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## CYSHN STRATEGIC PLAN 2013

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April 8, 2013

Edward P. Ehlinger, MD, MSPH
Commissioner
P.O. Box 64975
St. Paul, MN 55164-0975

Dear Dr. Ehlinger:

The Maternal and Child Health Advisory Task Force is pleased to forward for your acceptance the Children & Youth with Special Health Needs (CYSHN) Strategic Plan, 2013-2018. The Maternal and Child Health Advisory Task Force has approved this report at its last meeting on March 8, 2013.

The CYSHN Work Group was convened to inform the statewide CYSHN program of initiatives and strategies that will improve the quality, efficiency and effectiveness of the public health role in meeting the needs of children and youth with special health needs and their families. The group, comprised of parents whose child(ren) have special needs, representatives of agencies serving special health needs populations, local public health, medical providers and educators, was also convened to provide direction and advice on establishing priorities and developing plans for CYSHN activities.

The work group met four times from June through December 2012 to identify and explore strengths, challenges and opportunities affecting the state’s ability to effectively meet the needs of CYSHN, identify a compelling 3 – 5 year vision, and develop strategies to implement the vision. The vision elements, strategies, and implementation activities highlighted in this Strategic Plan do an excellent job of providing direction and support to establish priorities and develop plans for state-wide CYSHN activities.

This Strategic Plan will guide MDH in supporting the development and coordination of state and local systems for children and youth with special health needs. It recognizes that change comes through the commitment and collaboration of parents, families, partners, agencies and organizations to create more positive health outcomes that will improve the health of children and youth with special health needs children and the population as a whole.

The Maternal & Child Health Advisory Task Force believes the proposed strategies and implementation activities will provide useful guidance to those interested in creating more positive outcomes for children with special health needs and their families.

Sincerely,

/Julie Jagim/

Julie Jagim, Chair
Maternal & Child Health Advisory Task Force
St. Louis County Public Health and Human Services
April 22, 2013

Julie Jagim
St. Louis Co. Public Health & Human Services
325 West 1st St, Suite 300
Duluth, MN 55802

Dear Ms. Jagim,

Thank you for sending me the 2013–2018 *Children and Youth with Special Health Needs Strategic Plan* as developed by the Children and Youth with Special Health Needs Work Group.

The vision, strategies, and suggested implementation activities developed by the work group do an excellent job of encompassing a wide range of special health needs, and focusing on important priorities. I believe that the recommendations for the statewide strategies will contribute to the public’s understanding of the priority issues for children and youth with special health needs, and help to create more positive health outcomes for this population.

I applaud the work group for its ability to discuss and reach consensus on these strategies. I appreciate the work done to promote and protect the health of all Minnesotans, especially those with special health needs. It is my pleasure to accept this Strategic Plan and its recommendations.

Sincerely,

/Edward P. Ehlinger/

Edward P. Ehlinger, MD, MSPH
Commissioner
P.O. Box 64975
St. Paul, MN 55164-0975
Overview

1912

US Children’s Bureau established.

With the establishment of the Children’s Bureau, the United States recognized the special vulnerability of women, infants, children and adolescents. The distinctive social, biological, developmental, and dependency factors that characterize this population create unique needs.

The Maternal and Child Health (MCH) Block Grant (Title V of the Social Security Act) has operated as a federal-state partnership since 1935, when the Social Security Act was passed. Title V is the longest-standing public health legislation in American history. The federal government, through Title V, pledged its support of state efforts to extend health and welfare services for mothers and children. Since its beginning, the Title V MCH Block Grant has provided a foundation for ensuring the health of our nation’s mothers and children in every state.

The legislation authorizing the Title V MCH Block Grant is broad, encompassing a wide array of population-based programs that serve everyone in a community. Funds authorized for use by states and territories require program activities “to improve the health of all mothers and children.” As a “block grant,” states allocate their MCH investments to meet their specific needs. The flexibility of the Title V MCH Block Grant is its strength. It allows states to determine the best use of resources to meet the needs of their communities.

1982

Minnesota Maternal and Child Health Advisory Task Force (MCHATF) created.
The Omnibus Budget and Reconciliation Act of 1989 (OBRA ’89) amended the Social Security Act and mandated the Title V MCH programs for Children with Special Health Care Needs to “provide and promote family-centered, community-based care for children with special health care needs” and to “facilitate the development of community-based systems of services for such children and their families.” OBRA ’89 led directly into key objectives related to children and youth with special health care needs being incorporated into Healthy People 2000, 2010 and 2020:

1. Increasing the proportion of States and territories that have community-based service systems for children with special health care needs.

