Minnesota Department of Health
Children & Youth with Special Health Needs (CYSHN)

SECTION OVERVIEW

Section Manager: Barb Dalbec (barb.dalbec@state.mn.us or 651-201-3758)
Website: www.health.state.mn/cyshn

Overview

The section provides state-level leadership in partnership with families and other stakeholders to achieve a vision of ongoing improvement for community-based systems serving CYSHN and their families. This is done through emphasis on six national priorities for children and youth with special health care needs: Access to enhanced primary care within a medical home; Access to adequate funding for health care; Early and continuous screening to detect and address health and developmental conditions as early as possible; Well organized, community-based systems; Transition to adult health care, work and independence. Parents of CYSHN are partners in decision making at all levels and are satisfied with the services their children receive. The section provides a focal point for influencing the efforts of a broad range of agencies and programs committed to these goals. The role of the section is to:

- Monitor and report the health and well-being of children and youth with special health needs.
- Engage in the development, coordination and support of state and local systems for children with special health needs.
- Serve in an advisory capacity to a variety of policy-making bodies to assure the interests of children with special health needs are considered.

Section Priorities

The following priorities have been identified for the CYSHN Section:

- Improve birth outcomes.
- Improve the health of children and adolescents.
- Promote optimal mental health.
- Reduce child injury and death.
- Assure quality screening, identification and intervention.
- Improve access to quality health care and needed services.
- Assure healthy youth development.

Section Support

Newborn Screening Advisory Committee

The Minnesota statute that mandates newborn screening also created the MDH Newborn Screening Advisory Committee. This committee, which meets on a semi-annual basis, has members that include parents of affected infants and children, advocacy groups, health care providers, hospital representatives, and other medical and educational experts. One of the main purposes of the advisory committee is to discuss issues related to newborn screening, including making informed recommendations on adding new disorders to the newborn screening panel. This committee is supported by staff from the CYSHN section and the Public Health Lab (PHL).

Contact: Tony Steyermark (tony.steyermark@state.mn.us or 651-201-5098)
Website: http://www.health.state.mn.us/divs/fh/mcshn/ncfu/index.htm
Newborn Hearing Screening Advisory Committee
The Minnesota statute (144.966) that mandates newborn hearing screening also created a MDH Newborn Hearing Screening Advisory Committee. This committee meets four times per year to discuss issues surrounding newborn hearing screening. Members include parents of children with a hearing loss, advocates with expertise in issues affecting people who are deaf and hard of hearing, health care providers, hospital representatives, and other medical and education experts. One of the main purposes of the advisory committee is to make informed recommendations for newborn hearing screening and hearing loss management. The committee is staffed by staff from the CYSHN section and PHL.

Contact: Tony Steyermark (tony.steyermark@state.mn.us or 651-201-5098)
Website: http://www.health.state.mn.us/divs/fh/mcshn/ncfu/index.htm

CYSHN Data and Epidemiology: The section Epidemiologists provide overall leadership on CYSHN data and epidemiology. This includes technical assistance and consultation on the development and implementation of surveys, study design, program evaluation, data collection and analysis, and the review and coordination of state and local data. This staff also mentors and assists new epidemiologists on applying knowledge and skills to public health problems.

Contact: Barb Dalbec (barb.dalbec@state.mn.us or 651-201-3758)

Autism: The MDH provides consultation, data analysis and dissemination and policy development around autism and autism spectrum disorders. This includes the development of community collaborative teams to improve screening and evaluation systems. This work is done in partnership with the Departments of Education and Human Services, the University of Minnesota, the Minnesota Chapter of the American Academy of Pediatrics Autism Society Minnesota and other stakeholders.

