



Children and Youth with Special Health Needs (CYSHN)
Condition Follow-Up Onboarding for Local Public Health

Tribal-State relations acknowledgement statement

The State of Minnesota is home to 11 federally recognized Indian Tribes with elected Tribal government officials. The State of Minnesota acknowledges and supports the unique political status of Tribal Nations across Minnesota and their absolute right to existence, self-governance, and self-determination. This unique relationship with federally recognized Indian Tribes is cemented by the Constitution of the United States, treaties, statutes, case law, and agreements. The State of Minnesota and Tribal governments across Minnesota significantly benefit from working together, learning from one another, and partnering where possible.

Minnesota Department of Health recognizes, values, and celebrates the vibrant and unique relationships between the 11 Tribal Nations and the State of Minnesota. Partnerships formed through government-to-government relationships with these Tribes will effectively address health disparities and lead to better health outcomes for all of Minnesota.

CYSHN respect for identities statement

Short version

We strive to use language that honors individual preferences, recognizing health conditions and disabilities are a natural and valuable part of human diversity. While our program reflects statutory terms like "special," we remain open to changing our language practices based on community feedback to foster belonging, respect, and inclusivity.

Long version



www.health.state.mn.us/people/childreneyouth/cyshn/about.html#respect

Learning objectives



Describe CYSHN programs, goals, and processes.



Understand LPH's roles and responsibilities for CYSHN Condition Follow-up.



Identify resources to support LPH contacts.

CYSHN vision



A Minnesota where all children and youth with special health needs and disabilities can live a life of dignity, opportunity, joy, and belonging.

Activities to enhance positive outcomes for children and youth with special health needs and their families

- Education.
- Community partnerships.
- Public policy.
- Public health surveillance.
- Follow-up: identify child and family needs and ensure connection to appropriate information, resources, and services.





Birth defects

Birth defects facts



Birth defects are conditions that affect the structure or function of the body and can impact the way an infant develops.

Approximately 2,000 infants are born with a birth defect each year in Minnesota.

Although the causes of many birth defects are not known, there are ways to reduce the risk of certain birth defects.

Types of birth defects

Heart

Nose or mouth

Brain and spine

Chromosome or gene

Ear

Eye

Stomach, esophagus, intestinal,
or liver

Genital, urinary, or kidney

Muscle or bone

Common birth defects



Hypospadias (males only)

Ventricular septal defect

Atrial septal defect

Down syndrome

Pulmonary valve atresia and stenosis

Cleft palate

Cleft lip with cleft palate

Atrioventricular septal defect

Coarctation of the aorta

Renal agenesis and hypoplasia

Birth Defects Monitoring and Analysis program goals

- Monitor trends of birth defects to detect emerging health concerns and identify affected populations.
- Assure appropriate services are provided to affected families.
- Prevent birth defects through targeted education.
- Educate physicians and the public regarding birth defects.
- Stimulate research on risk factors, treatment, prevention, and the cure of birth defects.

Birth Defects Monitoring and Analysis process

- Hospitals and clinics report information to MDH about infants who were treated for any of the monitored birth defects.
- MDH medical abstractors enter information from the medical record into MEDSS.
- MDH nurse reviews the information and determines an acuity assignment. Medium and high acuity events are reimbursable for LPH follow-up.
- MDH sends a letter to the family.
- Two week waiting period to allow delivery.
- MDH refers child to LPH via MEDSS for nursing follow-up.



Early Hearing Detection and Intervention (EHDI)

Hearing loss facts



The sooner hearing loss is identified, the sooner children who are deaf and hard of hearing can receive help and begin developing critical language skills.

Permanent childhood hearing loss is identified in about 150 infants born in Minnesota each year, with about 100 additional young children identified after the newborn period.

Most babies who are deaf or hard of hearing are born to hearing parents and most often, these parents have no experience with hearing loss.

Types of permanent hearing loss

Sensorineural

Sensory cells in the cochlea

Neural

Cochlear nerve or brainstem

**Permanent
conductive**

Outer or middle ear, microtia/atresia, other craniofacial, etc.

Mixed

A combination, usually both sensorineural and conductive

Causes of hearing loss

- Genetic
- Co-occurring with other conditions
- Acquired
- Unknown



Hearing loss management

- The degree of hearing loss may range from slight to profound and may involve one (unilateral) or both (bilateral) ears.
- The degree of hearing loss affects the management plan.
- All children should have access to language
 - Hearing technology
 - Educational support to learn a full visual language

Early Hearing Detection and Intervention program goal

Maximize linguistic competence and literacy development for child who are deaf, deafblind, and heard of hearing ensuring all infants achieve the national recommendation of:

- Universal hearing screening before 1 month of age.
- Identification of hearing loss before 3 months of age for children who do not pass screening.
- Enrollment in Early Intervention before 6 months of age for children identified with hearing loss.

Early Hearing Detection and Intervention process

- All hospitals are required to perform a hearing screening on newborns within 48 hours of birth and report the results to MDH.
- The MDH Public Health Lab is responsible for ensuring infants receive screening and further evaluation to determine if hearing loss is present.
- When an infant missed or did not pass newborn hearing screening and the result of their hearing status is unknown, the Public Health Lab may contact LPH by email for assistance with contacting the family.

