Children and Youth with Special Health Care Needs

Section 3000 Organization

Contents

Washington State Department of Health

Alert! Each section listed in this table of contents has been created with a built-in link to take you directly to it—simply hover over the line item and Ctrl and Click to go directly to the page.

3100 Children and Youth with Special Health Care Needs Program

3110 Introduction

This section continues to use a number of acronyms that are listed in the Appendices.

The Children and Youth with Special Health Care Needs (CYSHCN) Program administration is housed in the Office of Family and Community Health Improvement (OFCHI). OFCHI is part of the Prevention and Community Health (PCH) Division in the Department of Health (DOH). See organizational charts in Appendices.

The CYSHCN Program promotes and facilitates an integrated system of services for infants and children with or at risk for special health care needs through partnerships with other state level agencies, local health jurisdictions, local private and nonprofit agencies, the University of Washington, Seattle Children's, Neurodevelopmental Centers, and other tertiary care centers; and in collaboration with other DOH programs.

Authority for services comes from Title V of the Social Security Act, the Revised Code of Washington (RCW), and the Washington Administrative Code (WAC) as defined in Section 2000. Funding for services comes from a variety of sources including the federal Title V MCH Block Grant, State General Funds, and interagency agreements with other state agencies. Title V of the Social Security Act, Section 505 outlines how CYSHCN receives funding:

> (3) except as provided under subsection (b), provides that the State will use—
>
> (A) at least 30 percent of such payment amounts for preventive and primary care services for children, and
>
> (B) at least 30 percent of such payment amounts for services for children with special health care needs (as specified in section 501(a)(1)(D)).

3120 Purpose

The CYSHCN Program works to give children and youth with special health care needs the opportunity to achieve the healthiest life possible and develop to their fullest potential. Emphasis is placed on the capacity of communities to support children and families and on developing and/or enhancing the capacity of statewide systems of care that are family centered, community-based, coordinated, and culturally competent.

At the state level, the CYSHCN Program collaborates with families, policy makers, health care providers, agencies and other public-private leaders to:

- Identify and address health system issues that impact children and youth with special health care needs and their families;
- Improve and enhance system infrastructure and quality;
- Evaluate and assess programs and services;
- Influence priority setting, planning, and policy development;
- Support family-led organizations in training families to partner with system professionals to improve systems of care and connect families to health and resource information; and
- Support community efforts in assuring the health and well-being of children and youth with special health care needs and their families.

The extent and scope of the above strategies fluctuate over time, as they are dependent on funding availability.

3130 Funding and the Consolidated Contract (ConCon)

Funding for this program comes from the Title V Maternal and Child Health Block Grant. Refer to Section 1000 for more information. These funds are dispersed by the Department of Health (DOH) and managed through the consolidated contract also known as the "ConCon". The ConCon is an interagency, cost reimbursement, client service contract between the DOH and the 35 Local Health Jurisdictions (LHJs) in Washington State. The contract combines many program activities and funding sources, including Maternal and Child Health Block Grant funds for LHJs, into one contract. By combining statements of work for many programs into one contract, the number of contracts between the DOH and the LHJs is streamlined. The two exceptions are Kittitas and Yakima. In these two counties, the CYSHCN program is managed through a subcontract with Community Health of Washington in Kittitas County and a direct contract with Yakima Valley Memorial Hospital/Children's Village for Yakima County. Funding for CYSHCN activities is allocated at 30% of the MCHBG funds in each LHJ's ConCon.

The day-to-day management of the ConCon is monitored at an Office level by the Healthy Communities Consultants within the Office of Family and Community Health Improvement (OFCHI) with technical support from program staff.

The Consolidated Contract Statement of Work (SOW) includes required responsibilities for CYSHCN activities including reporting of client data, management of diagnostic and treatment funds for children with special health care needs, and participating and sharing different activities from your county at the CYSHCN Regional meetings. Refer to Sections 5000 and 6000 for additional guidance. More detail is also provided in the ConCon CYSHCN Focus of Work (FOW) document. If you do not have the FOW, you can contact your Healthy Communities Consultant at DOH OFCHI and s/he will provide you with a copy.

The MCHBG has several reporting measures that are updated every year to meet the needs of the population. For the CYSHCN program there are MCHBG Reporting measures that are based on Medical Home activities.

See Appendices for the DOH Consolidated Contract website used by Local Health Jurisdictions.

