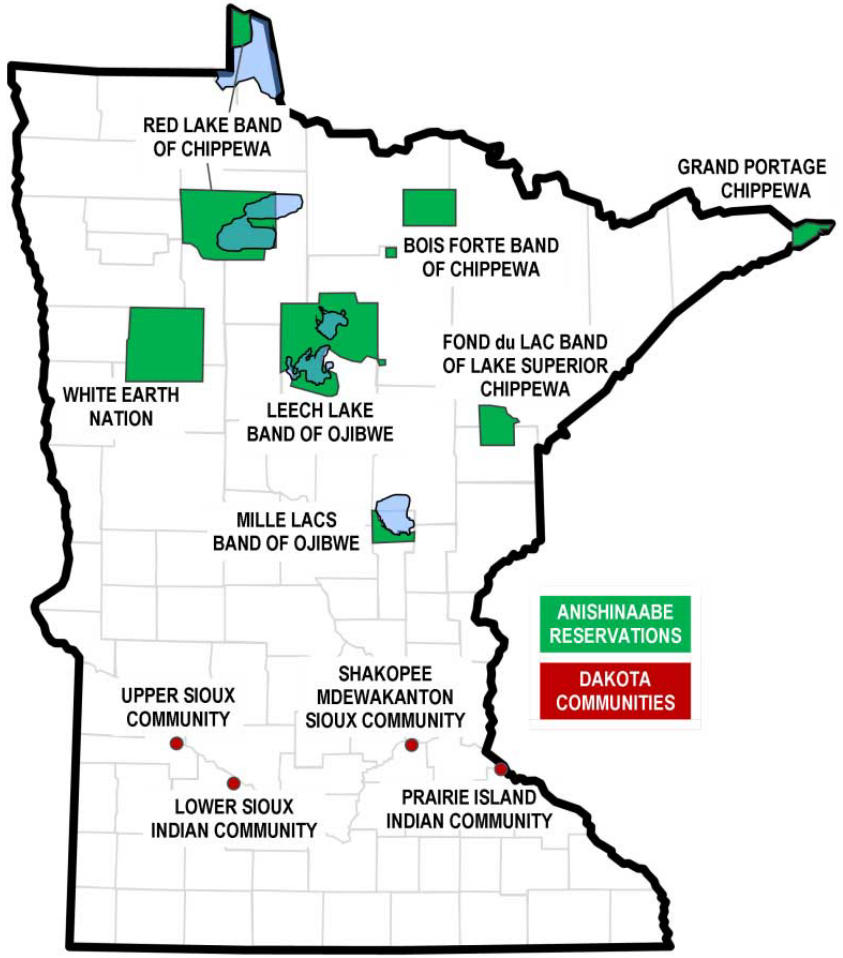
Children and Youth with Special Health Needs (CYSHN) Condition Follow-Up for Local Public Health

2025

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 status of the Minnesota tribal nations and their absolute right to existence, self-governance, and self-determination. The United States and the State of Minnesota have a unique relationship with federally recognized Indian tribes, formed by the Constitution of the United States, treaties, statutes, case law, and agreements. The State of Minnesota and the Minnesota Tribal governments significantly benefit from working together, learning from one another, and partnering where possible.

The Minnesota Department of Health (MDH) recognizes, values, and celebrates the vibrant and unique relationship between the 11 tribal nations and the State of Minnesota. MDH believes that the partnerships formed, through a government-to-government relationship, with the eleven tribal nations will effectively address health disparities and lead to better health outcomes for all of Minnesota.



Learning objectives

- Describe the MDH CYSHN program
- Explain processes for CYSHN Condition Follow-up
- List LPH roles and responsibilities for CYSHN Condition Follow-up
- Identify resources to support LPH contacts for CYSHN Condition Follow-up

MDH staff introductions

Dana Janowiak dana.janowiak@state.mn.us
- Outreach and Prevention Nurse Consultant
- Supports LPH staff who do follow-up for CYSHN programs

Karen Peterson karen.peterson@state.mn.us
- Nurse who follows the birth defects disorders
- Examples: Cardiovascular, Chromosomal, Ear, Eye, Orofacial, Central Nervous System, Gastrointestinal, Genitourinary or Musculoskeletal Conditions (List of all conditions)

Heather Pint heather.pint@state.mn.us
- Nurse who follows the critical congenital heart diseases (CCHD's)
- Examples: Tetralogy of Fallot, Hypoplastic Left Heart Syndrome, Transposition of the Great Arteries, Pulmonary Artesia, and Total Anomalous Pulmonary Venous Return

MDH staff introductions 2

Kristi Bentler kristi.bentler@state.mn.us
- Nurse who follows children with various newborn blood spot screening conditions
- Examples: metabolic, lysosomal, severe combined immunodeficiency, T-cell lymphopenia, spinal muscular atrophy

