



2017

Children and Youth With Special Health Needs Section

ANNUAL REPORT

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A LETTER TO THE READER



Dear Reader,

I invite you to join us as we reflect on the accomplishments of the Children and Youth with Special Health Needs Section in 2017. This report highlights major program achievements for our section. We will also describe our collaboration with our community partners.

We now collect information from local public health agencies about their follow-up with families with infants with a special health need. This valuable information gives us a snapshot of both the difficulties experienced by the families we serve and the most important supportive services they need. We will use this information to see what work still needs to be done to support Minnesota's children and youth with special health needs in meeting their full potential.

2017 brought both challenges and opportunities in our efforts to improve the quality of our work. Looking forward to 2018, I believe my team will continue to bring the same commitment to Minnesota's families with children and youth with special health needs to their work every day.

Sincerely,

Barb Dalbec, Section Manager



Children and Youth with Special Health Needs Program

Children and Youth with Special Health Needs *noun.*

1. Children and youth who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition. **2.** May need supportive services beyond what is generally required. **3.** Deserve a strong system of community resources to reach their full potential.



OUR COMMUNITY

One in five Minnesota families with children have at least one child with a special health need.

Over 228,700 children with special health needs live in Minnesota. This represents 18 percent of all children in Minnesota. Even more children have an increased risk of developing a special health need.

OUR VISION

To improve population health through building the capacity of all systems that serve families of children and youth with special health needs.

WHO WE ARE

The Children and Youth with Special Health Needs (CYSHN) Section at the Minnesota Department of Health serves families with children with, or at risk for, special health needs in multiple ways.

We work to prevent birth defects, monitor diagnoses of special health needs, coordinate follow-up for children with a special health need, promote care coordination, develop policies to support the community, and plan for the future of this work.

Ten years ago, legislation passed to create the Early Hearing Detection and Intervention (EHDI) program in Minnesota. This law required universal newborn hearing screening and founded the Newborn Hearing Screening Advisory Committee. It also funded family support programs like the Minnesota Hands & Voices, the Deaf Mentor Program, the Deaf and Hard of Hearing Role Model Program, and the Hearing Aid Loaner Program.

Over the last ten years, the EHDI program has been committed to improving early identification of hearing loss, promoting referral to supportive services, and strengthening community resources for families with a child who is deaf or hard of hearing.

Since universal hearing screening began, 2,937 children have been identified as deaf or hard of hearing.

Hands & Voices contacts nearly 90% of all families with children who are deaf or hard of hearing



Lifetrack Programs Support Families With Children Who Are D/HH



Lifetrack's family support programs like Minnesota Hands & Voices, the Deaf Mentor Family Program, and the Deaf and Hard of Hearing (D/HH) Role Model Program represent a crucial part of EHDI. In addition to supporting families directly, staff who are parents of children who are D/HH or are D/HH themselves participate in the EHDI Advisory Committee, and are an important resource to the EHDI program at MDH and professionals who work with children who are D/HH.

Contacting families soon after diagnosis, MN Hands & Voices provides parent-to-parent support, referrals to resources, and cultural parent guides. In the Deaf Mentor Family Program, a deaf adult teaches the family and child sign language, connects them to deaf culture, and gives them the chance to develop relationships within the deaf community. In the D/HH Role Model Program, adult role models who are D/HH offer unbiased support from someone who has experienced the challenges of being D/HH firsthand. The role models speak different languages, use various assistive listening devices, and have different types of hearing loss.

"The organization is absolutely amazing, and makes me not feel alone and 'different.'"

- Parent on the Hands & Voices Program

"We were so lucky to have [our deaf mentor] and now our son will always have a role model in the deaf community."

- Parent on the Deaf Mentor Program



Systems Integration Grant Project Launches CYSHN Navigator

Finalizing the Systems Integration Grant Project, the CYSHN Section partnered with multiple community organizations and stakeholders to accomplish the goals of the grant.

The grant aims to:

- Increase family and community engagement and partnerships
- Strengthen care coordination for CYSHN across the state
- Share information about community resources through the CYSHN Navigator

The CYSHN Navigator, completed in 2016, was improved and promoted to the public in 2017. This tool intends to help parents and providers of children and youth with special health needs. After being asked a series of questions, the CYSHN Navigator links people to the right resource for their needs. In addition to the website search engine, parents and providers can call a hotline or chat with a navigator online. Through the hotline and online messaging, navigators also connect parents to another parent through family support offered by Family Voices of Minnesota.

