

Children and Youth with Special Health Needs News

July 2026

CYSHN updates

Upcoming CYSHN local public health workshops

The Minnesota Department of Health (MDH) has opened registration for the final in-person [2026 Children and Youth with Special Health Needs Local Public Health Workshops](#). The purpose of these workshops is to bring together local public health professionals to connect, share best practices, and explore solutions to today's public health challenges and our theme is "Equipped for the Future: Tools and Resources for CYSHN Outreach."

- **Southwest workshop:** Wednesday, Oct. 7 at the Lyon County Southwest Health and Human Services Office in Marshall. Register by Monday, Sept. 7.
- **Northeast workshop:** Tuesday, Oct. 20 at the St. Louis County Public Health and Human Services - Duluth Government Services Center. Register by Monday, Sept. 21.



Program-specific updates

Follow Along Program Basecamp

Based on feedback from local public health, MDH has created a Follow Along Program Basecamp, a virtual space for local public health to collaborate and share resources. Follow Along Program contacts received an invitation by email. Basecamp guidance and additional information are available in the Basecamp “Docs & Files” section. Contact health.cyshn@state.mn.us with "Basecamp" in the subject line if you have any questions.

Upcoming webinars, trainings, and events

National Center's Title V virtual cafés

These monthly virtual cafés from the National Center for a System of Services for CYSHCN are designed for Title V children and youth with special health care needs programs and staff, offering a space to connect, learn, and share ideas with peers. Please be sure to register for each session individually. The next two sessions are listed below, but you can find registration links for all of the virtual cafés on the [American Academy of Pediatrics](https://www.aapedia.org) website.

- **Friday, July 17 at 11 a.m.:** [EPSDT 101: Supporting Access for CYSHCN](#)
- **Friday, Aug. 21 at 11 a.m.:** [Advancing Care Coordination & Medical Home for CYSHCN](#)

July 22 – CYSHN condition follow-up community of practice

Please register for the next virtual, optional [CYSHN condition follow-up community of practice](#) on **Wednesday, July 22 from 9 - 10:30 a.m.** The purpose of these meetings is to provide routine opportunities for local public health nurses who provide follow-up for children referred by CYSHN programs (birth defects, hearing loss, heritable conditions, congenital CMV) to learn condition-specific information and discuss nursing practice.

July’s session will include a presentation about Star Legacy Foundation and supporting families who experience infant loss. This meeting will be recorded.

If you have any questions you would like to submit in advance, email them to health.cyshn@state.mn.us with “local public health” in the subject line.

Regional systems gatherings

Join MDH for a series of in-person regional gatherings across Minnesota during summer and fall 2026 for [Supporting Well-Functioning Systems for CYSHN and Families](#). These conversation based gatherings will bring together partners from across health and related systems to reflect on what helps systems work well within each region, where families experience challenges or disconnection, and how systems can become more coordinated and supportive for children and youth with special health needs and disabilities and their families.

Regional gathering dates

All gatherings will take place from 10 a.m. – 3 p.m. and will include lunch.

- **Wednesday, July 22:** West Central (Alexandria)
- **Thursday, July 23:** Northwest (Bemidji)
- **Monday, Aug. 10:** Metro South (TBA)
- **Tuesday, Sept. 15:** Southwest (Mankato)
- **Thursday, Oct. 8:** Southeast (Rochester)
- **Thursday, Oct. 29:** Metro North (TBA)

Complete the [Regional Systems Gatherings Registration](#) form to attend.

September 2 – Introduction to using the ages and stages questionnaires

Family home visiting is offering a combined ASQ-3 and ASQ:SE-2 training on **Wednesday, Sept. 2, from 8:30 - 11:30 a.m.** via Microsoft Teams. This training is open to Follow Along Program contacts who want an introduction to understanding the use and purpose of these developmental and social emotional screening tools. To register, visit [training and professional development](#) webpage underneath “current trainings.”

Resource corner

Family Voices fact sheet for Department of Justice legal memorandum on Olmstead

The U.S. Department of Justice recently issued a legal opinion arguing that states do not have to provide in-home or community-based care to people with disabilities who need support. For your awareness, we are sharing information from Family Voices outlining implications and resources for CYSHN and their families.

- [Family Voices' Response to the Department of Justice's Legal Opinion Memorandum \(PDF\)](#)
 - Fact sheet on the [Department of Justice Legal Memorandum on Olmstead \(PDF\)](#)
-

Rare disease prevalence and eligibility for gene therapies in Minnesota

The MDH Health Economics Program, in collaboration with the Minnesota Rare Disease Advisory Council, has released [Preparing for the Gene Therapy Era: Estimating Rare Disease Prevalence and Eligibility for Gene Therapies in Minnesota, 2018-2022 \(PDF\)](#).

Using the [Minnesota All Payer Claims Database \(MN APCD\)](#), this analysis estimated how many Minnesotans may be eligible for FDA-approved gene therapies for nine rare diseases. These estimates are a critical first step in projecting the need for and potential costs of these treatments and providing evidence to payers and policymakers engaged in these discussions.

Visit the [Publications Using the MN APCD](#) webpage to access the issue brief and accompanying supplement.

New report highlights 10 years of health equity progress in Minnesota



A new report released by MDH shows the agency has made significant progress on health equity initiatives over the last decade. The [Advancing Health Equity at the Minnesota Department of Health: 2014-2024 \(PDF\)](#) report provides an assessment of the department's progress on recommendations included in the pivotal "Advancing Health Equity in Minnesota: Report to the Legislature," released in 2014.

Invoicing

Quarter 1	Quarter 2	Quarter 3	Quarter 4
Jan. 1 - March 31	April 1 - June 30	July 1 - Sept. 30	Oct. 1 - Dec. 31

Condition Follow-up

Complete nursing follow-up documentation in MEDSS by the end of the quarter after the one in which the referral was made. For example, if the date the event was sent to local public health is July 15 (in quarter 3), the follow-up documentation should be submitted by Dec. 31 (the end of quarter 4).

Invoice letters are sent to local public health by MDH in the month following the end of the quarter in which documentation was submitted, or training was completed. So, in the example, the invoice letter would be sent to local public health some time before Jan. 31 (the month following the end of quarter 4).

Follow Along Program

Follow Along Program semi-annual data reports are due every 6 months. Data for quarters 1 and 2 are due annually on July 31. Data for quarters 3 and 4 are due annually on January 31. Invoices for quarters 1 and 2 are due each year on August 20. Invoices for quarters 3 and 4 are due each year on February 20. Semi-annual data reports must be received prior to the invoice being paid.

About the CYSHN newsletter

Children and Youth with Special Health Needs (CYSHN) section staff at MDH work together to champion the health and well-being of people living in Minnesota with special health needs and disabilities, from the earliest states of life through transition to adulthood.

As the Child and Family Health Division works to coordinate and collaborate on communication, this newsletter may evolve to include a broader focus, but the following CYSHN programs are the primary focus: Birth Defects; Early Hearing Detection and Intervention (EHDI); Heritable Conditions (HC); Congenital Cytomegalovirus (cCMV); Critical Congenital Heart Disease (CCHD); Neonatal Abstinence Syndrome (NAS); and the Follow Along Program.