2. Improving access to a medical home for children & youth with special health care needs.

In future years, Healthy People 2010 and Healthy People 2020 expanded to include focus on 4 key goals.

Attain high quality, longer life
Achieve health equity
Create healthy environments
Promote healthy behavior
The federal Maternal and Child Health Bureau (MCHB) has worked since the initiation of OBRA ’89 to define “children with special health care needs.” This definition, published in 1998, is used widely today and will be used in this plan.

Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

This definition is purposely broad and inclusive and not condition specific. It encompasses children and youth who not only require health and health-related services, but who may also have other needs, including the Infant and Toddler Intervention Services - Part C, special education, parent-to-parent support and social services. Moreover, their families may need family support and other services, such as transportation and respite care as they raise their children. This definition also recognizes that all children and youth with special health care needs, regardless of their specific condition or disability, require a well-functioning, community-based system of resources to reach their full potential.

The National Survey of Children with Special Health Care Needs (NS-CSHCN) looks closely at the health and functional status of children in the United States with special health care needs – their physical, emotional and behavioral health. The NS-CSHCN survey has estimated there are 179,000 children and youth with special health care needs birth to age 18 (CYSHCN) in Minnesota (14.3%), not including children at increased risk. Among Minnesota households with children, 22.5% have at least one child with a special health care need.

The Healthy Minnesota 2020: Statewide Health Improvement Framework provides evidence for Minnesota that the populations experiencing the greatest disparities in health status are also the populations experiencing the greatest inequities in the opportunity for health, in education, income, health care, and living environments. Youth with disabilities often face the isolation, distress, and poor health outcomes that result from discrimination, social stigma, violence and victimization. Individuals with disabilities can also find it challenging to get enough physical activity, or can become isolated due to physical and social barriers.
The effect of early childhood experiences on lifelong health is far more important than previously imagined. A healthy start as a child has a powerful impact on adult health. Adverse childhood experiences (ACEs) in the early years create changes in the architecture of the brain that affect everything from physical growth to emotional development to capacity to make healthy decisions as adults. Traumatic experiences during childhood contribute, decades later, to poor adult health status and early death.

Children with physical, developmental, intellectual, emotional and sensory challenges or health needs are more likely to be bullied than their peers. Emerging research indicates that a child with a special health need is more likely to be physically or verbally bullied than his typically developing peers. In a study of 8-17 year olds a researcher found that children with Autism Spectrum Disorder (ASD) were more than three times as likely to be bullied as their peers. Children and youth with special health needs who are bullied are more likely to have depression and anxiety, health complaints and decreased academic achievement, which may lead to poorer health outcomes.

Historically the Children and Youth with Special Health Needs Program at the Minnesota Department of Health provided direct services to families of children with special health needs. Over time funding has changed from provision of direct service to a broader policy role as MDH partners with other agencies for providing services. MDH’s role is now looking at public health assessment, policy development and assurance. Essential public health services are committed to monitoring health status, informing and educating the public, mobilizing community partnerships, and developing policies to assure prevention, health promotion and protection.
TIMELINE
AND DEVELOPMENT OF CHILDREN & YOUTH
WITH SPECIAL HEALTH NEEDS PROGRAMS

1912
US
Children’s
Bureau
established

1935
MCH Block
Grant begins
operation

1982
MCHATF
created

1989
OBRA
Title V
mandated

1998
MCHB
publishes
definition
for “children
with special
health care
needs”

2000
NS-CSHCN
conducted
2000-2001
survey

2005
NS-CSHCN
conducted
2005-2006
survey

2009
Third
NS-CSHCN
survey
conducted
from
2009-2010

2010
Minnesota
conducts
a Needs
Assessment
regarding
maternal and
child health

2012
MCH
creates a
work group
for Children
& Youth
with Special
Health Needs

2013
Minnesota
releases its
Strategic
Plan for
Children
& Youth
with Special
Health Needs
for
2013 to
2018
OVERVIEW: Minnesota Needs Assessment

As part of the collaborative relationship with the Maternal Child Health Bureau (MCHB), Minnesota participates in extensive planning and evaluation processes, beginning with a comprehensive needs assessment conducted every five years. Minnesota assesses the state resources, identifies priority needs, and then determines how to measure success in meeting these needs for the MCH population.