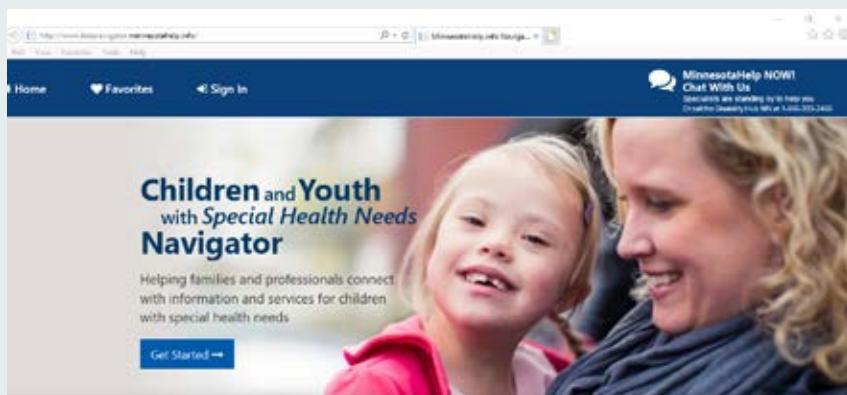
CYSHN Spotlight



CYSHN Navigator: helping families and professionals connect with information and services

Link to the Navigator on the [MDH CYSHN website](#)

117 views per day on the CYSHN Navigator



The Children and Youth with Special Health Needs Navigator on [MinnesotaHelp.Info](#)

PACER Youth Develop Training Videos



["Who Helps You Coordinate Your Health Care?" PACER Center Video](#)

The participating youth, recruited from PACER's Youth Advisory Board, picked the video topics related to transition to adult care, wrote the interview questions, and candidly answered the questions in a series of short videos called "Preparing for Adulthood: Taking Charge of My Own Health Care."



["How Do You Prepare for a Medical Appointment?" PACER Center Video](#)

Through the process of creating these videos, the youth participants felt more empowered to talk to their parents, providers, and teachers about their health care as well as more confident in making health care-related decisions.

A key part of the Systems Integration Grant, the CYSHN Section and PACER Center worked together to make training videos about transition to adult care. Youth with special health needs led the creation of these videos.



["What Can Medical Providers and Teachers Do to Help You Take Charge of Your Own Health?" PACER Center Video](#)

As of November 2017, these videos had over 500 views on Youtube.



["What Does Guardianship Mean to You?" PACER Center Video](#)

Family Voices of Minnesota Provides Parent-to-Parent Support

To learn available resources, parents with CYSHN prefer connecting to another parent experienced in navigating the health care system. This led to MDH creating the Family Support and Connections Grant Program, funded by the Title V Maternal and Child Health Block Grant. During 2017, a Request for Proposals was released, seeking applications from organization to coordinate the program. The grant was awarded to Family Voices of Minnesota.

"Being able to support another parent is a gift to me. I am able to lend an ear to someone who feels they have no one to talk to."

- Parent

In the Connected program, parent guides connect families to available resources. They also train parents on how to find services themselves and act as advocates for their children. Additionally, MDH uses data collected by Family Voices of Minnesota to identify ways to improve how care is delivered to CYSHN in the state.



Local Public Health Partners With CYSHN Families



Minnesota has many supportive services for children with special health needs and their families. However, when a baby has just been diagnosed with a birth defect or hearing loss, finding these resources can be overwhelming and stressful. The Minnesota Department of Health has asked local public health to follow up with these families to assess their needs and refer them to helpful resources.

The process begins with an initial letter sent to all families of children newly diagnosed with a birth defect or hearing loss. Then, parents of children with more serious conditions receive a phone call to evaluate any difficulties experienced by the families and to connect them with resources and services that help to ease the burden of these concerns. Follow-up can be very straight-forward, with some families already connected to the programs addressing their needs, or it can be very complex to help families get the supportive services they need.

"Some moms will cry because they'll miss the [early intervention] teacher so much. And they were glad their baby made such progress."