Contact: Jeanne Carls (jeanne.carls@state.mn.us, 651-201-3654)

Programs

Part C of the Individuals with Disabilities Education Act (IDEA) – Help Me Grow: Part C Early Intervention staff provide training, technical assistance and educational materials to health care and early intervention providers relevant to eligibility guidelines for Minnesota’s Early Intervention Program, “Help Me Grow” and health conditions/disorders with a high probability of resulting in developmental delays at school age. Part C refers to services under the Individuals with Disabilities Education Act (IDEA) for infants and toddlers ages birth to three through Part C of the Act, and for ages three to five years through Part B619 of the Act. Part C staff provide leadership, oversight and staff support to this program, partially funded by Part C of IDEA through a MN Department of Education interagency agreement.

Contact: Shawn Holmes (shawn.holmes@state.mn.us or 651-201-3641)
Website: http://www.health.state.mn.us/divs/fh/mcshn/ecip.htm

Minnesota System of Interagency Coordination (MnSIC): In accordance with Part B of the IDEA, Minnesota law requires a statewide, interagency, coordinated service system for students with disabilities ages 3–21 who need services from the school and at least one other public agency. The MnSIC initiative brings together seven state public agencies (the Minnesota Departments of Education, Employment and Economic Development, Commerce, Corrections, Health, Human Rights, and Human Services) charged with developing and implementing the system, including identifying and removing barriers to local coordination of services, identifying funding sources and developing a standardized written plan for service provision. Section staff provide leadership for the state interagency committee as well as staff to achieve these goals. At the community level, school boards and county boards develop local interagency agreements for service provision and payment arrangements. Each eligible child has an individual interagency intervention plan (IIIP) setting out the child's programs, services and funding
sources. The contents of other service plans, such as IEPs, home care plans and Medicaid plans are to be incorporated into the IIIP.

Contact: Barb Lundeen (barbara.lundeen@state.mn.us or 651-201-3646)

**Follow-Along Program**: MDH provides technical assistance and training to local public health agencies to support the Follow-Along Program. This program provides periodic monitoring and assessment of infants and toddlers at risk for health and developmental problems and to ensure early identification, assistance and services. This program uses the Ages and Stages Questionnaire (ASQ-3) as the developmental screening tool and its social/emotional component – the ASQ/SE.

Contact: Shawn Holmes (shawn.holmes@state.mn.us or 651-201-3641)
Website: [http://www.health.state.mn.us/divs/fh/mcshn/fap.htm](http://www.health.state.mn.us/divs/fh/mcshn/fap.htm)

**Birth Defects Monitoring & Analysis Program**

**Supervisor**: Kristin Oehlke (kristin.oehlke@state.mn.us or 651-201-3648)

**Website**: [http://www.health.state.mn.us/divs/eh/birthdefects/index.html](http://www.health.state.mn.us/divs/eh/birthdefects/index.html)

The Birth Defects Monitoring and Analysis (BDMA) Program at MDH gathers data about 45 selected birth defects diagnosed in the first year of life, estimated to affect over 2,000 babies born in Minnesota each year. The primary goals of the Birth Defects Program are to monitor trends of birth defects to detect emerging health concerns and identify affected populations through the Birth Defects Information System (BDIS), ensure appropriate services are provided to affected families, prevent birth defects through targeted education, educate physicians and the public regarding birth defects, and stimulate research on risk factors, treatment, prevention, and the cure of birth defects.

**Prevention**

The causes of many types of birth defects are still unknown, but progress is being made in understanding how some birth defects can be prevented. Prevention efforts occur to maintain, enhance and evaluate current collaborations supporting targeted birth defects prevention programs. Efforts include providing prevention information to health providers and the general public. Implementation of the Preconception Health in Minnesota grant program began in 2012. Folic acid activities are coordinated by BDMA and the MCH program.

