



Annual Report

Children & Youth with Special Health Needs



2013-2014

To obtain this information in a different format, please call the CYSHN Main Line at 651-201-3658, or toll free at 800-728-5420. These numbers are answered during regular business hours.

Dear Reader,

It is my pleasure to present to you the second Children & Youth with Special Health Needs (CYSHN) Program Report. This report highlights program activities for the last two calendar years (2013-2014). Projects are highlighted through the report, such as a KAIZEN event to decrease processing time for each birth defects case, adding critical congenital heart disease to the list of conditions for long term follow-up, and creating standards for developmental screening and follow-up for young children in partnership with local public health agencies.

The activities in this report help support our mission to improve population health through building the capacity of all systems that serve families of children and youth with special health needs. As section manager, I am happy to report on a very productive couple of years. We now have a full complement of staff, adding another birth defects abstractor, health educator, Somali Nurse, and geneticist to our dedicated team.

Health reform is a great opportunity to improve policy and assure that children and youth with special needs and their families receive better care in their communities. In 2015, we hope to use this opportunity to focus some effort to bring awareness to disparities for children and youth with special needs and find strategies that complement the adult health care system while improving the outcomes for children and their families.

I invite you to read more about the important work our section does to help us meet the Minnesota Department of Health's mission to protect, maintain, and improve the health of all Minnesotans.

We hope you enjoy reading our 2013 -2014 CYSHN Report, and welcome any feedback you are willing to provide.

Sincerely,



Barb Dalbec
CYSHN Section Manager



Accomplishments: At a Glance

pg. 11 Symposium entitled, "Let Us Talk About Autism: Learning the Facts and Dispelling the Myths".

pg. 13 Critical Congenital Heart Diseases (CCHDs) were added to Long Term Follow-up.

pg. 17 Increased partnerships with parents of CYSHN through establishment of the CYSHN Parent Work Group.

pg. 18 Remote access from hospital and clinic facilities added for abstraction of birth defects.

pg. 20 CYSHN is looked to as a resource for Quality Improvement within MDH.

Abbreviations you will see in this report:

MDH: Minnesota Department of Health

CYSHN: Children & Youth with Special Health Needs

NCFU: Newborn & Child Follow-up Unit

BDMA: Birth Defects Monitoring & Analysis Unit

CBU: Capacity Building Unit

LPH: Local Public Health

Hearing test cover photo credit:
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What We Do

Children with Special Healthcare Needs (CSHCN) are defined by the Maternal and Child Health Bureau as: “Those who have one or more chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.” In Minnesota, nearly one in every seven children has a special health need, and one of every five households with children has a child with a special health need.¹

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

Working together with statewide partners, the Children & Youth with Special Health Needs (CYSHN) section strives to reduce the number of children who have special health needs and assure that those children and youth with special health needs, and their families, are well supported in the communities they live in.

Programs impact this population’s health through Assessment, Assurance, and Policy Development - the core functions of public health.

Assessment

Collecting, analyzing, and monitoring data to identify and solve health concerns.

Assurance

Growing a system of services that is available and accessible to all Minnesota families.

Policy Development

Informing, educating, and empowering Minnesotans about health issues. Policies are based on best practices and support individual and community health efforts.

