and other professionals about how to meet the needs of CYSHN.
Funds and supports two community-based programs that serve Oregon CYSHN in their communities:  <p><b>CaCoon (CAre COOrdination) Program</b> In-home nursing assessment and care coordination for CYSHN - provided by specially trained public health nurses in every Oregon county.</p> <p><b>Community Connections Network (CCN) Program</b> Multidisciplinary teams in rural communities - bringing families together with health, education, and community service providers to address the unmet needs of CYSHN.</p>

OCCYSHN is funded by the federal Title V Block Grant from the Maternal and Child Health Bureau. Every state receives Title V funds, and 30% of the money is dedicated to serving children and youth with special health needs (CYSHN).

OCCYSHN's work is guided by six Title V performance measures. Those measures are listed below, along with some highlights of OCCYSHN activities in 2011/2012. The complete text of OCCYSHN's Block Grant Report can be found online at [www.occyshn.org](http://www.occyshn.org).

<b>PERFORMANCE MEASURE: Families of CYSHN partner in decision making at all levels, and are satisfied with the services they receive.</b>
<b>2011/2012 HIGHLIGHTS</b>
OCCYSHN hired, trained and supported nine Family Liaisons (FL's) to serve on Community Connections Network teams. FL's are people who have their own children with special health needs. They bring the family perspective to CCN care coordination efforts.
Family Liaisons participated in CCN meetings serving 91 kids, and supported the families of those children through the CCN process.
The Family-to-Family Health Information Center provided forums for families of CYSHN around the state to share information, resources and support. 260 families of CYSHN were served.
Held six "Family Listening Sessions" in communities around Oregon. OCCYSHN and families exchanged information about needs and resources, in both English and Spanish.
The Family-to-Family Health Information Center produced monthly newsletters (in English and Spanish) with information helpful to families of CYSHN.
Provided four webinars aimed at helping families of CYSHN meet the needs of their children.
OCCYSHN staff who are also family members of CYSHN participated on the Oregon Pediatric Improvement Project, the Assuring Better Child Development Project, and the Early Childhood Council.

**PERFORMANCE MEASURE: CYSHN receive coordinated, ongoing, comprehensive care within a medical home.**

**2011/2012 HIGHLIGHTS**

CaCoon and CCN programs provided care coordination for 1,952 children and youth, helping to ensure that they were linked to medical homes.

OCCYSHN's Medical Home Initiative helped set state standards for implementing and measuring medical home for Oregon's children.

Developed an extensive "toolbox" of resources for healthcare providers for OCCSYHN's Medical Home website.

Collaborated with the Oregon Pediatric Society and the Oregon Pediatric Improvement Project to promote implementation of medical home efforts across the state.

Designed and implemented regular "Coffee Time Consultations," web-based training and consultation for pediatricians with pediatric specialists.

Increased local capacity to serve CYSHN through training professionals in communities. 54 trainings were held, at no cost to trainees. 977 people around the state were trained on subjects that impact CYSHN.

**PERFORMANCE MEASURE: Families of CYSHN have adequate insurance to pay for the services they need.**

**2011/2012 HIGHLIGHTS**

Tracked healthcare reform and its impact on Oregon CYSHN.

Sponsored two free webinars about the Affordable Care Act and how it impacts CYSHN.

Administered Sidney and Lillian Zetosch Funds from the Oregon Community Foundation. The funds are used to purchase equipment which supports the education of CYSHN from low-income families. \$69,524 worth of educational equipment was purchased for 85 CYSHN.

CaCoon and CCN provided assessment and care coordination 1,952 Oregon CYSHN at no charge to families.

Advocated for licensing genetic counselors in Oregon, with the goal of improving insurance coverage for families who need genetic counseling.

**PERFORMANCE MEASURE: Families of CYSHN report that community-based service systems are organized so they can use them easily.**

**2011/2012 HIGHLIGHTS**

CaCoon public health nurses made 8,979 home visits to 1,836 families of CYSHN, helping those families care for their children and access local resources.

Worked with hospital Neonatal Intensive Care Units to link families going home with a baby at risk for health issues with a CaCoon nurse in their area.

72 CCN team meetings were held. Gaps in local systems of care were identified and addressed. Local professionals devoted 535 hours to CYSHN in those meetings.

Collaborated with state and local partners on redesigning the Home Visiting system in Oregon. Ensured CYSHN needs were addressed.

Developed regional brochures to direct families of children with Autism Spectrum Disorder to resources in their areas.

**PERFORMANCE MEASURE: Youth with special health needs receive the services necessary to transition to adult life (including adult health services, work, and independence).**

**2011/2012 HIGHLIGHTS**

Convened the Youth Health Forum, an event that brought together youth with special health needs, families, policymakers, and state agencies to identify and address transition needs.

Developed and distributed a report highlighting key issues and actions steps identified at the 2011 Oregon Youth Health Forum.

Sponsored youth interns who worked on transition issues through research and planning.

Served on a “transition” subcommittee of the Oregon Commission on Autism Spectrum Disorder, to address the unique needs of youth with ASD.

Hosted Dr. Carl Cooley to provide training and consultation on medical home and transition for CYSHN.

Developed a resource guide of Oregon supports and services for young people transitioning to adulthood.

Piloted “CaCoon for Youth” in three Oregon counties (Deschutes, Union, and Benton) to increase CaCoon services to transition-age youth and their families.

OCCYSHN also works on goals specifically aimed at the needs of Oregon families. The following 2011/2012 activities that addressed those state priorities:

<b>STATE PERFORMANCE MEASURE: Increase linkages to mental health services for Oregon CYSHN.</b>
<b>2011/2012 HIGHLIGHTS</b>
Sponsored a webinar for healthcare providers about how to help their patients access local mental health services.
Participated in the Oregon Addictions and Mental Health family leadership conference and committee.
Participated on the Oregon Mental Health Task Force.
Gathered information about access to mental health services for Oregon CYSHN (researching available data, interviewing mental health providers, asking families of CYSHN, etc.)

<b>STATE PERFORMANCE MEASURE: Increase access to specialized health-related services for underserved CYSHN.</b>
<b>2011/2012 HIGHLIGHTS</b>
Healthcare reform tracking helped identify gaps and resources for specialty care.
Partnered with the Oregon Commission on Autism Spectrum Disorder to promote state recommendations for screening for and diagnosing ASD.
Assessed insurance needs to cover genetic counseling. Promoted insurance coverage for genetic counseling.
Collaborated with OSHU's LEND program (Leadership in Education in Neurodevelopment and Other Disabilities) to provide community trainings on diagnosing and treating ADHD.

<b>STATE PERFORMANCE MEASURE: Increase access to family support services for families of CYSHN</b>
<b>2011/2012 HIGHLIGHTS</b>
Developed a statewide virtual network of families and organizations that support families of CYSHN.
Recruited and supported Family Liaisons to provide family-to-family support in communities around the state.
Partnered with other family organizations to provide support to rural Oregon families with CYSHN.