The needs assessment process evaluates the needs of three populations:
- pregnant women and infants,
- children and adolescents, and
- children and youth with special health care needs.

MINNESOTA’S NEEDS ASSESSMENT

In 2010, Minnesota conducted surveys, collected and analyzed data to determine areas of greatest need and areas of greatest capacity to address MCH opportunities and challenges.

The needs assessment process engages and seeks a perspective from our partners, including families, providers and other key stakeholders. The goals of the Minnesota needs assessment are to:

DETERMINE
Minnesota’s priority needs for maternal and child health, including children and youth with special health needs (CYSHN) populations

ENHANCE
stakeholders and department staff commitment to identified priority needs

INCREASE
the state’s commitment to addressing the final priorities
The Minnesota Title V needs assessment led to the identification of two overarching goals and seven priority needs for the Title V target populations that reflect the comprehensive nature of the Title V block grant and the complexity and inter-relatedness of the target populations.

### OVERARCHING GOAL 1

**Increase health equity** and **reduce health disparities** for women who are pregnant, mothers and infants, children and adolescents, and children and youth with special health care needs.

### OVERARCHING GOAL 2

**Focus efforts** on activities that result in **positive outcomes** across the lifespan.

### PRIORITY NEEDS

1. **IMPROVE** birth outcomes.
2. **IMPROVE** the **health** of children and adolescents.
3. **PROMOTE** optimal **mental health**.
4. **REDUCE** child injury and death.
5. **ASSURE** quality **screening, identification and intervention**.
6. **IMPROVE** access to quality health care and needed services.
7. **ASSURE** healthy **youth development**.

Please refer to Appendix B, Minnesota Title V Fact Sheet, for the national and state performance measures.
OVERVIEW: Maternal & Child Health Advisory Task Force

In 1982, the Minnesota State Legislature created the Maternal and Child Health Advisory Task Force (MCHATF) to advise the Commissioner of Health of the Minnesota Department of Health (MDH), on the health care services and needs of maternal and child health populations. The MCHATF, consisting of MCH professionals, representatives from local public health and consumer representatives, also reviews and reports on the health care needs of Minnesota’s mothers and children including those with special needs, recommending priorities for activities.

The MCHATF receives updates on activities related to the overall implementation of the Title V Block Grant. The Task Force members provide input for the annual work plan based on needs identified through the needs assessment.

Work groups of the MCHATF are often convened with a specific charge to bring back recommendations to the full task force following more in-depth research and discussion. While Minnesota’s needs assessment and plan outlines a number of activities related to CYSHN, the MDH and the Task Force convened a CYSHN work group to more specifically outline a plan for the role of our state public health department to meet the priority needs specific to this population.
OVERVIEW: Children & Youth with Special Health Needs Work Group

As a part of the MCH Advisory Task Force’s action plan, a CYSHN Work Group was convened in June 2012. This Work Group’s charge was to inform the statewide CYSHN Program to improve the quality, efficiency and effectiveness of the public health role in meeting the needs of children with special health care needs and their families. The Work Group provided the Department with direction and advice on defining statewide activities to build capacity in the systems that support CYSHN and their families. Work Group membership included parents of CYSHN, representatives of partnering agencies and organizations, local public health, medical community, multicultural advocates and supporting MDH staff.

The Work Group met four times from June-December 2012 to identify and explore strengths, challenges and opportunities affecting the state’s ability to effectively meet the needs of CYSHN, identify a compelling 3-5 year vision, and develop strategies to implement the vision.

The vision and strategies will guide the work of MDH’s CYSHN Program, in collaboration with many partners and stakeholders, to improve the quality, efficiency and effectiveness of the public health role in prevention and in meeting the needs of children with special health needs and their families. The CYSHN Strategic Plan will also provide direction and support on establishing priorities and developing plans for CYSHN activities.

MDH’s CYSHN Program, acting in tandem with the Work Group, will consider the health needs of Minnesota’s CYSHN. This will be accomplished through the implementation of surveillance and data systems for enhanced assessment. The assessment information gained will be used to focus on prevention and program efforts to advocate effectively on behalf of CYSHN in the development of policies that concern organizational and operational issues of health systems and have the potential to improve their health. The CYSHN Program provides state-level leadership in partnership with families and other stakeholders to achieve a vision of ongoing improvement of community-based systems serving CYSHN and their families.