- Local public health nurse

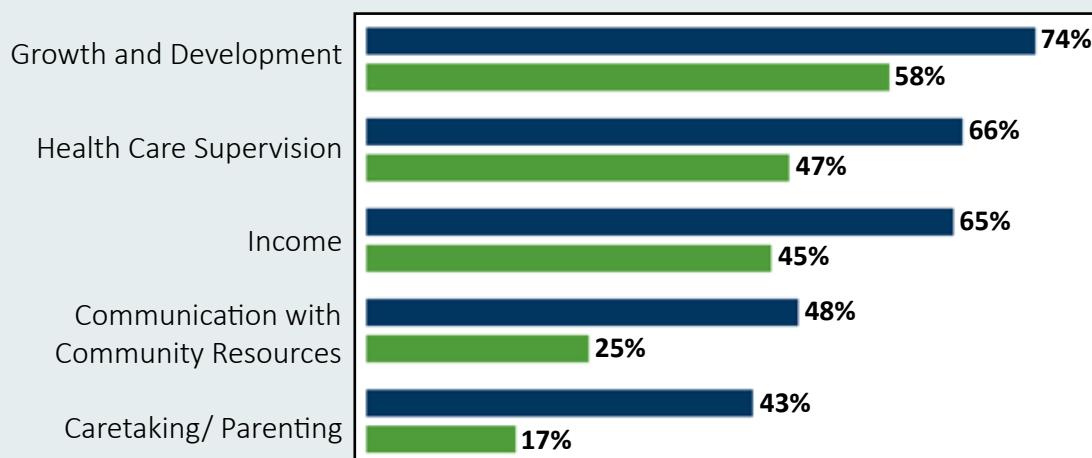
Sharing a story of follow-up with one family, Virgeana Olberg of Hennepin County Public Health reflected on a baby boy with hearing loss whose mother was incarcerated. The mother had a network of family, both chosen and biological, who helped care for her child while she was incarcerated. Her cousin became primary caregiver for the boy. After looking into many options for support, Olberg was eventually able to assist the cousin in receiving financial, food, and childcare support.

Describing her love for her work, Olberg said, "I explain to people that people love to have the [early intervention] teacher come to their home. I've had parents where they were wrapping up the service because their baby has graduated, basically, early intervention. Some moms will cry because they'll miss the teacher so much. And they were glad their baby made such progress [...] I can get really enthused about early intervention."

Local Public Health Follow-Up With Minnesota CYSHN Families

There are five different topic discussed during follow-up with families of children with a birth defect or hearing loss. Based on the six national core outcomes for CYSHN created by the federal Maternal and Child Health Bureau, the topic areas include: growth and development, health care supervision, income, communication with community resources, and caretaking or parenting.

Percentage of topic areas discussed during first and second assessments



TOP 3 CHALLENGES FOR FAMILIES WHEN INCOME ASSESSED



Low/No Income



Uninsured Medical Expenses



Only Able to Buy Necessities

TOP 3 SIGNS OR SYMPTOMS OF THE CHILD WHEN GROWTH AND DEVELOPMENT ASSESSED



Delay in Development



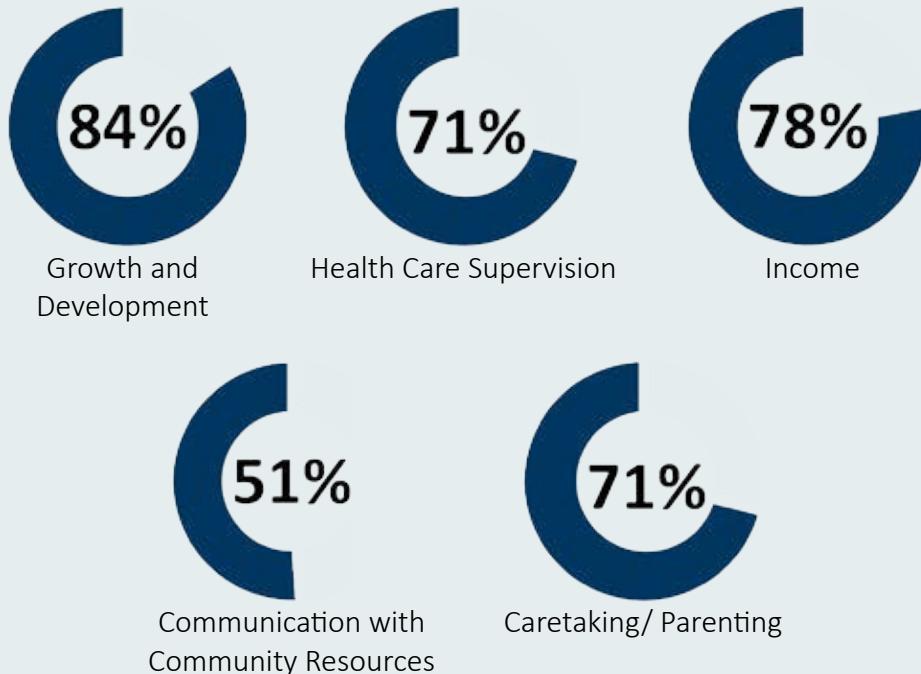
Abnormal Developmental Screening Results