Early Hearing Detection and Intervention process (continued)

- Audiologists are required to report all cases of hearing loss in children until age 11.
- MDH mails letter to primary care provider with recommendations.
- MDH mails letter and binder of information and resources for the family.
- MDH refers child to Minnesota Hands & Voices.
- MDH refers child to LPH via MEDSS for nursing follow-up.



Heritable Conditions (HC) and Congenital Cytomegalovirus (CMV)

Heritable conditions and congenital CMV facts



Heritable conditions are often rare, hidden disorders that if left untreated, can lead to illness, physical disability, developmental delay, or death.

Newborn screening identifies infants at risk for more than 60 conditions affecting metabolism, hormones, the immune system, blood, breathing, digestion, hearing, or the heart.

cCMV is the most common infectious cause of birth defects, childhood hearing loss, and neuro- developmental disabilities.

Hundreds of newborns are identified with a heritable or congenital disorder by blood spot screening each year.

Heritable conditions and congenital CMV program goals

Support children as they grow and families as they navigate education, health care, family supports, and other systems.

- Connect children with resources and services early in life.
- Collect and study data.
- Use a health equity lens to guide policy and decision-making.

Heritable conditions and congenital CMV process

- Health care provider confirms newborn screening condition and reports to MDH.
- MDH nurse reviews reported information.
- MDH mails letter and informational resources to the family.
- MDH refers child to LPH via MEDSS for nursing follow-up.




Local public health (LPH) roles and responsibilities

CYSHN condition follow-up process

CYSHN condition identified through medical abstraction or newborn screening lab results.




MDH staff review child's information and enter data into LPH Workflows in MEDSS. Family is notified via mail that they may be contacted by LPH.



LPH staff contact family to complete assessment and provide interventions, documenting in MEDSS.



Initial assessment is closed or a second assessment is completed at nurse discretion.



Invoices are automatically generated through the nursing documentation in MEDSS. There is no need to submit an invoice.

LPH roles and responsibilities

- Identify concerns and needs with the family through a nurse assessment focusing on **income, connection to community resources, caretaking/parenting, growth and development, and health care supervision.**
- Document current services being used.
- Identify and connect families to any additional services which may be beneficial and for which the family is eligible.
- Update address and contact information in MEDSS.
- Submit required data real time (as it is collected) in MEDSS.

Examples of nursing assessments and interventions

Primary and specialty care

Health insurance including
TEFRA

Disability waiver programs

Early intervention/Help Me
Grow

Family Home Visiting

Follow Along Program

Family Support Organizations

Health education

Family well-being

Early intervention referrals

Refer *all* children with the following conditions to early intervention through

[Help Me Grow Minnesota](#)

unless they are already connected with these services.

- Confirmed hearing loss.
- High acuity birth defects.
- cCMV.

Some children with heritable conditions or other birth defect conditions may also be eligible for EI.

If a parent/legal guardian has concerns about a child's development and believes the child might need extra help to learn and grow, LPH should refer the child to Help Me Grow.

Consider Follow Along Program as another intervention.

Important timelines

- Contact family within 1 month of the referral.
- Make at least 3 attempts to contact the family if you are not able to reach them.
- Complete nursing follow-up and submit documentation in MEDSS before the end of the next quarter following the quarter the referral was made.
 - If a referral was made in quarter 4, complete the follow-up and submit documentation before the end of quarter 1.

Quarter 1	Quarter 2	Quarter 3	Quarter 4
January 1 – March 31	April 1 – June 30	July 1 – September 30	October 1 – December 31

Reimbursable and non-reimbursable events

- Referrals (events in MEDSS) are categorized as “reimbursable” or “non-reimbursable.”
- LPH is required to follow-up on “reimbursable events.”
- LPH is not required to follow-up on “non-reimbursable” events.
- When a child has multiple CYSHN events within MEDSS, one or more of the events may be sent as “non-reimbursable”. These events are sent to help LPH tailor their conversations with families when completing follow-up for the reimbursable event.

Additional requests for LPH follow-up

- Address check for birth defects cases.
 - Request assistance from LPH to identify current address when mailed parent letter is returned to MDH as undeliverable.
- Hearing screening follow-up.
 - Newborn did not pass hearing screening at birth and MDH is unable to obtain documentation of rescreen.
 - Request assistance from LPH to attempt to contact family and help address barriers that prevent family from completing rescreen.



Resources

Inclusive language

- State the specific disability or condition.
- Some prefer the terms “birth condition” or “congenital condition.”
- People may self identify as deaf, deafblind, hard of hearing, a person with hearing loss, DeafPlus, a person with hearing difference, DeafDisabled, or other terms.
- MDH uses the term “hearing loss” when referring to a medical diagnosis.



Minnesota statutes allow MDH to collect health information pertinent to birth defects, newborn hearing screening, confirmed hearing loss, and heritable/congenital disorders identified by newborn screening.

HIPAA does not prevent health care providers from sharing protected health information with local public health.

[HIPAA and birth defects](#)

[HIPAA and newborn hearing screening, diagnosis, and intervention](#)

[HIPAA and newborn screening](#)

CYSHN resources for LPH



Webpages



E-newsletter



**Community
of practice**

Thank You!

Children and Youth with Special Health Needs

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