The MCHB, together with its partners, has identified six national core outcomes for achieving the community-based systems of services for all CYSHN. These outcomes give us a concrete way to measure our progress in making family-centered care a reality and in putting in place the kind of systems all CYSHN deserve.
**OVERVIEW: The Six National Core Outcomes**

**THE SIX NATIONAL CORE OUTCOMES**

The Work Group used the Six National Core Outcomes listed below as a base and starting framework to establish their Vision Elements for the children and youth with special health needs strategic planning process.

1. Children and youth with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.

2. Families of children and youth with special health care needs will have access to adequate private and/or public insurance and financing to pay for the services they need.

3. Children and youth will be screened early and continuously for special health care needs.

4. Community-based service systems will be organized so families can use them easily.

5. Children and youth with special health care needs and their families will partner in decision-making at all levels and will be satisfied with the services they receive.

6. Youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including health care, work, and community.


OVERVIEW: Ten Essential Public Health Services

TOGETHER these organizations worked to define elements of personal and public health systems and services that are necessary to assure appropriate focus on the needs of women, children and youth.

From this initiative the Ten Essential Public Health Services to Promote Maternal and Child Health in America was developed as a framework to function as a tool for state, local and federal MCH programs as they serve their communities, provide leadership in addressing public health problems, create linkages and partnerships with other agencies and organizations, educate policymakers, and prepare strategic plans for the future.

Ten Essential Services
Necessary to Improve Population Health

1. Assess and monitor health status and identify and address problems.
2. Diagnose and investigate health problems and health hazards.
3. Inform and educate the public and families.
4. Mobilize community partnerships between policy makers, health care providers, families, the general public and others.
5. Provide leadership for priority-setting, planning, and policy development to support community efforts.
6. Promote and enforce legal requirements that protect the health and safety and ensure public accountability.
7. Link CYSHN and their families to health and other community and family services, and assure access to comprehensive, quality systems of care.
8. Assure the capacity and competency of the public health and personal health workforce.
9. Evaluate the effectiveness, accessibility, and quality of personal health and population-based child health services.
10. Support research and demonstrations to gain new insights and innovative solutions to child health related problems.

These ten essential services serve as a base to support the six core outcomes of the CYSHN Strategic Plan – leading to the establishment of the MDH CYSHN vision. This structure is illustrated on page 17 of this document.
This strategic plan will guide MDH in supporting the development and coordination of state and local systems for children and youth with special health needs. It recognizes that change comes through the commitment and collaboration of parents, families, partners, agencies and organizations to create more positive health outcomes that will improve the health of children and youth with special needs – and the population as a whole.

The Work Group focused on establishing vision elements based on the six core outcomes - keeping children with special health needs and their families in the center of the focus - with desired 3-5 year outcomes toward which MDH’s CYSHN Program will direct their efforts. These vision elements will assist progress toward the overall vision to build the capacity of all systems that serve families of CYSHN.

In the CYSHN Strategic Plan the vision elements are numbered, followed by lettered strategies listed to help achieve the vision element. Strategies are followed by possible implementation activities that suggest potential action steps for MDH, diverse agencies, community groups, and individuals to work together toward accomplishing the state’s strategic plan.
To improve population health through building the capacity of all systems that serve families of children and youth with special health needs.

**Vision**

- Screened early and continuously
- Organized services families can easily navigate
- Best Practice
- Culturally Responsive
- Proactive Preventative Investing
- Adequate private and/or public insurance
- Transition services to adult health care, work and community
- Ongoing, coordinated, comprehensive care within a health care home
- Families are partners in decision-making

**Minnesota Overarching Themes**

- Family Centered
- Best Practice
- Proactive Preventative Investing
- Culturally Responsive
- Ongoing, coordinated, comprehensive care within a health care home
- Adequate private and/or public insurance
- Transition services to adult health care, work and community
- Families are partners in decision-making
Though I possess a Master’s Degree in Counseling Psychology, as a single parent of a boy with special health needs and disabilities, I was unable to find gainful and flexible employment. Employers would not offer me a decent wage or allow flexibility with my schedule in order to make all of my son’s medical appointments.

For a time, I had to rely upon county assistance to survive. While I am certainly appreciative of the support provided to families of CYSHN, there is still much work to do. We need to continue to bring CYSHN families together to discuss the issues directly impacting them, their healthcare, and ultimately their lives. Much can be learned by bringing our voices to the decision-making table.

Parent of a CYSHN child
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.
VISION

Health Care Home

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

A child’s HCH integrates:
- **preventive** services
- **acute illness** management
- **chronic condition** management.