3140 CYSHCN Population

Children and youth with special health care needs are those who have or are at increased risk for developing chronic physical, developmental, behavioral, or emotional conditions and require health and related services of a type or amount beyond that required by children generally.[1]

The population includes children who have or are at risk for:

- A disability or disabling condition(s);
- Chronic illness or condition(s);
- Health-related educational or behavioral condition(s); or
- A risk of developing disabilities, chronic conditions, or health-related educational and behavioral conditions.

[1] McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics,* 102(1):137–140, 1998

3200 Regional System

3210 Introduction

In 1988, a regional system was established in WA to improve service coordination and statewide communication between the state CYSHCN Program and local CYSHCN Programs and local health jurisdictions (LHJs). A LHJ is the county health department or district. The two exceptions are Yakima and Kittitas. In these two counties, the CYSHCN program is managed through contracts with Yakima Valley Memorial Association/Children's Village for Yakima County and Community Health of Washington in Kittitas County.

Prior to 2017, the state was sectioned into four geographical CYSHCN regions. This valuable system continues today, but has been updated to align with the nine Accountable Communities of Health (ACH) regions. This creates and maintains communication among those who serve and know about children and youth with special health care needs and larger health systems in their region. These are as follows:

BETTER HEALTH TOGETHER

Adams	Lincoln NE Tri-County (includes Ferry, Pend Oreille, & Stevens)	Spokane

CASCADE PACIFIC ACTION ALLIANCE

Cowlitz Grays Harbor	Lewis Mason	Pacific Thurston Wahkiakum

GREATER COLUMBIA

Asotin Benton-Franklin Columbia	Garfield Kittitas	Walla Walla Yakima

KING COUNTY

NORTH CENTRAL

Chelan-Douglas	Grant	Okanogan

NORTH SOUND

Island Skagit	San Juan Snohomish	Whatcom

OLYMPIC COMMUNITY OF HEALTH

Clallam Island Jefferson	Jefferson Kitsap San Juan	Kitsap Snohomish Whatcom

PIERCE COUNTY

SOUTHWEST WASHINGTON

Clark	Klickitat	Skamania

3220 Membership

Members of the CYSHCN Regional System include local CYSHCN Coordinators and administrative support staff, and others involved with children and youth with special health care needs (e.g., representatives of parent organizations, neurodevelopmental centers, Medicaid managed care plans, and schools).

3230 CYSHCN Communication Network Meetings

The statewide Communication Network Meeting occurs quarterly and complements the CYSHCN regional meeting schedules. Attendees include: Representatives from family-led organizations, other family advisors, Medicaid managed care plans, neurodevelopmental centers, University of Washington's Medical Home Partnerships Project and Nutrition Program, state agencies such as the Department of Children, Youth and Families, Early Support for Infants and Toddlers (ESIT) Program, Health Care Authority (HCA), Office of Superintendent of Public Instruction (OSPI), other entities involved with children with special health care needs, and CYSHCN Program staff.

The Communication Network Meeting provides for the exchange of information among the various stakeholders listed above and facilitates opportunities to learn about local and statewide policies, programs and issues critical to this unique population. A variety of on-going technical assistance, consultation and training opportunities are made available through the Communication Network meetings.

Communication Network Meeting Minutes are distributed to a statewide audience. Minutes include current reports from participants and the entities they represent, and website address links. These are posted on the DOH CYSHCN Program home page at: http://www.doh.wa.gov/YouandYourFamily/InfantsChildrenandTeens/HealthandSafety/ChildrenwithSpecialHealthCareNeeds/CommunicationNetwork

3300 CYSHCN Services

Children and youth with special health care needs benefit from services such as:

- Quality primary and specialty medical care, ideally provided in a medical home model,
- screening and/or assessment of the child according to recommended screening schedules and families' concerns, priorities and strengths;
- early identification of health or developmental conditions;
- tracking or monitoring,
- therapeutic intervention(s) including but not limited to family empowerment, education and support,
- linkages to needed services and referrals, and
- care coordination and case management.

These and other services are provided by a range of agencies and service providers including but not limited to: prenatal and well child clinics, WorkFirst/TANF activities, home-based, center-based, or school based therapy services, neurodevelopmental and early intervention centers, local public health departments and health care providers, community health centers and providers, physicians and other health professionals, schools, and hospitals. Funding for the development and provision of these services requires multiple payment sources which include but are not limited to Title V, Title XIX (Medicaid), local tax dollars, TRICARE (military insurance

program), private insurance, Developmental Disabilities Administration, Title XX (Social Services Block Grant), and client fees.