Abnormal Physical Development

Interventions Provided to Minnesota CYSHN Families

Percentage of families getting at least one intervention from local public health during follow-up, by topic area



TOP 3 INTERVENTIONS PROVIDED WHEN INCOME ASSESSED



TOP 3 INTERVENTIONS PROVIDED WHEN GROWTH AND DEVELOPMENT ASSESSED



During Autism Awareness Month, the CYSHN Section worked with Leadership Education in Neurodevelopmental and Related Disabilities (LEND) fellows from the University of Minnesota to spread the message of “Learn the Signs, Act Early” at community events. This CDC campaign encourages parents to monitor their child’s development and talk to a provider if they see any signs of developmental delay.

Additionally, working with the Minnesota Departments of Human Services, Education, and Employment and Economic Development, the CYSHN Section helped to build a website where the Minnesota autism community can connect, share, and learn together.

This website, called the Minnesota Autism Resource Portal, provides the Minnesota autism community with up-to-date information and resources related to autism spectrum disorder. Nonprofit organizations, state and federal agencies, and other autism-related organizations post information to the site for the community to use.

About 1 in 59 children are diagnosed with autism spectrum disorder in the U.S.



New interagency website (mn.gov/autism)

Somali Community Responds to Measles Outbreak



After the measles outbreak, the Somali community came together to educate families about the MMR vaccine and the myth about it causing autism spectrum disorder. The outbreak occurred during the month of Ramadan when many Somali families attend mosques in the community.

Working with local imams, the CYSHN Section and the Infectious Disease, Epidemiology, Prevention, and Control Division created the Faith and Medicine program.

Recognizing imams as highly respected leaders in the community, the program paired imams with medical providers to deliver educational sessions about autism spectrum disorder and vaccines in the mosques.

Abuubakar Islamic Center in Minneapolis was one of MDH's community partners in this program. Sheikh Abdirizak Hashi, the imam of Abuubakar, hosts religious speeches broadcast by conference call, allowing families to listen to his sermons remotely. During Ramadan, Sheikh Hashi held one sermon about the measles outbreak and its effects on the Somali community. This partnership allowed the Faith and Medicine program to reach many more members of the Somali community.

Through the tireless work of Somali leaders during the measles outbreak last year, the rates of immunization increased dramatically. MDH and its community partners plan to continue this positive momentum by creating messages grounded in Somali culture, language, and religion.



Zika Reporting Improves Birth Defects Data Collection

When the CDC began requiring new information in data reports for conditions associated with the Zika infection, the Birth Defects program saw an opportunity to improve their data collection practices overall. For the reports on Zika infections, the program began including a summary of key evidence for the diagnoses of the conditions associated with the Zika virus. Seeing the benefit of this additional information, the program expanded reporting for all of the conditions monitored.

13 conditions newly monitored by MDH as a result of the Zika infection outbreak

Previously, medical abstractors reviewed medical records of children with a birth defect and assigned a code, which was sent in the data reports. Adding a summary of the evidence of birth defects readily available prepares the Birth Defects program for future data reports or research projects on birth defects.

To respond to the Zika outbreak, the Birth Defects program also partnered with the Vectorborne Disease program, the women's health consultant, and the Follow Along Program at MDH. The partners monitored adults with Zika infections; provided preconception health education; and gave parents tools to monitor their child's development.



