

Local Public Health Follow-Up Manual

CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

04/29/2025

Children and Youth with Special Health Needs Local Public Health Follow-Up Manual

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- CYSHN general email: health.cyshn@state.mn.us
- EHDI email: ehdi@state.mn.us
- MEDSS help: health.medss@state.mn.us
- Public Health Lab Hearing Screening/reimbursement questions: health.newbornscreening@state.mn.us

Secure fax numbers

- Public Health Lab Short-Term Follow-up fax: 651-215-6285
 - Use this number to fax hearing screening or audiology diagnostic reports
- CYSHN fax: 651-201-3655
 - Use this number as a backup for emailing documents meant for Birth Defects, Early Hearing Detection & Intervention, or Heritable Conditions

Children and Youth with Special Health Needs

The Minnesota Department of Health's (MDH) Children and Youth with Special Health Needs (CYSHN) section works to champion the health and well-being of people living in Minnesota with special health needs and disabilities from the earliest stages of life through transition to adulthood. The CYSHN activities in Minnesota include education, follow-up, community partnerships, public policy, and surveillance to enhance positive outcomes for children and families served.

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

Partnership with local public health

The MDH CYSHN program coordinates follow-up for children with birth defects and conditions identified through newborn screening. CYSHN staff refer these children to local public health (LPH) requesting follow-up with their families to assure connections to appropriate information, resources, and services. Together, CYSHN and LPH agencies serve children with these conditions and their families in all areas of the state.

Referrals began for children served by early hearing detection and intervention (EHDI) in 2009 through federal grant funding. In 2011, small grants were offered to expand referrals to include children with confirmed birth defects. Follow-up for infants with a confirmed newborn blood spot screening condition (hereafter referred to as "heritable conditions/cCMV [congenital cytomegalovirus]") was piloted with one county in 2020 and later expanded. By 2022, a system was in place to refer all children followed by CYSHN to LPH.

Birth Defects Monitoring and Analysis Program (BDMAP)

The Birth Defects Monitoring and Analysis Program (BDMAP) at the MDH gathers data about selected birth defects diagnosed in the first year of life. An estimated 2,000 infants are born in Minnesota each year with a birth defect. The mission of the program is to help children thrive, grow, and lead a healthy life. The primary goals of BDMAP are to:

- Monitor incidence trends of birth defects to detect potential public health problems, predict risks, and assist in responding to birth defects clusters.
- Ensure appropriate services are provided to affected families.
- Prevent birth defects through targeted education.
- Educate health professionals and the public regarding birth defects.
- Stimulate research on risk factors, treatment, prevention, and the cure of birth defects.

Knowledge of the occurrence of birth defects helps MDH link families to the services they need. Tracking when and where birth defects occur, and potential links to risk factors, provide critical information which may help prevent birth defects in the future. More information about birth

defects surveillance can be found on the [Birth Defects Monitoring and Analysis \(www.health.state.mn.us/birthdefects\)](http://www.health.state.mn.us/birthdefects) webpage.

Process overview

Hospitals and clinics report a limited set of information to MDH about infants discharged from their facilities who were treated for any of the monitored birth defects. These children are identified by diagnostic codes used for billing (i.e., ICD-10 codes). MDH abstractors obtain access to charts and review the medical records for additional details about the conditions.

Information from the medical record supporting a diagnosis of a birth defect is entered into the birth defects database in the Minnesota Electronic Disease Surveillance System (MEDSS). Each potential case is verified by ensuring it meets strict case definitions consistent with national standards. If the case definition has been met, the abstractors assign the most appropriate birth defect code based on the confirmatory evidence from the medical records.

Finally, an MDH nurse specialist reviews the completed case abstraction to ensure the most accurate and consistent birth defect codes have been assigned. The MDH nurse specialist determines the justification for the code from the abstraction and [acuity assignment \(https://www.health.state.mn.us/people/childrenyouth/cyshn/local/bdacuity.pdf\)](https://www.health.state.mn.us/people/childrenyouth/cyshn/local/bdacuity.pdf) for each case based on the severity of the child's birth defect(s). High acuity is assigned to the following cases:

- Children with a high probability condition which makes them automatically eligible to receive Minnesota's infant and toddler Early Intervention (EI) Services. Information is available online for [Diagnosed Conditions Affecting Development \(http://helpmegrowmn.org/HMG/HelpfulRes/ResourcesProf/DiagCondAffectDev/index.html\)](http://helpmegrowmn.org/HMG/HelpfulRes/ResourcesProf/DiagCondAffectDev/index.html).
- Children with critical congenital heart disease (CCHD). Even though these conditions are not currently considered automatically eligible for EI, there is high risk for developmental delay associated with the complexity of a heart condition and surgery the child may receive. It is important they are referred for evaluation.
- Children who are very low birth weight (VLBW). All children born < 1500 grams fall into this category. VLBW is not a condition tracked by MDH; however, if the child has a tracked condition and it is noted the child is VLBW the acuity will be assigned as high due to the birth weight.

If necessary, MDH staff may consult with medical specialists for further clarification of complex conditions. At this point, a birth defects "case" has been created.

This is depicted in the [Birth Defects Follow-up Process \(https://www.health.state.mn.us/people/childrenyouth/cyshn/birthdefectflow.pdf\)](https://www.health.state.mn.us/people/childrenyouth/cyshn/birthdefectflow.pdf).