3310 Local CYSHCN Services

The CYSHCN Program contracts with LHJs and, in limited cases, hospitals, and clinics, if approved by the CYSHCN Program, to administer services to children and youth with special health care needs at the local level. CYSHCN core service activities can include (and vary according to LHJ CYSHCN Program priorities and capacity):

- Early identification through screening and assessment.
- Linking families to needed diagnostic and treatment services and other needed resources.
- Entering data into the Child Health Intake Form (CHIF) Automated System, and submitting the data to the state CYSHCN Program.
- Administering diagnostic and treatment funds as needed.
- Facilitating access to comprehensive, community-based, and family-centered care.
- Coordination of services.

CYSHCN Coordinators work with local agencies and communities to provide leadership in promoting or developing coordinated, family-centered, culturally competent services for children and youth with special health care needs and their families. *(See Appendices for CYSHCN Coordinators list and their contact information.)*

Staff in local agencies may consist of public health nurses, social workers, registered dietitians, occupational therapists, physical therapists, speech therapists, dental hygienists, administrative staff, and others. Together they carry out a combination of clinical and administrative activities for children with special health care needs.

CYSHCN Coordinator decisions to request use of CYSHCN funds to pay for client services such as respite and specialty camps, therapy, diagnostic evaluations, medical treatment, and equipment or supplies are based on many factors, including the family's financial status, the child's special health or developmental need, the expected outcome with intervention, other available sources of payment, the number and magnitude of requests for CYSHCN funds, and the availability of CYSHCN funds. See Section 6000, Authorization and Payment.

For details on the CYSHCN Coordinator roles and responsibilities, see Section 7000.

3320 Neurodevelopmental Center Services

CYSHCN contracts with 19 Neurodevelopmental Centers (NDCs) located in 12 counties through a DOH granting process. The centers are located across the state, each one meeting needs specific to its community.

The NDCs provide evaluation, diagnosis, and coordinated speech, occupational and physical therapies for eligible children. At the discretion of the child's primary care provider, referral for additional medical specialty consultation is also available. Other services may include nursing, nutrition, social work, educational services, adaptive equipment, computer augmented communication therapy, hydro-therapy, and more.

The NDCs also promote statewide capacity for quality, community-based, early intervention services for children and youth with special health care needs of all ages, emphasizing the needs of low income and Medicaid–eligible children, 0-36 months of age. DOH's CYSHCN Program's state-funded grants support NDC infrastructure and service system development. Direct client services are paid from other funding sources

including Title XIX (Medicaid) and private insurance. *See Appendices for a list of Neurodevelopmental Centers and their contact information.*

For more information about NDCs, go to:
http://www.doh.wa.gov/YouandYourFamily/InfantsChildrenandTeens/HealthandSafety/ChildrenwithSpecialHealthCareNeeds/Partners/NeurodevelopmentalCenters

3330 Provider Information

DOH's CYSHCN Program supports training and technical assistance to a variety of health care providers in collaboration with the University of Washington (UW), local county agencies, and others. The CYSHCN Program also collaborates with several training programs. Examples of program and training collaborative activities include:

- *The Medical Home Partnerships Project for Children and Youth with Special Health Care Needs* at the UW: This partnership is a joint effort between DOH's CYSHCN Program and the UW. A Medical Home is an approach to delivering primary health care through a "team partnership" that ensures health care services are provided in a high-quality, cost effective and comprehensive manner. The Medical Home Leadership Network within the Medical Home Partnerships Project at the UW, and the CYSHCN Program, work to increase access to the medical home model of care for children in WA.
- *The Pediatric Pulmonary Training Grant:* Provides leadership training for health care providers for children using pulmonary conditions to model systems of care that are interdisciplinary, family centered, and culturally competent. Recognition of MCH priorities, access, and disparities are emphasized.
- *The University of Washington Leadership Education in Neurodevelopmental Disabilities (LEND):* Provides leadership training for health care providers serving children with neurodevelopmental conditions to model systems of care that are interdisciplinary, family centered, and culturally competent. Recognition of MCH priorities, access, and disparities are emphasized.

3340 Nutrition Services

The UW Center on Human Development and Disability (CHDD) supports a statewide network of community-based, interagency, interdisciplinary feeding teams for feeding assessment and treatment services to children with nutrition and feeding concerns. The CHDD also trains and supports a statewide network of certified dietitians who provide nutrition assessment and follow-up to children with special health care needs.

Funding through the diagnostic and treatment funds to DOH's Newborn Screening Program supports provision of low protein foods to children with specific metabolic conditions such as Phenylketonuria (PKU).