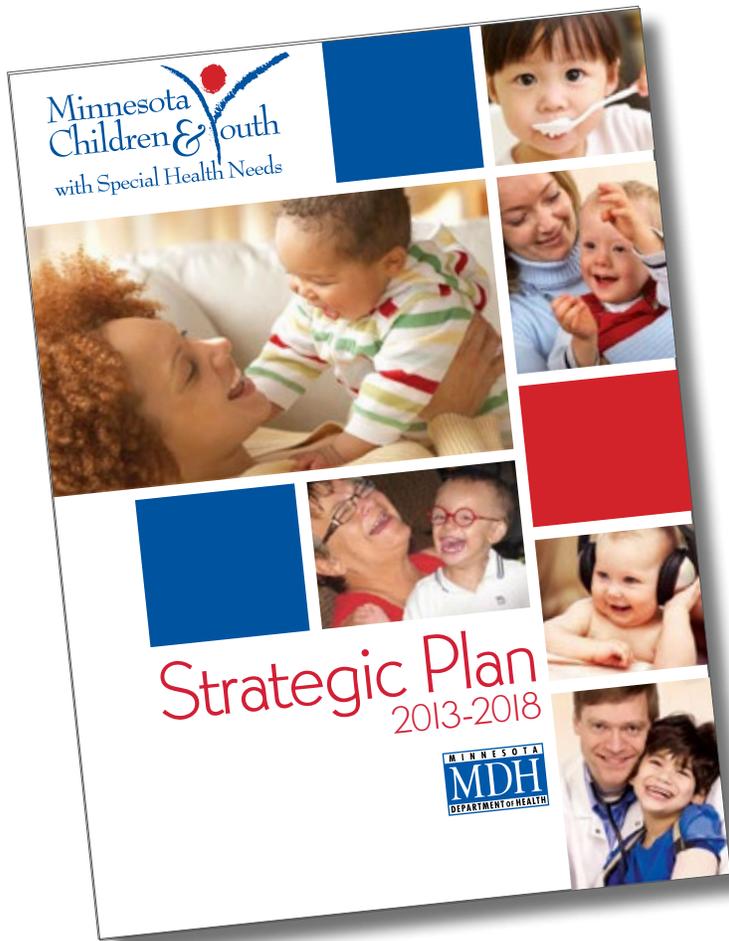
By building the capacity of local public health, health care systems, and community organizations that serve children and youth with special health needs, the CYSHN section is working toward protecting, maintaining, and improving the lives of Minnesota children and youth with special health needs and their families every day.

¹2009/2010 National Survey for Children with Special Health Needs



The 2013-2018 Strategic Plan was released in 2013, and includes a detailed history and overview of the CYSHN section. All of the efforts and services within the CYSHN section are guided by at least one of six Vision Elements and the Overarching Themes.

Vision Elements:



Health Care Homes

Minnesota children & youth with special health needs and their families have increased access to health care homes as their primary care source.

Insurance & Financing

Children and families have flexibility to obtain insurance and financing tailored to individualized needs to increase positive health outcomes.

Early & Continuous Screening

An infrastructure to support best-practice screening is in place, including education, support, and culturally responsive best practices.

Easy Access to Services

All children with special health needs and their families, including under-served populations, have easy access to appropriate services that meet their needs.

Family-Professional Partnerships

Families of Minnesota children and youth with special health needs are engaged in providing perspectives and information affecting decision-making at all levels.

Transitions to Adulthood

All youth with special health needs receive services necessary to access high quality and developmentally appropriate healthcare services as they transition to adulthood.

OVERARCHING themes

The CYSHN Strategic Plan supports a structure of overarching themes or **values** which apply to the long-term vision and embraces all vision elements and strategies.

These overarching themes work toward **achieving public health policies** that will provide more **positive health outcomes** and better serve children and families statewide.

The following overarching themes can be applied and implemented to individual, community and system strategies.



Family-centered Care ■

All services will strive to meet the criteria of family-centered care which is culturally responsive to individuals and families.

Culturally Responsive ■

Developing and maintaining partnerships with diverse families' and youth who are the recipients of services is essential to creating culturally responsive programs that truly meet their needs.

Best Practice ■

Successful best practices will be utilized, promoted and maintained to prevent disease or disability and achieve optimum outcomes for children with special health needs.

Proactive and Preventive Investment ■

An early investment in children and youth with special health needs now may be beneficial due to potential cost savings to society in the future.

Data Driven Decision-Making ■

There will be standardized, rigorous evaluation of all processes and outcomes, with the results used to guide future decisions, priorities and funding for CYSHN.

You can find the Overarching Themes highlighted throughout this Annual Report.