Early Hearing Detection and Intervention (EHDI)

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

The majority of infants who are deaf or hard of hearing are born to hearing parents and most often they have no experience with hearing loss. Without early identification and intervention, children with hearing loss often experience delayed development in language and learning.

The MDH Early Hearing Detection and Intervention (EHDI) program collaborates with hospitals, midwives, physicians, audiologists, LPH departments, early intervention programs, and other partners to ensure infants with hearing loss are identified early and receive appropriate and timely intervention services for optimal developmental outcomes. The goal of the EHDI program is to maximize linguistic competence and literacy development for children who are deaf, deafblind and hard of hearing (DHH) by 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 services before 6 months of age for children identified with hearing loss.

MDH respects the many terms families and children who are DHH use to describe their identities. “Deaf, deafblind and hard of hearing” is meant to be all-inclusive. Please see the Minnesota Commission of the Deaf, DeafBlind & Hard of Hearing (MNCDHH) [“Respect for Identities” statement](https://mn.gov/deaf-commission/what-we-do/respect-identities/) (<https://mn.gov/deaf-commission/what-we-do/respect-identities/>) for more information. The term “hearing loss” is commonly used by providers to convey audiology concepts or describe results from a hearing test and is used in this manual. However, MDH recognizes the term “hearing loss” can feel offensive to some, depending on one’s cultural perspective.

Process overview

The EHDI program at MDH consists of two teams: the newborn screening program within the Public Health Lab (PHL) and the CYSHN program. These teams work together to ensure children in Minnesota with hearing loss are identified as early as possible and are connected to the resources they need to have the best health and educational outcomes possible.

In general, PHL is responsible for ensuring infants receive screening and follow-up evaluation, if needed. They provide follow-up for infants until a hearing loss is either identified or ruled out. Once a child is identified as having a hearing loss, the CYSHN program works to improve systems for children who are DHH and to ensure families are connected to important services and supports. The EHDI process is illustrated in [Hearing Screening & Diagnosis: Provider and MDH Roles](https://mn365.sharepoint.com/sites/MDH/cfh/CYSHNresources/Shared%20Documents/MDHtimeline_ForEHDI.pdf) (https://mn365.sharepoint.com/sites/MDH/cfh/CYSHNresources/Shared%20Documents/MDHtimeline_ForEHDI.pdf)

MDH rescreening/diagnostic follow-up

All hospitals in Minnesota are required to perform a hearing screening on newborns within 48 hours of birth and report the results to MDH. If a newborn does not pass his or her hearing

screen (also known as receiving an “alert: refer” result), MDH’s PHL tracks the child until documentation of a “pass” result, or a diagnostic test is obtained.

MDH has a well-defined protocol to obtain rescreening results from health care providers. PHL staff call the child’s primary care provider (PCP) to make sure they are aware the child did not pass their newborn hearing screening. PHL staff ask for information on the follow-up plan. If the child is referred by the PCP to an audiology clinic for a rescreen or diagnostic testing, PHL staff call the audiology clinic to ensure a follow-up appointment has been scheduled by the family. MDH generally does not call families of newborns who do not pass their hearing screening to prompt follow-up unless the child’s PCP is unknown.

MDH obtains documentation of a passing rescreen or hearing loss diagnosis for most newborns who do not pass initial screening. However, if MDH is unable to obtain this documentation, the cases are considered lost to follow-up/documentation (LTF/D). PHL sends these “lost” cases to LPH agencies to contact the families and help address barriers preventing them from completing follow-up.

Common reasons why MDH is unable to obtain needed documentation:

- Family does not respond or refuses additional testing.
- Unable to determine where the infant is receiving primary care.
- The PCP does not understand the importance of follow-up and is not addressing the need for a rescreen.
- The PCP is unresponsive to MDH’s request for follow-up information.
- The family does not schedule the needed follow-up appointment.
- The family lacks the resources or transportation needed to make the follow-up appointment.
- The family does not attend or cancels multiple follow-up appointments.

MDH confirmed hearing loss follow-up

Audiologists in Minnesota are required to report all cases of hearing loss identified in children through the age of 10 years (until their 11th birthday). Documentation of hearing loss is sent to PHL. PHL notifies staff in the CYSHN program of a new child with hearing loss has been identified.

The type of follow-up provided by CYSHN staff depends on the child’s type of hearing loss. Follow-up for children whose hearing loss is permanent or long-term (sensorineural, neural, or mixed hearing loss, atresia, or a permanent conductive hearing loss) includes the following:

- MDH sends the PCP a letter with information from the Joint Committee on Infant Hearing (JCIH) recommending referrals to medical specialists (ENT, ophthalmology and genetics) and the vast system of supports for families who have a child who is DHH, including Help Me Grow.

- MDH sends the parent/legal guardian of the child an [EhDI Parent Letter and FAQ](http://www.health.state.mn.us/docs/people/childrenyouth/improveehdi/parentletter.pdf) (www.health.state.mn.us/docs/people/childrenyouth/improveehdi/parentletter.pdf). This letter includes a Q&A page about EhDI and is included in a binder of printed resources. An electronic list of the printed resources is here: [What You Need to Know: Resources for Families about Hearing](http://www.health.state.mn.us/docs/people/childrenyouth/cyshn/ehdibinder.pdf) (www.health.state.mn.us/docs/people/childrenyouth/cyshn/ehdibinder.pdf)
- MDH refers the child's family to [Minnesota Hands & Voices](http://www.lssmn.org/mnhandsandvoices/) (www.lssmn.org/mnhandsandvoices/), an organization providing parent-to-parent support for families of children with hearing loss.
- MDH notifies LPH of children living within their jurisdiction. LPH staff are responsible for identifying the needs of the family and ensuring the child has been connected to early intervention and other needed services.
- LPH is not notified of children with a hearing loss which is likely temporary (mild to moderate conductive hearing loss). This type of hearing loss is typically caused by fluid in the ears and most often will resolve on its own or with placement of pressure equalizing (PE) tubes. The EhDI program attempts to obtain follow-up results from the audiologist and MDH staff consults with the PCP when appropriate.

