

OCCYSHN improves the health, development and well-being of all of Oregon's children and youth with special health care needs (CYSHCN). Our vision is that all of Oregon's CYSHCN are supported by a system of care that is family centered, community-based, coordinated, accessible, comprehensive, continuous and culturally competent.

FAMILY

The **Family Involvement Program** supports families and professionals to partner as equals in caring for CYSHCN. FIN hires, trains, and supervises family members of CYSHCN to provide peer support, and to serve on local child health teams. OCCYSHN includes family members of CYSHCN on the staff, and incorporates their perspective into the comprehensive effort to promote family-centered care.

The **Oregon Family to Family Health Information Center** provides peer support to families of CYSHCN across the state. Support is provided through telephone support, publications, family meetings, tip sheets and other printed information, and a website /Facebook page with current resources, news and information.

OCCYSHN administers an annual distribution of the **Sidney and Lillian Zetosch Fund** of the Oregon Community Foundation. Funds are used to purchase educational equipment for CYSHCN from low-income families.

COMMUNITY

OCCYSHN partners with communities around the state to increase local capacity to meet the needs of CYSHCN and improve local systems of care. **Community-based programs** provide care coordination for CYSHCN and increase family capacity to meet the needs of CYSHCN. These programs also help families and youth navigate the transition to adulthood.

The **CaCoon** program contracts with county public health departments throughout Oregon to support home-visiting public health nurses for families of CYSHCN. OCCYSHN provides ongoing training and mentoring to the nurses. The goals of CaCoon are to:

- Promote the development of effective care teams which center on the child/family.
- Increase family knowledge, skills, and confidence in caring for their children and youth with special health care needs (CYSHCN).
- Promote effective and efficient use of the healthcare system.
- Assure capacity of the workforce to support OCCYSHN's mission and vision.

The **Community Connections Network (CCN)** establishes and supports multidisciplinary child health teams in nine rural and semi-rural communities. The teams bring together family, healthcare, education, and community services to address unmet needs of referred CYSHCN. CCN improves local systems of care and fosters cross-agency collaboration.

The **ACCESS Project** (Assuring Comprehensive Care through Enhanced Service Systems) supports eight medical-education teams around the state. These community-based teams provide timely and valid evaluations to identify Autism Spectrum Disorder and other developmental delays in children under the age of five.

SYSTEMS & POLICY

OCCYSHN collaborates with health, education, and social service agencies on **committees and task forces** addressing the needs of CYSHCN.

OCCYSHN provides **subject matter expertise**, data, and the family perspective to policy-makers and administrators.

The **Enhancing Oregon's System of Care for CYSHCN (SOS for OR CYSHCN)** project is developing statewide, cross-systems collaborative to achieve a comprehensive, coordinated and integrated system of care for Oregon CYSHCN.

The **Public Health Genetics Specialist** promotes increased access to genetics health care and expertise for children with heritable conditions and their families.

The **Nutrition Consultant** links with key partners to provide training and resources to the developing OCCYSHN Pediatric Nutrition Network, and designs activities to address workforce development through the Nutrition Network.

OCCYSHN participates in statewide efforts to address CYSHCN **childcare and oral health** needs.

OCCYSHN partners with OHSU/IDD's Child Development and Rehabilitation Center to foster **interdisciplinary, family-centered clinical care** for CYSHCN.

ASSESSMENT & EVALUATION

OCCYSHN's **Assessment & Evaluation (A&E)** staff conducts surveillance, needs assessment, and program evaluation functions for OCCYSHN. A&E carries out ongoing population surveillance to assess the wellbeing of Oregon's CYSHCN and monitor the issues that impact them. The staff designs and implements ongoing and 5-year needs assessment activities to inform strategic planning, and program development. A&E implements program evaluation and quality improvement activities for OCCYSHN's community-based and grant funded programs. The staff work with program leadership to disseminate results of these activities to OCCYSHN stakeholders.