This is accomplished by **partnering with parents** to address a broad spectrum of needs, both current and future.

HCH professionals, families, and appropriate service providers work as a team to **coordinate** all **medical** and **non-medical services** necessary to help children reach their full potential.
IMPLEMENTATION ACTIVITIES:

1. Define and promote coordinated, culturally competent, family-centered care for families and providers.

2. Build awareness that the HCH of the CYSHN population should focus on quality of life indicators in addition to clinical indicators. Examples of ways to evaluate quality of life include developmental and functional status outcome measures.

3. Use plain language for definitions, especially for care coordination.

4. Provide families clear definitions of roles for existing care coordinators that will provide efficient and effective services to meet children’s and family’s needs.

5. Provide tools for parents to identify and manage their child’s services and providers, including knowledgeable contacts in a resource directory.

6. Develop tools that will encourage providers and parents to release information for sharing among health care professionals for the purpose of better coordination of care.

---

**STRAATEGY A**

Increase demand for quality pediatric health care home services by improving knowledge and understanding of health care home among families, providers and communities.

**STRAATEGY B**

Build capacity of quality pediatric health care homes to work with children and youth with special health needs.

**STRAATEGY C**

Evaluate and monitor Health Care Homes to determine if families of children and youth with special health needs are receiving quality family-centered, culturally responsive, coordinated, ongoing, comprehensive and cost-effective care.

IMPLEMENTATION ACTIVITIES:

1. Partner with physician organizations such as the Minnesota American Academy of Pediatricians, Minnesota Association of Family Practice, and Minnesota Medical Association to educate and inform providers of best practices that will encourage certification as a health care home.

2. Provide incentives to non-certified practices to encourage application to become a health care home.

3. Pilot, evaluate and implement different models of care coordination across the state.

4. Provide technical assistance to evaluate patient satisfaction with health care homes for the CYSHN population.

5. Pilot a program that uses parent peers or care coordinators with similar racial or ethnic background as the community being served.

6. Improve care coordination reimbursement.
Children and families have flexibility to obtain insurance and financing tailored to individualized needs to increase positive health outcomes.

Families and providers have access to user-friendly tools that will more easily navigate coverage and service information to determine child and family eligibility.

Funding is available for wraparound services (e.g. respite and mental health coverage) to support parents and caregivers of children and youth with special health needs, including those who are undocumented.
STRATEGY A

Enhance and improve tools for navigating health insurance and financing options for children and youth with special health needs to **maximize use of resources.**

**IMPLEMENTATION ACTIVITIES:**

1. Develop an algorithm (electronic user-friendly, culturally inclusive “navigator” tool) that can help families and providers know which services are available and appropriate (e.g. Medicaid, SSI, waivers).

2. Educate families, providers, and other stakeholders on financing options for CYSHN including review of public and private resources, including family options for appealing denial of insurance or services. Methods could include presentations, webinars, YouTube videos, clickable internet-linked documents, resource guides, fact sheets, etc.

3. Collaborate with partners to enhance and improve the Disability Linkage Line, DB 101, MNHELP.INFO, Help Me Grow, MN 211, and other referral and information systems to assure tools are user-friendly.

4. Develop/support **one-on-one real time patient navigators to assure families are able to utilize all public and private health care insurance benefits available** to meet specific needs and situations.

5. Educate families about the Patient Protection and Affordable Care Act for CYSHN, including health insurance plan choices offered, through the newly developed Health Insurance Exchange.

6. Monitor the quality and adequacy of the insurance and financing system.

---

STRATEGY B

Assure that children and youth with special health needs are a **priority in policy-making and allocating resources.**

**IMPLEMENTATION ACTIVITIES:**

1. Educate policy makers about the “real needs” of CYSHN and their families. Create partnerships to improve awareness of CYSHN needs and issues by “putting a face on this population” through social marketing, public relations, etc.

2. Increase funding for reimbursement of health care home care coordinators.

3. Assure flexibility of financing health care services to match the level and timing of need for CYSHN children.

4. Create systems that will improve coordination between multiple private and public insurers and payers.

5. Advocate for parity across mental, physical and dental access to services through partnerships to include these services in the Health Insurance Exchange and essential benefits set.

6. Promote CYSHN within the Accountable Care Organization model or other health reform efforts.

7. Partner with Departments of Human Services and Education to improve the system of care for CYSHN.

8. Encourage health plans to offer services for the prevention of birth defects to their members.


10. Facilitate and assure connection to adequate health insurance for infants identified with a birth defect or condition found through newborn screening.
VISION 3

Early & Continuous Screening

An infrastructure to support best-practice screening prenatally and birth through adolescence is in place to ensure early and continuous screening for special health needs including education on the importance of screening, supporting evidence-based and culturally responsive best practices, and working closely with screening partners.