Best practice for congenital hearing loss is to begin EI services as soon as possible, but no later than six months of age to support language development. Research shows there is a critical window for language development, especially in the first three years of life. Children with congenital hearing loss who begin EI services before six months of age have significantly better language and educational outcomes than children who start EI later. Even if a child is identified with a hearing loss after six months of age, connecting them to EI services as soon as possible can make a significant difference in language development and educational outcomes.

If hearing devices (amplification) are recommended and *if families choose amplification*, the best practice is for amplification to be fit within one month of diagnosis. In addition, several specialist referrals should be made by the PCP after a hearing loss is identified. Children identified with hearing loss should be seen by:

- an ENT by four months of age.
- an ophthalmologist by six months.
- a geneticist by 12 months.

It is not LPH's responsibility to ensure all these appointments occur. The role of the LPH contact is to educate about the importance of further medical evaluation/care and assist the family in enrolling in any public health insurance programs or transportation services they may qualify for if they are having difficulty accessing medical care.

Families receive the [Road Map for Hearing](http://www.health.state.mn.us/people/childrenyouth/improveehdi/roadmap.html) (www.health.state.mn.us/people/childrenyouth/improveehdi/roadmap.html) in the MDH resource binder. This road map, available in several languages, may help the family ensure their

infant is receiving best practice care. LPH contacts may want to refer to this document when contacting families.

Heritable Conditions and cCMV Longitudinal Follow-up

The blood spot screen is one of three parts of an infant's newborn screening done soon after birth. Currently, Minnesota screens newborns for more than 60 conditions affecting metabolism, hormones, the immune system, blood, breathing, digestion, hearing, or the heart. Hundreds of newborns are identified with a heritable or congenital disorder by blood spot screening in Minnesota each year.

Heritable conditions and cCMV longitudinal follow-up aim to understand and optimize outcomes for the health and well-being of children identified through newborn blood spot screening by:

- Connecting children with resources and services early in life.
- Collecting and using data to:
 - Ensure children and their families get the support and resources they want and need.
 - Help evaluate the benefits of early identification through newborn screening in reducing condition-related morbidity and mortality in childhood.
 - Inform policy and decision-making through a health equity lens.

Process overview

After the infant's health care provider confirms the infant has one of these conditions, they report it to MDH. CYSHN program staff then starts longitudinal follow-up, typically taking the following steps:

- MDH CYSHN reviews the child's reported information and mails a letter to the parents of a child with a heritable condition or cCMV. The letter includes a Q&A about data collection and resources including health care; financial; education and development; family support and networking; and other information.
- About one week after the mailing, CYSHN notifies LPH of a child with a heritable condition or cCMV for follow-up within their jurisdiction. This allows the parent/legal guardian time to receive the information and to contact MDH with questions.

LPH contact roles and responsibilities

MDH asks each LPH agency to identify at least one person within their agency to be the CYSHN LPH contact. The primary responsibilities of LPH contacts are to ensure quality, timely follow-up and documentation on all reimbursable cases sent to their LPH agency. Per the grant agreement, the roles and responsibilities of LPH contacts include:

- Receive referrals of new cases and assign cases to other staff for follow-up, if appropriate.
- Make at least three attempts to contact the family of all cases.
- Obtain and maintain access to MEDSS and the [CYSHN LPH Partner Resources](https://mn365.sharepoint.com/sites/MDH/cfh/CYSHNresources/SitePages/Home.aspx) (<https://mn365.sharepoint.com/sites/MDH/cfh/CYSHNresources/SitePages/Home.aspx>) SharePoint page.
- Inform current supervisors/managers of updates and needs MDH has communicated to the LPH contact.
- Update staff within the LPH agency on best practices and relay communications from MDH as appropriate.
- Identify staff from within the LPH agency who will be involved in the follow-up of cases. If the staff member needs access to MEDSS to perform follow-up, the staff member must complete training and provide contact information to MDH.
- Update MDH with any change in LPH contact status or contact information, including when a staff member no longer needs access to MEDSS or SharePoint.
- Participate in trainings MDH determines necessary to perform program requirements.

MEDSS

MEDSS is the secure database used to organize and document on all CYSHN cases, except hearing screening follow-up. Only those who have completed training and received authorization from MDH are allowed to access and document within MEDSS. The [CYSHN MEDSS User Manual](https://www.health.state.mn.us/people/childreneyouth/cyshn/local/medssmanual.pdf) (<https://www.health.state.mn.us/people/childreneyouth/cyshn/local/medssmanual.pdf>) has specific documentation instructions for LPH contacts. MEDSS organizes events into the following workflows:

- **LPH Follow-up to Complete:** Events with only one Agency Notified field listed.
- **LPH Additional Follow-up to Complete:** Events with an acuity change or more than one Agency Notified field listed (e.g. a child moved).
- **LPH Second Assessments:** Events where the LPH contact determined the family needed a second assessment and indicated they would be contacting the family again.
- **LPH Submit Follow-up:** Events where the LPH contact entered a date in the *Date LPH Completed Case* field but have not checked the Submit Event checkbox.