Contact: Erica Fishmann (erica.fishmann@state.mn.us or 651-201-5141)
Website: [http://www.health.state.mn.us/divs/eh/birthdefects/prevention.html](http://www.health.state.mn.us/divs/eh/birthdefects/prevention.html)

**Surveillance**

The Minnesota Birth Defects Information System (BDIS) Statute was enacted in 2004. The BDIS provides for surveillance of birth defects to detect potential public health problems, predict risks, and respond to birth defects clusters. The system helps accurately target intervention, prevention, and services for communities, patients, and their families; inform health professionals and citizens of the prevalence of and risks for birth defects; and enable scientific investigations of the causes, mortality, treatment, prevention, and cure of birth defects. The BDIS will be modified as necessary through demonstration projects. As more data becomes available, analysis of trends in rates of targeted birth defects will help assess the effectiveness of prevention efforts.

Contact: Barbara Frohnert (barbara.fronhert@state.mn.us or 651-201-5953)

**Services**

Legislation passed in 2010 authorized the statewide expansion of birth defects monitoring and analysis activities. Birth Defect Information System surveillance case information is used to improve access to health services and early intervention programs. Work continues to integrate birth defects surveillance
and service programs in MN and to provide and improve materials for parents of infants born with birth
defects. As part of expansion, MDH partners with local public health and tribal agencies across MN for
birth defects service delivery in the communities where those families live.
Contact: Jan Sieger (janice.sieger@state.mn.us or 651-201-3638)

Newborn Screening Long Term Follow-up
Supervisor: Tony Steyermark (tony.steyermark@state.mn.us or 651-201-5098)
Website: http://www.health.state.mn.us/divs/fh/mcshn/ncfu/index.htm

Staff from the section work in partnership at MDH with the Public Health Laboratories (PHL) on systems
development, data and tracking linkages, and providing education, outreach, and technical assistance.
Staff also collaborates with primary care providers, specialists, local public health nurses, special
education providers and other key stakeholders to assure infants find early treatment/intervention and
immediate support services after initial diagnosis of the condition. This collaboration also ensures that
ongoing medical/habilitative management, including specialty care, are provided within the context of
the health care home. MDH also provides grants to local health departments to facilitate connections to
local resources and reduce loss to follow-up of infants who fail their newborn hearing screening. These
grants also support connections to local and state resources for those diagnosed with a permanent
hearing loss.

Early Hearing Detection & Intervention Program:
One in every 350 babies is born deaf or hard of hearing in Minnesota each year (approximately 200 total).
Early Hearing Detection and Intervention (EHDI) program staff work in partnership with the PHL to assure
that all babies are screened for hearing at birth, rescreened as necessary before 1 month of age,
diagnosed by 3 months of age and receiving appropriate services by 6 months of age. Follow-up is
conducted through the EHDI tracking and surveillance system. In order to decrease the number of
children lost to follow-up, the EHDI program contracts with local public health to assist with data
collection and connection to services. Staff also evaluate and improve the system for children who are
identified with hearing loss after 6 months of age. Early identification of children with hearing loss
contributes to improved outcomes through connections to appropriate services such as early
intervention, medical home, and ENT, ophthalmology, and genetics evaluations.
Contact: Nicole Brown (nicole.brown@state.mn.us or 651-201-3737)
Website: http://www.improveehdi.org/mn/state/

Long Term Follow-up for Blood Spot Disorders
Long term follow-up of children identified with a condition during the newborn screening process
includes assistance to families with coordination of financial and community resources, development and
maintenance of a tracking system to collect data, coordination with specialists, development and support
of multidisciplinary clinics and care coordination models, and organization of family support group
activities. In Minnesota, every year approximately 80 children are diagnosed with an endocrine disorder
or a hemoglobinopathy and 70 children with a metabolic disorder or severe combined immune deficiency
(SCID) and SCID Variance.
For information on endocrine disorders and hemoglobinopathies:
Contact: Nancy Vanderburg (nancy.vanderburg@state.mn.us or 651-201-3757)

or information on metabolic disorders, SCID and SCID Variance
Contact: Carolyn Anderson (carolyn.anderson@state.mn.us or 651-201-3733)
Website: http://www.health.state.mn.us/divs/fh/mcshn/ncfu/index.htm