Policies are developed to define and implement appropriate referrals prenatally and birth through adolescence through shared access to health and developmental screening and follow-up data (virtual teaming), to improve health outcomes.
IMPLEMENTATION ACTIVITIES:

1. Create educational materials and campaigns to raise awareness about the importance of screening to identify children with special health needs.

2. Promote and assure that best-practice screenings (evidence-based, culturally responsive and inclusive, timely, continuous, unbiased) occur for children, youth and women who are pregnant.

3. Partner with MDE, DHS, Local Public Health (LPH), school nurses, parents and others to improve and expand school-based screenings throughout the child’s secondary education.

4. Collaborate with professional organizations and partners to improve Child & Teen Checkup (C&TC) outreach.

5. Promote evidence-based or best practice screening tools and recommendations, such as GAPS and Bright Futures.

6. Create policies and practices that ensure screening providers are qualified, competent, and use screening tools effectively.

7. Define the roles and responsibilities of screeners across various agencies (e.g., LPH, schools, primary care, parents and others).

8. Create policies to promote screenings throughout childhood and adolescence (addressing disparities) that impact health and development.

VISION ELEMENT THREE: Early & Continuous Screening

STRATEGY A

Create and promote an infrastructure to support best-practice screening prenatally and birth through adolescence.

STRATEGY B

Develop and implement best-practice recommendations for appropriate follow-up from screening prenatally and from birth through adolescence.

STRATEGY C

Develop policies that ensure cross-organization/cross-stakeholder data sharing to support best practice screening and follow-up.

IMPLEMENTATION ACTIVITIES:

1. Identify best practices and promising strategies for follow-up to assure best outcomes.

2. Monitor developmental disabilities in the population.

3. Create a child health profile/database to make health and developmental data, including screening results and follow-up information, accessible to providers (health and education) with parental consent.

4. Create multidisciplinary teams through common access of a child health profile/database which allows virtual teaming to achieve desired child outcomes inclusive of multiple perspectives (health and education).

5. Assure funding for the Follow Along program and high-risk family home visiting programs.

6. Promote evidence-based or best practice recommendations for follow-up from screening that includes supporting families with next steps.
VISION 4

Easy Access to Services

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

Access to services is facilitated by promoting best practice strategies and convening partners for effective collaboration.

User-friendly, easily-accessed services are organized for children with special health care needs and their families by enhancing and improving navigation tools for family and provider use.
Enhance and improve tools to access and navigate services for children and youth with special health needs.

**IMPLEMENTATION ACTIVITIES:**

1. Consolidate the myriad of gateways to services. Find the most effective entry point(s) (e.g., building the Part C Model as entry point) for families to easily access and improve services, expanding the model to include older ages.

2. Develop an algorithm (electronic) “navigator” tool to help families and providers be knowledgeable of available and appropriate services, including financial resources.

3. Create multidisciplinary teams (including virtual methods) that allow for common access to child health profile/database to achieve desired child outcomes that include multiple perspectives (health and education). Promote easily navigated models for parents and providers that are effective for service/care coordination.

4. Create clear data practice policies to promote the meaningful exchange of information between providers and parents.

Engage appropriate partners to create mechanisms that produce effective access and ease of use of services.

**IMPLEMENTATION ACTIVITIES:**

1. Create a systematic needs assessment that addresses identified gaps in services.

2. Identify models of effective service coordination.

3. Promote working relationships/community care team models among local providers; LPH, primary care, education, social services, etc., that result in more effective coordination of services.

4. Create practices/policies that incorporate health into Individual Family Service Plans (IFSPs) and Individual Education Plans (IEPs).

5. Promote greater coordination of interagency cooperation between home, school, community and health care to create more comprehensive and effective services and improved outcomes.

Promote best practice strategies for underserved populations to improve access to services to eliminate disparities.

**IMPLEMENTATION ACTIVITIES:**

1. Promote bilingual and bicultural cultural guides/ liaisons/brokers who are readily available to help guide diverse families through the system to more easily access all eligible services.

2. Translate surveillance data to provide guidance on best practices for specific conditions to specialty clinics and primary care.