LPH contacts have access to CYSHN cases as they are added to the workflows. Documenting the follow-up immediately will keep assessment workflows up to date and ensure timely reimbursement.

MDH sends email reminders to follow-up on birth defects, heritable conditions, and cCMV cases approximately every two weeks. LPH contacts may not have a new case each time an email is

sent, but it is a good reminder to log into MEDSS to check workflows and to keep MEDSS access active. EHDI emails notifications to LPH as cases are added to the workflows.

LPH follow-up for a child with a birth defect, hearing loss, heritable condition, and/or cCMV

The main goals of LPH follow-up are to identify child and family needs and assure connection with appropriate community resources and services. MDH does not provide a follow-up script because follow-up should be tailored to the family's needs. However, the following guidance is provided to meet grant agreement requirements.

Initial assessment for reimbursable referrals

Within one month of CYSHN referral, the LPH contact will:

1. Contact the family via phone, video, or home visit. The LPH contact may follow up via a secondary source (EI provider, PCP) to obtain follow-up information or updated contact information (address and phone number) if unable to contact the family directly.
2. Identify concerns and needs with the family through a nurse assessment with a focus on income/finance, health care supervision, growth and development, caretaking/parenting, and connection to community resources (minimum of at least one area assessed).
3. Document current services being used.
4. Identify and connect families to any additional services which may be beneficial and for which the family is eligible. These resources may include community resources, primary care, specialty care, EI, financial resources, transportation, parent-to-parent support, and other professionals/services as needed.

All children with permanent hearing loss or cCMV are eligible for EI. All high acuity birth defects cases are likely eligible for EI. **MDHs expects LPH contacts to refer *all* these children through [Help Me Grow Minnesota \(www.helpmegrowmn.org/HMG/index.html\)](http://www.helpmegrowmn.org/HMG/index.html)** unless they are already connected with these services.

Some children with heritable conditions or other birth defect conditions may also be eligible for EI. Help Me Grow has a [list of diagnosed conditions affecting development \(www.helpmegrowmn.org/HMG/HelpfulRes/ResourcesProf/DiagCondAffectDev/index.html\)](http://www.helpmegrowmn.org/HMG/HelpfulRes/ResourcesProf/DiagCondAffectDev/index.html) which are considered red flags for immediate referral. 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 \(www.health.state.mn.us/mnfap\)](http://www.health.state.mn.us/mnfap) as another important developmental resource for any young child.

5. Determine if the family would benefit from a second assessment.
6. Update address and contact information in MEDSS.

- a. If the LPH contact learns the family has moved out of the county or state, they should note this information in *Critical Updates* within the MEDSS LPH Assessment Wizard.
 - i. Cases still residing in Minnesota will be re-referred to the new county of residence by CYSHN program staff.
 - ii. Not all states have equivalent CYSHN programs, therefore, LPH should use their professional judgement about referring the family to supports in their new home state.
 - iii. If the LPH contact already completed the assessment in MEDSS, they should contact the LPH contact of the new county of residence and make a county-to-county referral.
7. Submit required data real time (as it is collected) into the appropriate LPH wizard in MEDSS.

Second assessment for reimbursable referrals

The LPH contact may provide a second assessment if they determine additional follow-up is needed. The focus of the second assessment should be on the areas of concern noted during the initial assessment but may also include new needs identified.

Approximately 1-3 months after the initial assessment, the LPH contact will:

1. Contact the family.
2. Confirm connection to referred services.
3. Identify additional needs and/or services which may be beneficial and for which the family is eligible with a focus on income/finance, health care supervision, growth and development, caretaking/parenting, and connection to community resources (minimum of at least one area assessed).
4. Connect families to additional services/resources.
5. Submit required data real time (as it is collected) into the appropriate LPH wizard in MEDSS.

Follow-up when another LPH nurse is involved

When another nurse within an LPH agency has already contacted the family, the LPH contact does not need to contact the family again for follow-up if the family is aware of and receiving appropriate services for the confirmed condition. However, the reimbursement will be at a reduced rate if the information is obtained from a third party.

- Document pertinent information obtained from the third party in the LPH Assessment wizard in MEDSS and indicate another nurse is involved with the family by checking *Previous PHN Assessment* in the *Parent/Guardian Contact* field.

- The *Date Initiated* field is the date the LPH contact started working on the case. The date must be the day of or a date after the case is sent to the LPH agency. This may not coincide with the date the family began services through another LPH program or nurse.

If the third party was not aware of the condition for which the LPH contact received the referral and did not discuss the condition, the LPH contact should contact the family to complete an initial assessment. Reimbursement will be at the same rate as an initial assessment.

LPH follow-up for Birth Defects address assistance requests

When a mailed parent letter is returned to MDH as “undeliverable”, BDMA program staff attempt to find a new address. If unsuccessful, the LPH contact from the county in which the family last resided is emailed to assist with finding the family’s current address. This family has not yet received the parent letter mailing; they do not know their child has been included in the BDIS and they have the right to remove their identifying information (opt-out). The request for address assistance is a separate process than follow-up. Follow-up begins two weeks *after* the parent letter mailing has been successfully delivered.

The LPH contact is given access to the case in MEDSS while looking for the family’s current address. The LPH contact documents the results of their search using the *New Address Request* wizard. Information should not be entered into the *LPH Assessment* wizard at this time. The critical update box should be checked to notify MDH staff of the results of the search.