3350 Maxillofacial Services

Services for children with maxillofacial conditions are available through multidisciplinary team review boards in four regions of the state and are organized by Regional Maxillofacial Team Coordinators. The DOH provides partial funding for review boards in three regions: 1) East Region in Spokane through the Maxillofacial Program at Providence Sacred Heart Children's Hospital, 2) Central Region in Yakima through Children's Village, and 3) Southwest Region in Tacoma at Mary Bridge Children's Hospital. In the NW region, Seattle Children's provides most maxillofacial services. DOH provides funding to public health in this region to assure coordination of services in collaboration with the NW region maxillofacial team at Seattle Children's and the other Regional Teams.

The purpose of the Maxillofacial Review Boards is 1) To ensure that care for children with craniofacial disorders such as cleft lip and palate is provided in a coordinated, consistent manner with the proper sequencing of evaluations and treatments within the framework of the patients overall developmental, medical, and psychological needs as described in the *Critical Elements of Care for Children with Cleft Lip and Palate (CEC)* and *The Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Differences* *and consistent with American Cleft Palate-Craniofacial Association (ACPCA) Team Standards* (http://www.acpa-cpf.org/team_care/standards/#standard1) and 2) The DOH CYSHCN works to ensure that interdisciplinary care coordination occurs in the context of the *National Standards for Systems of Care for Children and Youth with Special Health Care Needs* established by the Association of Maternal and Child Health Programs (AMCHP) to include the following system outcomes:

a. Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive.
b. Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home.
c. Families of children and youth with special health care needs have adequate private and/or public insurance to pay for the services they need.
d. Children are screened early and continuously for special health care needs.
e. Services are organized for children and youth with special health care needs (CYSHCN) and their families in ways that families can use them easily and include access to patient and family-centered care coordination.
f. Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.
g. CYSHCN and their families will receive care that is culturally and linguistically appropriate.

The Team coordinator works with the Review Board Members, providers (locally as well as statewide) families, and the network of CYSHCN coordinators to assure families access needed resources and so that the proper sequencing of care and treatment will occur.

A minimum core team must be present for a Maxillofacial Team Review. According to the ACPCA, minimum core team composition includes: Speech-Language Pathology, Surgery, Orthodontics, and Patient Coordinator.

Inclusion of other specialists in a Team Review is desirable for a comprehensive assessment and development of a plan of care. Examples of other specialists who would help promote comprehensive care include:

nurse
social worker
psychologist
geneticist or genetic counselor
pediatrician
prosthodontist
plastic surgeon(s)
orthodontist
otolaryngologist
dietitian / nutritionist
feeding therapist or feeding team

Families are partners in developing shared plans of care with the rest of the team.

The regional CYSHCN Coordinator collaborates with the maxillofacial team coordinator in these activities and may act as a liaison between family, team, and local resources and services. They authorize payment for team evaluation and treatment and provide their child-specific data to the LHJ where the child resides for entry into the Child Health Intake Form (CHIF) Automated System.

See Appendices for a list of CYSHCN Maxillofacial Teams and their contact information.

3360 Family Leadership and Engagement Services

The CYSHCN Program supports family-professional partnerships and culturally responsive, family-centered systems of care by connecting trained family leaders to leadership and advisory opportunities in planning, policy, program development and continuous quality improvement. These partnerships include ongoing collaboration with Washington State Fathers Network, PAVE/Family to Family Health Information Center, Medical Home Leadership Network teams, Open Doors for Multicultural Families and many others organizations and other state agencies across the state. CYSHCN relies on parents, caregivers and youth to identify strengths and areas of concern as well as priorities from a family perspective. The Program supports opportunities to develop personal networking systems with other families and organizations, as well as training and leadership opportunities at the local, regional, state and national levels. The DOH CYSHCN Family Engagement Coordinator supports a Washington State Leader Initiative with the above-mentioned partners with goals of supporting families, children and individuals in Washington State, including families in culturally and linguistically diverse communities and those with special health care needs, to be healthy, safe, informed, resilient and included.

3370 Other Services

- The WithinReach Family Health Hotline and Answers for Special Kids (ASK) Line services are supported by CYSHCN. ASK Line Information and Resource Specialists provide local and state resource information on health care coverage, specialty services, recreational opportunities, peer support, basic needs and more to families of children and youth with special health care needs who call this toll-free information service (1-800-322-2588 and 711 for TTY relay).
- CYSHCN assessment activities establish a systematic approach to using and developing data about children with special health care needs. This approach includes determining prevalence, identifying the needs of the population, and promoting inclusion of data in state and local health assessments. In collaboration with families and our other partners, these methods help paint the picture of children and youth with special health care needs and identify the needs and priorities for the systems of care.