3. Monitor and detect changes in birth defect trends in order to identify and better focus programs and educational efforts.
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, helping lead to greater satisfaction with the services they and future families receive.

Parents provide vital roles in staff/provider training; participate in conference planning; actively contribute to policy development or public comment/review process; assist with community/needs assessments and outreach activities.

Partnering with diverse families and youth who are the recipients of services is essential to creating culturally responsive programs that truly meet their needs.
VISION ELEMENT FIVE: Family-Professional Partnerships

STRATEGY A

Promote meaningful parent partnerships in program and policy development, implementation and evaluation, and decision-making at all levels.

IMPLEMENTATION ACTIVITIES:

1. Utilize existing multicultural community organizations to “meet the community of parents where they are at,” to assure input is received from all communities especially those that are typically underserved due to geography, economics or culture.

2. Connect to those initiatives that are already successfully working with parents and provide them additional support.

3. Work with Local Public Health as conduit to gather input and share information in local communities as a role model of what it means to work with families.

4. Increase families’ confidence and ability to advocate for their children.

5. Support learning collaboratives to promote parent/professional cooperation/collaboration.

6. Recruit and compensate parents/youth to support their participation with decision-making bodies that influence children and youth with special health needs.

7. Model the parent/professional partnership within all state agencies as demonstrated by co-leading and co-presenting at various venues.

8. Spread model of parent partnerships with technology and social media.

9. Identify best practices for engaging parents for participation at all levels in the health care system.

10. Promote the development of language interpreters who also have bicultural understanding.

11. Create a Minnesota Department of Health CYSHN Parent Advisory Group to promote family-professional relationships and provide guidance for accomplishing strategic goals.
TRANSITIONS TO ADULTHOOD

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

Clinicians will routinely integrate purposeful, person-centered transition planning, from the time of pediatric diagnosis to adult health care.

**Health, educational and work transition** planning will be integrated in order to maximize the quality of life of all children and youth with special health needs.

The transition process is tracked and evaluated based on guidelines and models from a life course perspective.
Identify and promote models for successful transition among youth, families, providers and community through collaboration.

IMPLEMENTATION ACTIVITIES:

1. Review and update information on the MDH website to include specific links to transition information for youth/family and providers.

2. Create a transition advisory board comprised of youth, parents, and professionals to address the needs of transitioning youth with special health needs.

3. Develop educational information and resources particularly for multicultural families using communication best practices for specific populations.

4. Partner with Parent Support Organizations to provide more training/conferences for youth and families with medical conditions regarding transition to adult health care systems.

5. Promote and provide training on integrating person-centered planning in transition.

6. Develop and implement provider education regarding transition and care coordination within the HCH.

7. Expand the work done with the Minnesota Transition Collaborative.

8. Assure CYSHN have appropriate educational, vocational, and employment opportunities by connecting youth and their families with Vocational Rehabilitation and other secondary educational resources.

9. Develop and promote transition guidance for youth that includes information on managing their own health care.

10. Define and promote the health role in education transition planning.

11. Provide training for youth and families regarding transition to adult health care systems.
The Work Group conducted an exercise to identify “where to start” among the strategies included in the plan. In the exercise, the group explored relationships between each pair of strategies to see whether a “cause-effect” relationship exists, and which of the two would be most likely to promote the success of the other, or which would “go first.” The results revealed the following sequence:

**TWELVE STEPS implementation**

1. **Promote meaningful parent partnerships** in program and policy development, implementation and evaluation, and in decision-making at all levels.

2. **Engage appropriate partners** to create mechanisms that produce effective access and ease of use of services.

3. **Build capacity of quality pediatric health care homes** to work with children and youth with special health needs.

4. **Assure that CYSHN needs are a priority in policy-making and allocating resources.**

5. **Enhance and improve tools for navigating health insurance and financing options for CYSHN to maximize use of resources.**

   Enhance and improve tools to access and navigate services for CYSHN.
Twelve Step Implementation: Steps 6 to 12

6  Create and promote infrastructure to support best-practice screening prenatally and birth through adolescence.

7  Promote best practice strategies for underserved populations to improve access to services to eliminate disparities.

8  Develop policies that ensure cross-organization/cross-stakeholder data sharing to support best practice screening and follow-up.

9  Increase demand for quality pediatric health care home services by improving knowledge and understanding of health care home among families, providers and communities.

10 Identify and promote models for successful transition among youth, families, providers and community through collaboration.

11 Develop and implement best-practice recommendations for appropriate follow-up from screening prenatally, and from birth through adolescence.