If LPH was unable to find a new address, MDH will mark the case as *Lost to Follow Up* and LPH will not be notified of the event again. If a new address is located, the MDH parent letter mailing will be re-sent. After the two-week waiting period, the appropriate LPH agency will be notified of the case for follow-up.

MDH will reimburse the LPH \$75 for address assistance requests, even if the address assistance search did not result in a new address. This reimbursement is *only* for circumstances when MDH specifically requests address assistance to resend the parent letter mailing. The standard updating of addresses taking place during follow up is considered part of the reimbursement for follow-up. Refer to CYSHN MEDSS User Manual for more information on using the *New Address Request* wizard.

LPH follow-up for Hearing Screening

All infants who do not pass their initial hearing screening need to be rescreened. When an infant missed or did not pass newborn hearing screening and the result of their hearing status is unknown, the newborn hearing screening program within PHL emails the LPH contact a referral using the [Hearing Screening Follow-up Form](https://mn365.sharepoint.com/:b:/r/sites/MDH/cfh/CYSHNresources/Shared%20Documents/LPH%20Reporting%20Form%202011.22.pdf?csf=1&web=1&e=RGnvM9) (<https://mn365.sharepoint.com/:b:/r/sites/MDH/cfh/CYSHNresources/Shared%20Documents/LPH%20Reporting%20Form%202011.22.pdf?csf=1&web=1&e=RGnvM9>). This form includes demographic information, most recent screening date, and case notes for the child. LPH contacts submit required data real time (as it is collected) in the electronic fillable form.

Alternatively, LPH contacts may print the form to fill out. Once documentation is complete, the LPH contact returns the form via email to health.newbornscreening@state.mn.us or faxes it to (651) 215-6285. LPH contacts should save a copy of the form for internal record keeping and track of the number of cases completed each quarter.

Hearing Screening follow-up goal

The main goal of hearing screening is to determine, as soon as possible, whether the child has a hearing loss. When MDH sends a Hearing Screening Follow-Up Form, the LPH contact will follow up with the family until one of the following outcomes occurs:

- MDH receives official documentation the child has received a ‘pass’ result for a screening or rescreening or diagnostic test in both ears.
- MDH receives official documentation the child has been diagnosed with a hearing loss.
- Family declines follow-up on missed or refer screening results.
- LPH contact determines the child no longer lives within their county/service area
- LPH contact determines the family is not going to follow up on screening, rescreening, or diagnostic test, despite LPH’s best efforts.
- LPH contact determines the child is lost to follow-up.

Initial newborn hearing screening results should be reviewed by the infant’s PCP at the first clinic visit. If the primary care clinic has the equipment needed to do an objective hearing rescreen, a rescreening should be done at this time. If the clinic does not have the needed equipment, the infant should be referred to a facility with the equipment for a rescreening appointment.

Objective hearing rescreening can be done in the hospital nursery, at the clinic or by an audiologist. Some communities have additional low-cost resources for screening, such as school audiologists and/or local Head Start agencies. Best practice is to complete the rescreening by one month of age.

If the infant does not pass the second screen, the family should be referred to an audiologist or ENT who evaluates very young children and performs diagnostic testing as soon as possible. The goal is for all infants referred from the screening process to have a complete diagnostic audiological evaluation by three months of age. For more information about follow-up for hearing screening see the [Newborn Screening Information for Providers: Hearing Screening for Primary Care Providers](https://www.health.state.mn.us/people/newbornscreening/providers/hearingprimary.html) <https://www.health.state.mn.us/people/newbornscreening/providers/hearingprimary.html> webpage.

Hearing Screening follow-up strategies

MDH has already tried to prompt an initial screening or a rescreen and obtain appropriate documentation for children considered “lost to follow-up.” The cases sent to LPH are likely families who experience challenges in accessing health care or who may need more information

about the importance of rescreening. Follow-up on these cases depends on the resources and health services available. There is no single “correct” way to follow up on these cases, however, LPH nurses across the state have compiled a [Local Public Health Hearing Screening Checklist \(https://www.health.state.mn.us/people/childrencyouth/cyshn/lphchecklist.pdf\)](https://www.health.state.mn.us/people/childrencyouth/cyshn/lphchecklist.pdf) of effective strategies.

Contacting the family directly

Once contact with a family is made, LPH contacts may need to provide the family with education about the importance of hearing screening follow-up. The parent/legal guardian may not understand the importance of follow-up. Infants who startle at loud noises or appear to be able to hear may have some degree of hearing loss. LPH contacts may find the [ALERT: REFER Result \(www.health.state.mn.us/people/newbornscreening/materials/hearingrefer.pdf\)](http://www.health.state.mn.us/people/newbornscreening/materials/hearingrefer.pdf) fact sheet useful when contacting families.

LPH contacts may need to assist the family with obtaining transportation to and from appointments or signing up for public health insurance programs. For families who do not speak English, LPH contacts may need to arrange interpreter services to communicate with them about the rescreening or assist them in obtaining an interpreter at medical appointments.

Contacting the child’s health care providers

Communicating with the child’s PCP may help gain a better understanding of the family’s situation and the role the PCP has played in the rescreening process so far.

Some primary care clinics support families by scheduling initial screening or rescreening appointments. Some clinics monitor children who do not pass their newborn screening and provide reminders to families about follow-up appointments. Other clinics simply give families the number they need to call to schedule the appointment for the rescreening.