View the full Strategic Plan
www.health.state.mn.us/cyshn



Best Practice

Partnering with Local Public Health

The 3rd annual statewide Minnesota Early Hearing Detection and Intervention/Birth Defects Conference for Local Public Health (LPH) Partners was held in March 2014. The conference objectives included:

- Building knowledge of best practices in providing support and services to CYSHN
- Identifying important strategies that MDH and LPH agencies can work on together to improve outcomes for this population

On the first evening of the conference, LPH nurses were joined by 50 Clinical Care Coordinators serving CYSHN throughout Minnesota to hear the Director of the Center for Medical Home Improvement, Jeanne McAllister, talk about planned, coordinated care. This session was provided in partnership with the Center for Children with Special Health Care Needs at the University of Minnesota. Additional sessions included a panel of parents of children with special health needs and representing the diverse communities served by the CYSHN programs and an “Ask the Expert Specialist Panel” of four pediatric medical specialists.

“This conference is one of the best that I have attended and gives me tools to do my BD/EHDI work in LPH. Thanks to all for the work done to make this conference a success.”

> Conference attendee

Making Connections

Each family with a child with a special health need faces unique challenges and their needs may change over time. Recently, a LPH nurse followed up with a mother whose child was born with a birth defect of the brain. She had been getting visits from a school teacher, and found them helpful, but the visits had stopped and the mother did not know why. The mother said a social worker from the hospital had helped her apply for Early Intervention (Part C) for her child, but it had been denied. This LPH nurse was able to discuss how to appeal the denial and reconnected the mother to Help Me Grow for Early Intervention (Part C).

Making the connection to a local resource provided this family with another opportunity to assess their needs and identify gaps with someone trained to assist them and connect them with the right programs and services in their community.

Transitioning to Adult Care

As youth with special health needs become older, they need to transition from pediatric medicine to adult health care. According to the 2009-2010 National Survey of Children with Special Health Needs, only 47 percent of youth in Minnesota receive the services necessary to make transitions to adult health care. This number is significant because it indicates the need for education and training around transition. In 2013, President Obama recognized the lack of transition services for youth and urged improvement in services in both education and health to prepare youth for adult life and the opportunity to live to his/her full potential. Youth with special health needs from diverse cultures or low income populations are faced with more challenges, such as barriers to accessing health care.

In 2013, the CYSHN program awarded Family Voices of Minnesota a grant to implement a model for transition within the clinic setting and develop strategies for spreading the model throughout licensed Health Care Homes in Minnesota. The clinics in this project are:

- Hennepin County Medical Center in Minneapolis
- HealthPartners-Como Clinic in St. Paul
- Essentia in Duluth
- CentraCare in St. Cloud

The clinics are developing strategies and engaging pediatricians and adult practitioners in the strategic planning. Parents and youth are involved as part of each team. The teams are adapting materials from the National Health Care Transition Center to meet their unique needs. An online transition in health care tool kit will be developed as part of this project. The grant continues into 2015.



Culturally Responsive

Responding to Community Concerns

Autism Spectrum Disorder (ASD) is the fastest growing developmental disorder in the United States affecting approximately one in every 68 children². ASD is a complex developmental disorder that affects a person's ability to communicate, form relationships with others, and respond appropriately to their environment. ASD occurs in all racial, ethnic and socioeconomic groups. Autism affects each individual in a different way – with varying degrees of severity – making it a “spectrum disorder.”

As part of the legislative ASD Task Force, program staff work to implement the 2012 ASD Strategic Plan. Key areas of focus include promotion of early and continuous developmental screening by training primary care providers and others in the community to help identify developmental concerns early and connect families to services and resources.

One vision element the CYSHN program has been focused on is early, timely and continuous, accessible screening and assessment. Key activities are to improve access to and quality of screening statewide through the Follow Along Program (page 12), as well as provider training on developmental screening, and follow-up for diagnostic assessment. Over 500 providers across the state were trained on best practices around developmental screening and follow-up.



Somali Public Health Advisors meeting and training for a group of women ambassadors from Cedar Riverside neighborhood. The training was organized with Fairview's community health department.

²Centers for Disease Control and Prevention. (2015). *Data & Statistics* (<http://www.cdc.gov/ncbddd/autism/data.html>)

Addressing Autism in the Somali Community

Autism concerns became worrisome in the Somali community and led to a continual decrease in the Measles, Mumps, and Rubella (MMR) vaccination rate for Somali children under the age of two years. Many parents and members of the Somali community expressed concerns about a higher rate, and more severe form of autism in their community, and asked for resources and assistance accessing early intervention services.