Amanda Maresh amanda.maresh@state.mn.us
- Nurse who follows children with endocrine or hemoglobinopathy newborn blood spot screening conditions
- Examples: congenital hypothyroidism, congenital adrenal hyperplasia, and sickle cell disease

Gina Liverseed gina.liverseed@state.mn.us
- Nurse who follows children with Congenital Cytomegalovirus (cCMV)

MDH staff introductions 3

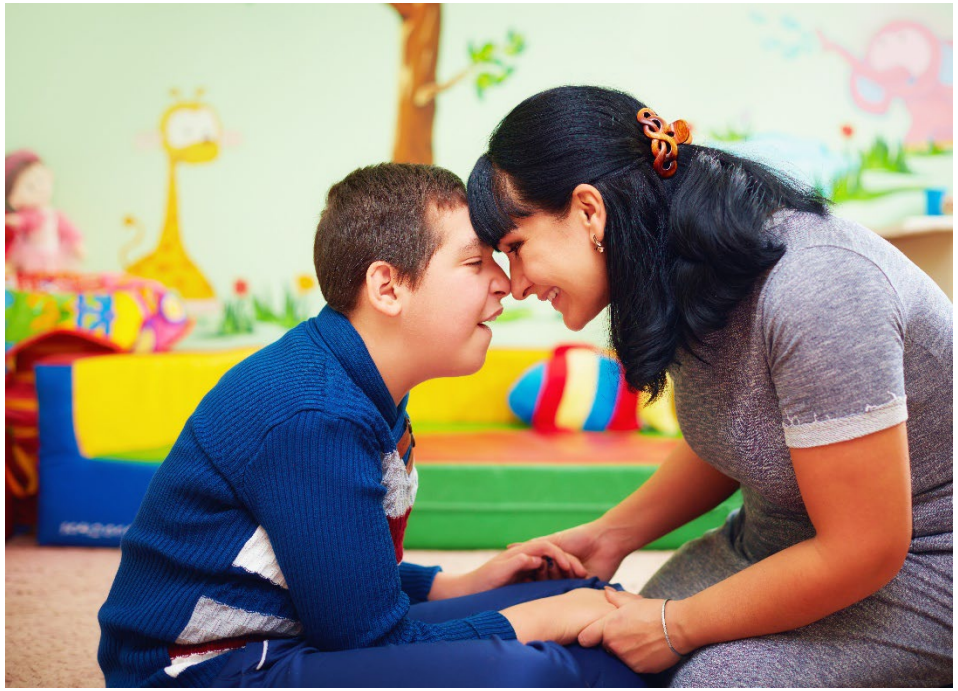
Annika Strong annika.strong@state.mn.us

- Follows children who refer from newborn hearing screening and still need follow-up to get to complete diagnosis.

Darcia Dierking darcia.dierking@state.mn.us

- Audiologist/Early Hearing Detection and Intervention Coordinator who follows children who are deaf, deafblind, and hard of hearing
- Examples: Permanent or persistent hearing conditions of all degrees and types (sensorineural, neural, permanent conductive, mixed). Can be unilateral or bilateral, congenital or acquired.

CYSHN vision



Vision

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

CYSHN program

Activities to enhance positive outcomes for CYSHN and their families

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

CYSHN Condition Follow-up process

Case identification through medical abstraction or newborn screening lab results.

CYSHN staff review cases and enter case data into LPH Workflows in MEDSS. Family is notified via mail that they will be contacted by LPH.

LPH staff contact family to complete follow-up, documenting in MEDSS.

Case 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.

Within one month of the referral

- Identify concerns and needs with the family through a nurse assessment focusing on income, connection to community services, 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.

Common needs and interventions

Common needs

- Navigating complex health care systems (primary, specialty, PCA services, insurance)
- Concerns about child growth and development
- Low income
- Language/cultural barriers
- Lack of transportation

Common interventions

- Offering support and encouragement
- Information (Health care systems, health education)
- Resources (Help Me Connect, Disability Hub, financial assistance, family support organizations)
- Services (Early intervention/Help Me Grow, Follow Along Program, Family Home Visiting)

Referrals to early intervention (EI)

Refer *all* children with the following conditions to early intervention through Help Me Grow Minnesota (www.helpmegrowmn.org/HMG) 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 the Follow Along Program as an additional resource for children who do not qualify for early intervention.

Additional requests

- 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 follow up rescreen.
  - Request assistance from LPH to attempt to contact family and help address barriers that prevent family from completing rescreen

Resources for LPH

- CYSHN Outreach and Prevention Nurse Consultant
  - Dana Janowiak dana.janowiak@state.mn.us
- CYSHN webpage
  - https://www.health.state.mn.us/people/childrenyouth/cyshn/index.html
- CYSHN Newsletter (email)
- Community of Practice (virtual)
- Annual LPH Conference (in person)

Thank You!

Children and Youth with Special Health Needs

health.cyshn@state.mn.us

651-201-3650