OCCYSHN Partners and Key Stakeholders

Agencies/Programs

- 211info
- Addictions & Mental Health
- Coalition of Local Health Officials – Healthy Families (MCH focus)
- Coalition of Local Health Officials (CLHO)
- Community Developmental Disabilities Programs (DHS)
- Division of Medical Assistance Programs (DMAP)
- Early Hearing Detection and Intervention Program (EHDI)
- Early Intervention/Early Childhood Special Education
- Emergency Medical System for Children (EMSC)
- Inclusive Child Care Program
- Multnomah County Health Department
- Newborn Screening Program
- Oregon Health Authority (OHA)
- OHA Maternal and Child Health (MCH) Section (Oregon's Title V MCH)
- OHA Office of Health Analytics
- OHA Transformation Center
- OHSU Center for Health Systems Effectiveness
- OHSU Child Psychology
- OHSU IDD Autism Clinic
- OHSU IDD Autism Research Center
- OHSU IDD Autism Research Center's SPARK for Autism grant
- Oregon Special Supplemental Nutrition Program for Women, Infants and Children (WIC)
- Oregon Department of Education (ODE)
- Oregon Head Start
- Oregon Insurance Division – Department of Business and Consumer Services
- Oregon Office on Disability & Health (OODH)
- Oregon Pediatric Improvement Partnership (OPIP)
- Oregon Post Adoption Resource Center (OPARC)

Agencies/Programs (continued)

- Oregon Rural-based Practice Network (ORPRN)
- Oregon Technical Assistance Corporation (OTAC)
- Oregon's Patient Centered Primary Care Home program (PCPCH)
- Pacific Source Community Solutions CCO
- University of Oregon University Center on Excellence in Developmental Disabilities (UO UCEDD)
- Western Oregon Advanced Health CCO
- Willamette Valley Community Health, LLC

Health Provider Associations

- American Academy of Pediatrics Council on Children With Disabilities (COCWD)
- American College Board of Genetic Counselors
- American College of Medical Genetics
- Child Development and Rehabilitation Center (CDRC)
- Children's Health Alliance/ Foundation (CHA)
- National Society of Genetics Counselors
- Nutrition Council of Oregon
- OHSU School of Medicine Department of Pediatric Specialty Providers
- Oregon Academy of Family Providers (OAFP)
- Oregon Academy of Nutrition and Dietetics
- Oregon Chapter of Child and Adolescent Psychiatry (OCCAP)
- Oregon Head Start Association Health Cluster
- Oregon Chapter of Child and Adolescent Psychiatry (OCCAP)
- Oregon Head Start Association Health Cluster
- Oregon Pediatric Nutrition Practice Group
- Oregon Pediatric Society (OPS)
- Oregon Primary Care Association (Association of FQHCs)
- Oregon Primary Care Association (OPCA)
- Western States Genetic Services Collaborative

OCCYSHN Partners and Key Stakeholders (continued)

OCCYSHN Representation on Committees/Workgroups/

Commissions

- American Academy of Pediatrics Family Partners Network
- Catalyst Center Advisory Board
- CDRC Clinic Planning Workgroup
- Emergency Medical Systems for Children – Family Representative
- IDD Diversity Taskforce
- IDD Transition Committee
- Joint Early Learning Council-Health Policy Board Subcommittee- Child and Family Well-being Measures Workgroup
- MCHB/211 Advisory Committee
- Medicaid Ombudsman Advisory Committee
- Megaconference Planning Committee
- National Center on Family/Professional Partnerships Advisory Board
- Newborn Screening Advisory Committee
- Oregon Commission on Autism Spectrum Disorders (OCASD)
- Oregon Council on Developmental and Disabilities
- Oregon Home Visiting Steering Committee
- Oregon Oral Health Coalition (OrOHC)
- Oregon Pediatric Improvement Partnership Partners Group
- Oregon Pediatric Improvement Partnership Steering Committee
- Real START Advisory Committee
- Salem Coalition (Evaluation Clinic Workgroup)
- State Interagency Coordinating Council
- Statewide Family Training/Outreach Collaborative
- Sustaining Families Work Group
- The Gorge Care Coordination for Kids Coalition

Families and Family /Youth/Consumer Organizations

- Autism Society of Oregon (ASO)
- Hands and Voices
- Northwest Down Syndrome Association (NWDSA)
- Oregon Coalition of Family Networks
- Oregon Council on Developmental Disabilities
- Oregon Deafblind Parents' Group
- Oregon Family Support Network (OFSN)
- Oregon PTI: Family and Community Together (FACT)
- Padres en Accion
- Sickle Cell Anemia Foundation, Oregon
- United Cerebral Palsy of Oregon and Southwest Washington

Enhancing the System of Services (SOS) for Oregon's Children and Youth with Special Health Care Needs

What is SOS?