In response to this situation, MDH decided to address the fear and misinformation in culturally- and linguistically-appropriate ways with the goals of providing Somali parents with evidence-based facts about autism, supporting parents of children with autism with timely information and connection to resources, and hence increasing MMR vaccination rates over time. In 2013, the CYSHN program added a bi-lingual Somali Registered Nurse Consultant to

the staff. Similarly, the Infectious Disease Epidemiology, Prevention and Control (IDEPC) Division of MDH created a bi-lingual Outreach Coordinator position for its immunization program. Work was done across divisions collaboratively to start changing the community beliefs and health outcomes.

At the same time, MDH staff worked with the University of Minnesota to estimate ASD prevalence in Somali and non-Somali seven- to nine-year-old children in Minneapolis. This was the largest project to date looking at the number and characteristics of Somali children with ASD in any U.S. community. Study findings demonstrated that Somali and White children were about equally likely to be identified with ASD in Minneapolis. For more information go to University of Minnesota [Minneapolis Somali Autism Spectrum Disorder Prevalence Project](#).



“This is an amazing event and the most people I have seen actually in one location to talk about Autism in the Somali community. This would never have happened two years ago – truly amazing.”

> Somali advocate, Symposium attendee

A major undertaking in addressing ASD in the Somali community was the Symposium entitled, “Let Us Talk About Autism: Learning the Facts and Dispelling the Myths”, was held in partnership with University of Minnesota’s Institute on Community Integration and Medical Center-Fairview. There were over 102 participants for the event including parents, care providers, faith leaders and other Somali community representatives. The event was presented in the Somali language. Experts presented on what is known around autism and developmental disabilities, the stigma in the Somali community, and the struggles and challenges families face when navigating the system of care and services.

Proactive & Preventive Investment

Ensuring Early Identification & Intervention

The Follow Along Program (FAP) is a developmental and social-emotional screening system delivered through LPH departments. The program ensures the early identification of young children with special health needs and facilitates referrals to early intervention and other community services. In Minnesota, this program is one of the “child find strategies” that is responsible for meeting the federal requirements for the Individuals with Disabilities Education Act (Part C). Not only does FAP identify infants and toddlers that are eligible to receive early intervention services, but it also provides primary and secondary prevention and outreach activities that meet the needs of our maternal and child health population.



Eighty counties are currently providing FAP services for families with children 0-36 months of age, and 90 percent of these counties offer universal eligibility. There were 28,142 children active in the FAP during 2013. All of these children/families were connected with a local public health professional multiple times throughout the year.



FAP providers delivered information or referred families over 6,000 times to 46 different community services, such as child care assistance and health care assistance programs.

The FAP Index of Standards

An advisory group comprised of local FAP staff from each region in the state met to review the current procedures, national developmental screening best practice recommendations, and guidance documents outlining standards used in other health and early childhood programs. The resulting Index of Standards asks all participating agencies to complete a self-assessment of their FAP practice in six categories:

- Target Population
- Outreach
- Screening Periodicity and Materials
- Response to Caregivers
- Follow-up, Referral and Connection to Services
- Program Evaluation

The self-assessment will provide a baseline of the current level of the FAP across the state, identify technical assistance needs and quality improvement opportunities, and encourage consistency. Each agency will receive a summary of their assessment, suggested steps for quality improvement activities, and statewide assessment comparison data in 2015.

Adding New Conditions to the Newborn Screening Panel

Critical Congenital Heart Diseases (CCHDs) are the latest addition to the Newborn Screening Panel in Minnesota. It is a good fit with the goal to identify conditions that are not associated with clinical signs or symptoms during the newborn period but that benefit from early detection. CCHDs, as a group, are the most common type of birth defect, accounting for 30 percent of infant deaths due to birth defects. CCHD screening, like hearing screening, is a point-of-care newborn screening test, meaning that the screening is done at the site where the newborn is receiving care. Minnesota now offers CCHD screening by pulse oximetry (seen in image to the right) to all newborns born in Minnesota. The implementing of CCHD screening within birthing hospitals and messaging of results to the Public Health Laboratory (PHL) has been the focus of implementation plans. The CYSHN program will work with the Newborn Screening program, part of the PHL, in designing the long term follow-up plan for newborns, infants, children, and their families, with a CCHD.