LPH contacts may call the PCP to understand how assertively the clinic has tried to get the infant in for follow-up and remind the clinic further follow-up is necessary. LPH contacts may find the PCP is unconcerned the infant needs to be rescreened. LPH contacts play an important role in educating the PCP in these situations. Hearing loss is a developmental emergency. If the child does have hearing loss, they could miss a critical window for language development if there is a delay in diagnosis. Some providers think they can monitor the infant’s hearing at well child checks without using objective testing. LPH contacts should inform PCPs objective testing, such as otoacoustic emission (OAE) screening or auditory brainstem response (ABR) audiometry, is the only accurate way to rule out hearing loss in a newborn.

If the clinic does not own screening equipment, the child may be referred to audiology for the follow-up appointment. LPH contacts may call the audiology clinic to see if there are any upcoming appointments for the child. If not, LPH contacts should contact the family to identify why the appointment has not been made and reinforce the importance of follow-up. LPH contacts may contact the primary care clinic to see if the child has any upcoming appointments where the PCP could remind the family about the importance of following up.

Hearing Screening outcome options

Child passed screening/rescreening

Request a copy of the screening report from the clinic and submit it with the Hearing Screening Follow-Up Form. Provide the [HIPAA and Medical Information Related to Newborn Hearing Screening, Diagnosis, and Intervention](https://www.health.state.mn.us/people/childrencyouth/cyshn/local/hearinglosshipaa.pdf) (<https://www.health.state.mn.us/people/childrencyouth/cyshn/local/hearinglosshipaa.pdf>) document if the clinic is hesitant to share the report. If still unwilling, inform clinic staff they are required to send the report to MDH and provide the PHL fax number (651-215-6285).

Child diagnosed with a confirmed hearing loss

Request a copy of the diagnostic report from the clinic and submit with the Hearing Screening Follow-Up Form. Provide the [HIPAA and Medical Information Related to Newborn Hearing Screening, Diagnosis, and Intervention](https://www.health.state.mn.us/people/childrencyouth/cyshn/local/hearinglosshipaa.pdf) (<https://www.health.state.mn.us/people/childrencyouth/cyshn/local/hearinglosshipaa.pdf>) document if the clinic is hesitant to share the report. If still unwilling, inform clinic staff they are required to send the report to MDH and provide the PHL fax number (651-215-6285).

Family declined to follow up on screening result

The family specifically states they do not intend to follow-up on their infant's "missed" or "refer" screening result. This option should not be selected in cases of "soft declines" where the family does not respond to LPH or does not follow through in scheduling or attending appointments.

If known, indicate the reason the family chose to decline. Identify whether health insurance or transportation are barriers to follow-up. Offer support in connecting them with services to address these barriers, if available. If the family is not following up because the infant's PCP is not concerned, contact the PCP to provide education on the importance of following up on hearing screening.

Family not following up despite LPH best efforts

After three attempts, **the family says they will schedule the appointment, yet never do so.** Indicate if the lack of follow through is because the family or PCP does not consider hearing screening follow-up a serious concern.

Or

The family cancelled or no-showed at least two rescreening or diagnostic follow-up appointments since the LPH contact received the Hearing Screening Follow-Up Form. Do not count any cancelled or missed appointments indicated in the case notes of the Hearing Screening Follow-Up Form.

Unable to contact after at least three tries

The family has received the LPH contact's messages and/or letters but is choosing not to respond. Select this option if unable to contact the family, but there is no indication the family has moved (i.e., letters haven't been returned to sender). Send a letter to the family if unable to reach them by phone. Contact child's primary care clinic and/or other social service agencies to obtain updated contact information for the family.

Unable to locate after at least three tries

LPH is unable to determine the family's correct contact information (e.g., the family's phone number is incorrect or disconnected and letters are returned undeliverable).

Child lives in Minnesota but not within my LPH service area

Provide updated address information on the Hearing Screening Follow-Up Form. The Hearing Screening Follow-Up Form will be re-sent to the LPH agency where the child lives.

Child does not live in Minnesota

Provide updated address information on the Hearing Screening Follow-Up Form. MDH does not follow-up on children living outside of Minnesota. The case will be closed and MDH will refer the case to the state of residence.

Other

None of the categories apply to the situation.

Reimbursement

Children and Youth with Special Health Needs (CYSHN) Program will reimburse when LPH contacts submit the required data through MEDSS on a quarterly basis based on the following criteria:

CYSHN Level One

Payment of \$75.00 per case when the LPH contact provides minimal data to the STATE (update of Address/Phone Number, Primary Language, Insurance status, home visiting status, Referral to IDEA Part C & Part B status) or attempts to contact the family but was unsuccessful in identifying needs with an initial nurse assessment. This includes:

- the LPH contact did not make contact with the family but was able to provide minimal data to STATE via a secondary source and documents the information in MEDSS; or
- the LPH contact did not make contact with the family but was able to provide an updated address to the STATE when requested; or
- the LPH contact made contact with the family and was only able to provide minimal data to STATE but was not able to assess and document family needs in MEDSS; or

- the LPH contact attempted to contact the family using multiple methods but was unsuccessful.

CYSHN Level Two

Contact with family in order to identify needs through an initial nurse assessment.