SOS is shorthand for “Enhancing the System of Services for Oregon’s Children and Youth with Special Health Care Needs (CYSHCN).” SOS is an initiative of the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN).

SOS aims to ensure a comprehensive, coordinated, integrated and sustainable system of care for Oregon’s CYSHCN. The focus is on coherent, statewide systems and policies. SOS is funded by one of 16 state implementation grants awarded in 2014 by the federal Maternal and Child Health Bureau (MCHB).

What is OCCYSHN?

OCCYSHN is a public health program serving Oregon’s children and youth with special health needs.

OCCYSHN fosters the optimal health and function of Oregon CYSHCN by supporting Oregon families and communities, and by informing policy-makers. OCCYSHN’s work is guided by MCHB, Oregon’s Title V Block Grant program, and statewide Health Care Transformation efforts.

OCCYSHN’s current priorities are to build and support a system of care ensuring that CYSHCN receive care within a medical home, make an effective transition from pediatric to adult health care, and receive culturally and linguistically appropriate care. These priorities are based on established standards for systems of care for children and youth with special health needs.¹

Nearly one in five Oregon children under age 18 has a special health care need.

Source: National Survey of Children’s Health, NSCH 2011/2012



Who are children and youth with special health needs?

Children and youth with special health care needs (CYSHCN) either have chronic health conditions, or they are at risk for having them. Those conditions can be physical, developmental, behavioral, or emotional. CYSHCN need more health and related services than other children.

How does SOS work?

The SOS initiative focuses on three strategies, each of which has a specific goal for improving the system of care for CYSHCN. A cross-systems CYSHCN Advisory Group informs and collaborates on ways to achieve these goals. The three strategies and their goals are as follows:

Cross-systems care coordination. Goal:

Starting from a baseline of 0, by October 2017, 20% of Oregon's targeted CYSHCN will have a shared plan of care (a written, evolving document where needs, goals, roles and plans are recorded and shared with families of CYSHN and their various providers of care and services).

Integration of information between education, mental and physical health. Goal:

By October 2017, an agency-level written agreement will be developed between two or more state or regional-level entities to improve the timely receipt of information following the initial referral of a CYSHCN by a medical home.

Creation of a statewide shared resource.

The shared resource (which is web and phone-based) offers information and resources to families of CYSHCN, young adults with special health needs, and providers who serve CYSHCN and their families. **Goal:** *By October 2017, 50% of families and medical home providers of CYSHCN contacting a shared resource (SR) for a needed specialist, support or service, will obtain that specialist, support, or service.*

The CYSHCN Advisory Group directing the work of SOS is comprised of representatives from

- Families of CYSHCN
- Early Intervention/Early Childhood Special Education
- Multnomah County Department of Health
- Oregon Child Development Coalition
- Oregon Health Authority Maternal and Child Health Section
- Oregon Health Authority's Patient-Centered Primary Care Home program
- Oregon Health Authority's Health Policy and Analytics Division
- Oregon Medicaid Health Systems Division
- Oregon Pediatric Improvement Partnership
- Oregon Pediatric Society

When the SOS grant funding concludes in late 2017, OCCYSHN will continue to convene the SOS CYSHCN Advisory Group. The Advisory Group's efforts will be integrated into OCCYSHN's ongoing work on behalf of CYSHCN. The group will retain its systems and policy focus, and will form a cohesive voice for advising state-level leadership on behalf of Oregon's CYSHCN and their families.

¹VanLandeghem, 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 and Child Health Programs.

OCCYSHN is funded by the federal Maternal and Child Health Bureau. With the passage of the Social Security Act in 1935, the U.S. government pledged to support state efforts to improve the health, safety, and well-being of mothers and children. That support comes in the form of annual Title V block grants awarded to every state. A portion of each state's Title V funds is designated to serve CYSHCN. OCCYSHN is Oregon's Title V Block Grant program for CYSHCN