

***OCCYSHN improves the health, development and well-being of all of Oregon's children and youth with special health care needs. 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 Network** 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 seven 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.

The **Oregon Medical Home Initiative (OMHI)** provides support and training to health care providers and care coordinators to implement effective medical home practices on behalf of children and youth with special healthcare needs.

## 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

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**Institute on Development & Disability**

**Oregon Center for Children and Youth with Special Health Needs**

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**OCCYSHN Partners and Key Stakeholders**

**Agencies/Programs**

- Oregon Health Authority (OHA)
- Oregon Department of Education (ODE)
- Early Hearing Detection and Intervention Program (EHDI)
- Division of Medical Assistance Programs (DMAP)
- Pacific Source Community Solutions CCO
- Willamette Valley Community Health, LLC
- Western Oregon Advanced Health CCO
- Newborn Screening Program
- Oregon’s Patient Centered Primary Care Home program
- Oregon Title V Maternal and Child Health (MCH)
- Oregon Head Start
- Community Developmental Disabilities Programs (DHS)
- Addictions & Mental Health
- Emergency Medical System for Children (EMSC)
- Council of Health Leaders of Oregon (CHLO)
- Council of Health Leaders of Oregon – Healthy Families (MCH focus)
- Oregon Post Adoption Resource Center (OPARC)
- Oregon Technical Assistance Corporation (OTAC)
- University of Oregon University Center on Excellence in Developmental Disabilities (UO UCEDD)
- Oregon Special Supplemental Nutrition Program for Women, Infants and Children (WIC)
- Oregon Pediatric Improvement Partnership (OPIP)
- Inclusive Child Care Program
- Oregon Insurance Division – Department of Business and Consumer Services
- Oregon Office on Disability & Health (OODH)
- Oregon Rural-based Practice Network (ORPRN)

**Families and Family/Youth/Consumer Organizations**

- Oregon Family to Family Health Information Center (OR F2F HIC)
- Swindells Resource Center
- Family Voices
- Family and Community Together (FACT)
- Autism Society of Oregon (ASO)
- Northwest Down Syndrome Association (NWDSA)
- United Cerebral Palsy of Oregon and Southwest Washington
- Emerging Leaders Northwest
- Oregon Council on Developmental Disabilities
- Oregon Family Support Network (OFSN)
- Autism Clinic Family Advisory Committee
- Hands and Voices
- A Gift of Time
- Oregon Consortium of Family Networks (seven non-profit family groups)
- Oregon Deafblind Parents’ Group
- Padres en Accion

## OCCYSHN Partners and Key Stakeholders (continued)

### **Health Provider Associations**

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

### **OCCYSHN Representation on Committees/Workgroups/Commissions**

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