- Level 2A (Electronic or office/clinic) = Payment of \$225 per case for successfully providing an electronic or office/clinic initial nurse assessment (e.g., phone visit or telehealth) with the family in order to identify current services being used, identify needs and/or additional services that may be beneficial and for which the family is eligible, and connect families to identified resources. The assessment, interventions provided, and required data are documented in the appropriate LPH Wizard in MEDSS.
- Level 2B (Home Visit)- Payment of \$375 per case for providing a home visit with the family and successfully conducting an initial nurse assessment to identify current services being used, identify needs and/or additional services that may be beneficial and for which the family is eligible, and connect families to identified resources. The assessment, interventions provided, and required data are documented in the appropriate LPH Wizard in MEDSS.

CYSHN Level Three

Confirm connection to referred service and second nurse assessment when indicated.

- Payment of \$125 per case when an LPH contact has identified needed services/resources during the initial nurse assessment and has determined that a second assessment to confirm connection to referred services, identify additional needs and/or services that may be beneficial and for which the family is eligible, or connect families to additional services/resources that may be beneficial. The second nurse assessment, interventions provided, and the status of connection to the services recommended by the LPH contact during the initial nurse assessment are documented in the appropriate LPH Wizard in MEDSS approximately 1 to 3 months after initial assessment.

Early Hearing Detection and Intervention (EHDI) Program Lost to Follow-up Cases

Payment of \$75.00 per case for follow-up of each infant or child identified as lost to follow-up by the EHDI Program when the LPH contact submits the required data using the form provided by MDH on a quarterly basis.

Additional Reimbursement information

Agencies will be reimbursed for follow-up on birth defects cases assigned as a medium or high acuity condition. While the LPH contact may follow-up on low acuity birth defects cases and

document them in MEDSS, the LPH agency will not be reimbursed for it. All other events (heritable conditions, cCMV, and EHDI) are reimbursable.

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.

Event documentation should be completed and submitted by the end of each quarter. Approximately two weeks before the end of each quarter, MDH sends a reminder email to LPH contacts to complete assessments and submit events in MEDSS to receive payment for those events.

MDH will reimburse \$150 for required training. If an LPH contact changes, MDH will still reimburse \$150 for a new LPH contact to complete the required trainings.

Reimbursements will be made to the appropriate CHB and the reimbursement summary will be emailed to the LPH contact(s). The LPH contact may review the payment information and notify health.cyshn@state.mn.us if a correction is needed. Corrections will be made in the next quarter, if necessary.

All invoicing is completed according to the following schedule:

Date work/training completed	Complete documentation by	Invoicing month
Jan. 1 to March 31	March 31	Apr.
April 1 to June 30	June 30	Jul.
July 1 to Sept. 30	Sept. 30	Oct.
Oct. 1 to Dec. 31	Dec. 31	Jan.

Opt-out

A child's parent/legal guardian may contact MDH directly to opt-out of CYSHN follow-up at any time. Each program area within CYSHN may have a different opt-out process and it is possible for the parent/legal guardian to opt-out of one program area and not another. If a parent/legal guardian has questions about the opt-out and de-identification process or indicates a desire to opt-out, refer them back to CYSHN staff at MDH. Families receive contact information for MDH staff in the mailing sent to them. Once an opt-out request has been processed, follow-up information pertaining to the child is de-identified.

Appendix 1 – Important MDH websites

- [Birth Defects Monitoring and Analysis](https://www.health.state.mn.us/people/childrenyouth/birthdefects/index.html)
(<https://www.health.state.mn.us/people/childrenyouth/birthdefects/index.html>)
- [Children and Youth with Special Health Needs](https://www.health.state.mn.us/people/childrenyouth/cyshn/index.html)
(<https://www.health.state.mn.us/people/childrenyouth/cyshn/index.html>)
- [CYSHN LPH Partner Resources](https://mn365.sharepoint.com/sites/MDH/cfh/CYSHNresources/SitePages/Home.aspx)
(<https://mn365.sharepoint.com/sites/MDH/cfh/CYSHNresources/SitePages/Home.aspx>)
- [Early Hearing Detection and Intervention \(EHDI\)](https://www.health.state.mn.us/improveehdi)
(<https://www.health.state.mn.us/improveehdi>)
- [Find a Local or Tribal Health Department or Community Health Board](https://www.health.state.mn.us/communities/practice/connect/findlph.html)
(<https://www.health.state.mn.us/communities/practice/connect/findlph.html>)
- [Follow Along Program](https://www.health.state.mn.us/people/childrenyouth/fap/index.html)
(<https://www.health.state.mn.us/people/childrenyouth/fap/index.html>)
- [Local Public Health Partner Resources](http://health.state.mn.us/people/childrenyouth/cyshn/partnerresources.html)
(<http://health.state.mn.us/people/childrenyouth/cyshn/partnerresources.html>)
- [Longitudinal Follow-up for Newborn Screening](https://www.health.state.mn.us/people/childrenyouth/ncfu/index.html)
(<https://www.health.state.mn.us/people/childrenyouth/ncfu/index.html>)
- [Minnesota Electronic Disease Surveillance System](https://medss.web.health.state.mn.us/medss/login.do)
(<https://medss.web.health.state.mn.us/medss/login.do>)
- [Newborn Screening Information for Providers](https://www.health.state.mn.us/people/newbornscreening/providers/hearingresults.html)
(<https://www.health.state.mn.us/people/newbornscreening/providers/hearingresults.html>)

Appendix 2 – Glossary

See also: [Minnesota Public Health Data Access Glossary of Terms](https://data.web.health.state.mn.us/glossary)
(<https://data.web.health.state.mn.us/glossary>)

Abstraction: The process of recording information identified when reviewing documentation in a medical record or other information source and entering the information into data fields in a specified format. Information may be recorded on print forms or on a computer.