“Eve is a testament to what works. She was diagnosed before discharge from the newborn nursery - getting the right medical intervention at the right time. Early detection of critical heart defects allows the medical teams to do what they do best - plan and treat babies so they can heal and thrive.”

>Annamarie, Mother of Eve

Family-Centered Care

Providing Newborn & Child Follow Up

Newborn and Child Follow-Up (NCFU) provides long-term follow up for infants, and their families, with a newborn screening condition. The Minnesota Newborn Screening Program screens for more than 50 treatable disorders. Approximately 450-500 infants are diagnosed with one of these disorders each year, and NCFU provides follow-up services. These infants require early intervention, close medical supervision, and life-long treatment to prevent serious permanent problems. Financial and emotional stress for families is significant, and appropriate linkages made early to community and state resources help the family support their child's needs.

Best practice recommends and research shows that parent to parent support provides emotional, social and practical help to parents of children with special health needs.



Early Hearing Detection & Intervention

Early Hearing Detection and Intervention (EHDI) programs are state-run programs designed to identify newborns and infants who are deaf and hard of hearing (D/HH) through universal screening so that those infants can receive timely and appropriate interventions. Children who are D/HH who receive timely services often develop language skills equal to their hearing peers. The ultimate mission of EHDI programs is for all infants and children to develop the language skills — whether they use visual, spoken, or a combination of communication methods — needed to reach their full academic and social potential.

The main objectives of EHDI programs are:

1. Early identification of children who are D/HH through universal newborn hearing screening and timely audiological evaluation
2. Prompt and appropriate early intervention (medical, audiological, and developmental) and culturally competent social and financial services that result in the best possible outcomes for the infant or child
3. Monitoring and evaluation of the EHDI system to improve its effectiveness and impact



Empowering and connecting families

“Through a contract with the CYSHN program, I provide follow-up services for children newly identified as deaf or hard of hearing and assure connections to early intervention and resources. I recently contacted a family whose 4-month-old daughter was identified as hard of hearing. The family had not responded to the school district’s attempts to contact them and offer early intervention services. Fortunately, I was able to connect with mom.

The mother was overwhelmed with her daughter’s diagnosis and what it meant for her family.



I talked with her about the importance of early intervention and assisted her in connecting with the school district. Her daughter had loaner hearing aids at the time that came from the University of Minnesota Lions Hearing Aid Loaner Program, which is supported by the CYSHN program. However, the mother was concerned about how she would pay for the permanent set of hearing aids. I discovered she was eligible for medical assistance (MA) to help cover the copays and deductibles of her private insurance, and I walked her through the online application. She was able to secure MA as her daughter’s secondary insurance coverage, was enrolled into early intervention through her school district, and was connected to our local WIC program.

I love knowing that I’ve been able to help families connect to the resources they need!”

>Jane, Public Health Nurse



Read the EHDI Annual Report
improveehdi.org/mn





Connecting families to resources as their child grows

MDH has been screening babies for life-threatening conditions since the early 1960's, continually adding more conditions to the list since that time. However, it wasn't until 2008 that evaluation of the health outcomes for infants beyond just the identification of disorders and assurance that they were receiving treatment began. Across the nation, these efforts are just beginning to provide long-term follow-up for a newborn with a confirmed diagnosis.

Staff providing long term follow-up have been working to identify the major overarching questions that need to be answered to assure that newborn screening is achieving its goal of providing improved health outcomes for children affected and their families.

The questions being answered include:

- Do children receive coordinated care through a medical home?
- Are families remaining in treatment at specialty centers that provide evidence-based treatment?
- Do families have easy access to a variety of educational resources to better understand their child's condition?
- Are there disease-specific registries for enrollment of children in clinical research related to their disorder that parents can choose to participate in?