Preconception Health Grant Addresses Pre-Diabetes



Preconception health does not usually focus on diabetes prevention. However, type 2 diabetes and obesity during pregnancy increase the risk for birth defects. With this in mind, the Birth Defects Unit adapted the CDC Diabetes Prevention Program (DPP) to include messages about preconception health and birth defect prevention for the Preconception Health Grant. Additionally, this grant targets preconception health by funding DPP groups of women of child-bearing age.

In 2017, the four grantees—West Side Community Health Services, Indian Health Board, Pillsbury United Communities, and the University of Minnesota—recruited for and began holding DPP classes promoting both diabetes prevention and preconception health. Lifestyle coaches recruited participants through patient registries, outreach at family and women-centered community events, and collaboration with other community organizations.

Looking forward to 2018, grantees will conduct activities for National Birth Defects Prevention Month, continue DPP classes started in 2017, and start the next round of DPP classes.



"Attendance and class participation in and out of class has been the best we've seen from the three previous DPP programs. More than 50% of the class have experienced weight loss since the start of the program."

- DPP grantee

CYSHN Plans Long-Term Follow-Up Program for Newly Screened Conditions

Based upon new recommendations from the Department of Health and Human Services, MDH started newborn screening for three new conditions—X-linked adrenoleukodystrophy, mucopolysaccharidosis I, and Pompe disease.

Unlike many other conditions, these conditions do not show any symptoms until later in life. Once symptoms begin, there is no cure. However, if caught early, symptoms can be prevented altogether. Also, because they are genetic disorders, diagnosing a newborn can lead to family members being diagnosed as well.

Funded by the Association of Public Health Laboratories, the CYSHN Section began planning a long-term follow-up program of these new conditions. To provide the best care to families, the section is collecting feedback about what the program should look like. First, they held interviews with experts on the conditions. Future steps include an online survey to primary care providers, interviews with families who have children with these conditions, and stakeholder meetings to put together final recommendations for this program.

***Over 50
adrenoleukodystrophy
diagnoses, including family
members, in 2017***



Parent Workgroup Strengthens MDH-Parent Partnerships



The CYSHN Parent Workgroup, made up of seven parents and guardians of children and youth with special health needs, worked with the CYSHN Section to explore ways to promote collaboration between MDH and parents. Throughout this long-standing partnership, the Parent Workgroup has given feedback on section programs, grant applications, and health education materials.

The workgroup helps identify key issues faced by families with CYSHN. The team of parents explained that many families do not understand the benefit of medical home services for their children. Their input led to MDH beginning work to improve care coordination for CYSHN.

Additionally, the Parent Workgroup has participated in various other activities, like evaluating parent surveys, helping a graduate student with research on experiences of families with CYSHN, and improving the CYSHN Navigator.

"I walked away from every meeting feeling like I'd been lifted and could do this because people ARE interested in making the change we need."

-Parent



Program Measure	Outcome
Number of babies confirmed by CYSHN as having a birth defect	1,810
Number of babies reported to CYSHN as deaf or hard of hearing	234
Number of babies reported to Long-Term Follow-Up as having a newborn screening condition	175
Percent of families connected to local public health agencies	76%
Number of families newly connected to Minnesota's Follow Along Program	7,353
Number of participants enrolled in Minnesota's Follow Along Program	26,209
Number of families connected to Family Voices of Minnesota parent-to-parent support	479
Percent of families connected to Minnesota Hands & Voices	83%

A Final Word on 2017...

As we look back on the year, 2017 had both great successes and great challenges. Our country saw the spread of Zika infections and our state suffered from the measles outbreak. By working together, we responded to these health concerns while improving the work we do to serve children and youth with special health needs and their families.

To better meet the needs of our community, our section reflected on ten years of the EHDI program, created the CYSHN Navigator, assessed the needs of families with CYSHN, spread awareness about autism and immunizations, helped to develop the Minnesota Autism Resource Portal, and began planning for follow-up of new newborn screening conditions.

These are just some of the highlights of the great work done by our passionate and motivated team in 2017. We look forward to what 2018 has in store for us.



Working on the state level, we rely on our partner like you to provide the support and advocacy our state's children and youth with special health needs and their families deserve. Your hard work and dedication create a community where Minnesota's children and youth with special health needs can thrive.

THANK YOU!



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