ABR: The Auditory Brainstem Response (ABR) is an objective test which can be used to estimate hearing sensitivity and to identify neurological abnormalities of the auditory nerve and the auditory pathway up through the brainstem.

Birth Defect: An abnormality present at birth caused by a genetic mutation, an unfavorable environment during pregnancy, or a combination of both. The effect of a birth defect can be low or high acuity, or incompatible with life. Other terms utilized include congenital anomalies, congenital defects, and birth variations/differences.

Congenital disorder: A disorder present at birth. The causes of a congenital disorder include infection, injury, genetics, environmental factors, and others.

Event: The term used to describe where information about a person's disease or condition is stored in MEDSS. One person may have multiple events in MEDSS if they have several different conditions tracked by MDH. For example, a child could have both a hearing loss and birth defect event. Each event is tied to the person's core person information (name, birth date, address), but is stored separate from other events in MEDSS. Each event can only be viewed by users who have permission to view those types of conditions in MEDSS.

Event ID: The number associated with a confirmed case in MEDSS.

Heritable Conditions: The CYSHN program area focusing on longitudinal follow-up of children with Minnesota blood spot newborn screening conditions other than cCMV. Not all conditions followed by MDH Heritable Conditions are inherited.

MEDSS (Minnesota Electronic Disease Surveillance System): MEDSS is an electronic disease surveillance system allowing public health staff to receive, manage, process, and analyze disease-related data. MEDSS allows secure communication and coordination between state and local health departments. MEDSS allows for immediate exchange of information. In addition to reporting, MEDSS's security environment displays only the data someone needs and is authorized to see.

Monitoring: Performance and analysis of routine measurements using statistical methods aimed at detecting changes in the environment or health status of populations.

OAE: Otoacoustic emissions (OAEs) are sounds produced by the inner ear when the cochlea is stimulated by a sound.

Registry: A system of ongoing registrations, where cases of a disease or other health-relevant condition are defined in a population and can be related to a population base. Birth and death registration systems are examples.

SharePoint site: A secure web application platform in the Microsoft Office suite. SharePoint combines various functions which are used to store, organize, share, and access information from any device.

Surveillance: Ongoing, systematic collection, analysis, interpretation, and dissemination of health data on an ongoing basis. Surveillance is conducted to identify potential public health threats or patterns of disease occurrence and risk in a community. May also be referred to as tracking.

Appendix 3—Statutory Language and Health Insurance Portability and Accountability Act (HIPPA)

Birth Defects

The 2004 Minnesota Legislature amended the [MN Birth Defects Statutes \(www.health.state.mn.us/people/childrenyouth/birthdefects/statute.html\)](http://www.health.state.mn.us/people/childrenyouth/birthdefects/statute.html) to enable establishment of the Minnesota Birth Defects Information System (BDIS). This included clarifying language on goals, data sources, reporting without liability, data privacy, an opt-out clause, and guidelines on conducting research. The definition of a “birth defect” is consistent with what is used by CDC, other states, and national organizations. This language became effective March 2005, when MDH received a federal grant to support implementation of a regional birth defects program. During the 2010 legislative session, financial support was provided to expand birth defects activities statewide.

Early Hearing Detection and Intervention (EHDI)

In May 2007, legislation [Minnesota Statutes, chapter 144, section 966](#) was enacted to mandate reporting of newborn hearing screening results and added hearing loss to the panel of rare conditions for which every newborn in Minnesota is screened. This legislation requires:

- All hospitals to screen every newborn for hearing loss (unless a parent/legal guardian declines) and report the results to the MDH.
- Professionals who conduct diagnostic procedures to confirm hearing loss to report the results to the parent/legal guardian, primary care providers, and MDH.
- MDH to design, implement, and evaluate a system of follow-up and tracking.
- MDH to evaluate program outcomes to increase effectiveness and efficiency and ensure culturally appropriate services for children with a confirmed hearing loss and their families.

Newborn Screening

In Minnesota, newborn blood spot screening is mandated by [Sec. 144.125 MN Statutes](#) - [Sec. 144.128 MN Statutes](#); newborn hearing screening (EHDI) is mandated by [Sec. 144.966 MN Statutes](#); critical congenital heart disease (CCHD) screening is mandated by [Sec. 144.1251 MN Statutes](#); and congenital cytomegalovirus (cCMV) is mandated by [Sec. 144.064 MN Statutes](#) and [Sec. 144.125 MN Statutes](#) - [Sec. 144.128 MN Statutes](#).

These statutes govern the responsibilities of healthcare providers and the Minnesota Department of Health in newborn screening, specimen collection, reporting of results, and follow-up services. These statutes also govern the Newborn Screening Program’s retention practices.

Confidentiality and the Health Insurance Portability and Accountability Act

If the LPH contact chooses to contact primary care or specialty providers, they may be hesitant to share information due to the Health Insurance Portability and Accountability Act (HIPAA). As a contractor with MDH, LPH contacts are working on MDH's behalf as a public health authority. Documents regarding CYSHN programs and HIPAA are available on the [LPH Partner Resources webpage](http://health.state.mn.us/people/childrenyouth/cyshn/partnerresources.html) (<http://health.state.mn.us/people/childrenyouth/cyshn/partnerresources.html>). If needed, LPH contacts may make a copy of these documents and share them with health care providers.