Partnering with Parents

The CYSHN program has been working to increase engagement with families of children and youth with special health needs across the state. One such initiative is the establishment of the CYSHN Parent Work Group. The Work Group represents the CYSHN population to identify gaps, assess services available to families, and determine next steps for action in better meeting the needs of Minnesota families. The work group acts as an advisory resource to the CYSHN program and provides meaningful input on program policies and activities.

During 2014, the CYSHN Parent Work Group was comprised of eight parents/guardians who have a child with a special health need. They were chosen to participate based on an application process. Members of the group represented rural and urban areas, and also diverse populations. Their experience extended to various special health needs, including fetal alcohol spectrum disorders, asthma, food allergies, Down syndrome, mental health needs, and autism spectrum disorders.



The Parent Work Group aims to:

1. Maintain and promote improved relationships between families of CYSHN and Section staff.
2. Provide a vehicle for communication between families of children with special health needs and MDH.
3. Provide an opportunity for families of CYSHN to relay information and feedback from community members and organizations on CYSHN priorities and initiatives.
4. Provide a venue for families to provide input into policy and program development.
5. Provide an opportunity for families to actively participate in the development of new programs.
6. Review and provide feedback on policies, procedures, reports, and other MDH CYSHN programmatic materials.
7. Provide education and training that fosters an increased understanding of the needs and concerns of families of CYSHN.
8. Invest in building leadership skills of families of CYSHN by;
 - a) facilitating the development of advocacy skills in parents, and;
 - b) encouraging families to participate in policy / decision-making bodies.
9. Report and make recommendations to the MDH Maternal and Child Health (MCH) Advisory Task Force on issues and priorities on topics impacting CYSHN and their families.
10. Promote meaningful parent partnerships in program and policy development, implementation and evaluation, and decision-making at all levels.

Data Driven Decision-Making

Understanding and Monitoring Birth Defects

The Birth Defects Monitoring & Analysis (BDMA) unit works to understand birth defects in Minnesota – how often birth defects happen and who is at risk. This helps to detect if there are emerging public health problems, target prevention efforts to people at greatest risk of having a child with a birth defect, and assess whether these efforts are effective. By connecting with families whose children are born with a birth defect, staff can link them with community programs and services to help them be as healthy as possible.

The program tracks the prevalence of specific conditions present at birth and diagnosed by age one. By the end of 2014, the program received reports covering 50 birth hospitals, which accounted for 85% of 2013 deliveries in Minnesota. In addition, MDH received reports from all

pediatric centers and neonatal intensive-care units (NICUs), where children from throughout the state with critical conditions receive specialty care. To ensure children with less critical conditions are identified, the remaining birth facilities report potential cases to MDH.

Since 2013, the birth defects program has added eleven facilities, including seven within the Essentia health system and two remaining birth facilities in the greater metro area. The program has benefited greatly from the integration of electronic health records by large health systems and from centralized reporting; MDH receives a single report including children born at any of the birth facilities within the health system. In the coming year, a greater effort will be required to incorporate the remaining 53 facilities since most are smaller, independent hospitals.

Counts and prevalence of the 10 most common birth defects in Hennepin & Ramsey county* (2007-2011)

Birth defect	Count (per 10,000 live births)	Prevalence (per 10,000 live births)
Hypospadias**	332**	54.6**
Atrial septal defect (includes patent foramen ovale)	629	52.9
Ventricular septal defect	469	39.5
Obstructive genitourinary defect (renal pelvis and ureter only)	244	20.5
Patent ductus arteriosus	232	19.5
Down syndrome	196	16.5
Pyloric stenosis	174	14.6
Pulmonary valve atresia and stenosis	93	7.8
Cleft lip with cleft palate	71	6.0
Microcephalus	70	5.9

*BDMA currently reports data only for Hennepin and Ramsey counties.

**Per 10,000 male births

Total live births: 118,860; Male live births: 60,781

Improving Pregnancy Outcomes and Preventing Birth Defects

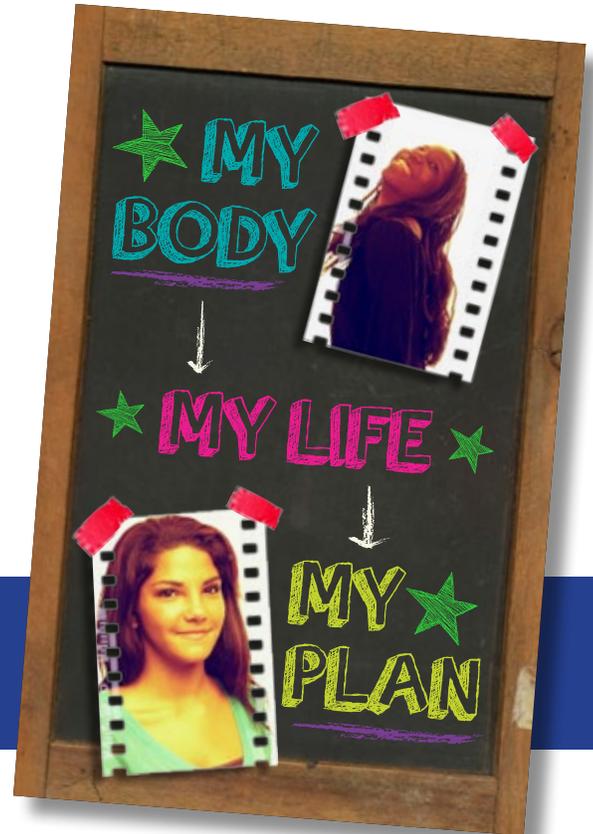
The purpose of the Preconception Health (PCH) grant program is to fund community-based organizations to conduct projects that utilize evidence- or practice-based interventions that share the goals of enhancing the health of reproductive age women and their partners in order to improve pregnancy outcomes and prevent birth defects. The approaches used in the 2012-2014 cycle included interventions at the individual and systems levels: improving nutrition and weight, chronic disease prevention and control, reducing substance use, reproductive life planning, and identifying familial risk factors for birth defects before to pregnancy.

13,930

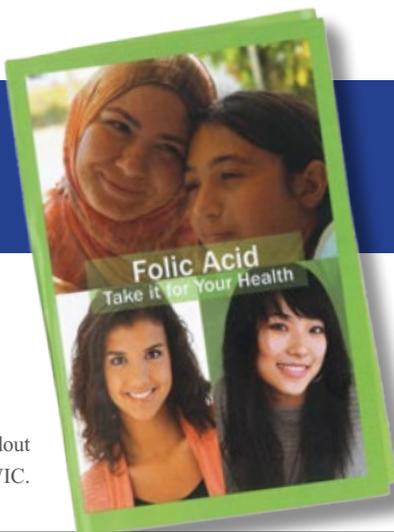
The number of eligible women seen during the grant cycle.

6,738

The number of Reproductive Life Plans distributed by grantees.



A Reproductive Life Plan (RLP), developed by PCH Grantee, The Family Tree Clinic. A RLP is a tool that a person can use to help them plan for how and when children will, or will not, fit into their life goals.



Folic Acid handout distributed by WIC.

1,429

The number of women who received nutrition education with an emphasis on folic acid.

"The Governor's Continuous Improvement Awards celebrate individual and organizational achievements that have increased the productivity and efficiency of state government services, while improving the delivery and responsiveness of customer service. Thirty-three teams from across the administration were nominated for this year's awards. These projects already have saved Minnesota taxpayers more than \$1 million."

>State of Minnesota Newsroom



Continuous Improvement

In order to enhance quality improvement (QI) knowledge and skills, CYSHN staff was provided opportunities to obtain training in QI and LEAN 101, and to participate in small and large QI projects.

One of the projects completed by BDMA, *Eliminating Delays to Identify Children with Birth Defects*, was awarded a Governor's Continuous Improvement Award. The project was initiated when staff identified delays in the processing times for reviewing reports. The unit held a Kaizen event in 2013 and began work on the identified action steps. In the year after the Kaizen, decreases were measured in:

- Median number of days to review case reports and;
- Number of cases requiring review by the team.



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2015



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