12 Evaluate and monitor Health Care Homes to determine if families of CYSHN are receiving quality family-centered, culturally responsive, coordinated, ongoing, comprehensive and cost-effective care.
APPENDIX A
WORK GROUP MEMBERS
Member names in red(*) were unable to attend the day the above photo was taken.

Carolyn Allshouse  Family Voices of Minnesota
Sue Benolken*  Minnesota Department of Education
Tricia Brisbane*  Parent
Holly Collom  Parent
Mary M. Erickson*  Children’s Hospitals & Clinics of Minnesota
Marybeth Fitzgerald*  Gillette Children’s Specialty Healthcare
Kathy Girdler  Polk County Public Health
Carol Grady*  Maternal & Child Health Task Force
Wendy Looman*  University of Minnesota, School of Nursing
Suzanne Renfroe  Parent
Wendy Ringer  PACER Center
Hassan Samantar*  Parent
Stephanie Seubert  Hennepin County Public Health
Michael V. Severson  American Academy of Pediatrics
Ceci Shapland  Family Voices of Minnesota
Kara Hall Tempel  Minnesota Department of Education
Jesus Villasenor*  Parent
Dao Xiong*  Parent
Barb Deming, Facilitator  Minnesota Management & Budget

MINNESOTA DEPARTMENT OF HEALTH STAFF
Nicole Brown  Newborn & Child Follow-up Unit
Jeanne Carls  CYSHN Section
Barb Dalbec  CYSHN Section
Erica Fishman  Birth Defects Monitoring & Analysis Unit
Shawn Holmes*  CYSHN Section
Barb Lundeen  Health Care Home Section
Kris Oehlke  Birth Defects Monitoring & Analysis Unit
Tony Steyermak  Newborn Child Follow-up Unit
Nancy Vanderburg  Newborn Child Follow-up Unit
THE FEDERAL MATERNAL & CHILD HEALTH BUREAU (MCH-B) provides funds through the Title V Maternal and Child Health (MCH) Block Grant to every state and territory in the nation to address concerns for the populations of children and adolescents; children and youth with special health care needs; and pregnant women, mothers, and infants. State MCH programs engage in ongoing monitoring and assessment of:

- trends in population characteristics
- health status indicators
- risk factors
- health system attributes
- the availability and accessibility of quality services for MCH populations

By providing grants to states, this program aims to reduce health disparities, increase access to health care and improve the quality of health care. Title V is the only federal program whose sole purpose is to improve the health of all women, children, and families. It is a state-federal partnership where both partners focus on leadership, performance, and accountability.

Title V Funding in Minnesota

The federal Title V Block Grant provides funds to every state and territory. The Title V Block Grant is currently funded at $666 million. Full funding for Title V would be $850 million. Currently, Minnesota received approximately $9 million. Of that, approximately two-thirds, or just over $6 million, is distributed to the state’s local health departments. This funding makes up approximately 18% of the total funding to community health boards through the Local Public Health Act.

Title V Priorities in Minnesota

As part of Minnesota's Title V Block Grant activity requirements, the MDH reports annually to the MCHB on activities and expenditures supported through this grant, progress made on performance measures (18 national performance measures and 10 state performance measures), as well as plans for the coming year.

The program also requires states to conduct a statewide needs assessment every five years. The needs assessment, along with required national performance measures, provides guidance to Minnesota's Title V activities for the next five years by identifying state-specific priority health issues affecting:

- Pregnant Women, Mothers, and Infants;
- Children and Adolescents; and
- Children and Youth with Special Health Care Needs.

Minnesota identified two overarching goals and seven priority needs for the Title V target populations that reflect the comprehensive nature of the Title V block grant and the complexity and interrelatedness of the target populations.

**OVERARCHING GOAL 1:**

Increase health equity and reduce health disparities for pregnant women, mothers, and infants; children and adolescents; and children and youth with special health care needs.

**OVERARCHING GOAL 2:**

Focus efforts on activities that result in positive outcomes across the lifespan.

- **Priority Need 1:** Improve birth outcomes.
- **Priority Need 2:** Improve the health of children and adolescents.
- **Priority Need 3:** Promote optimal mental health.
- **Priority Need 4:** Reduce child injury and death.
- **Priority Need 5:** Assure quality screening, identification, and intervention.
- **Priority Need 6:** Improve access to quality health care and needed services.
- **Priority Need 7:** Assure healthy youth development.

Minnesota also identified 10 state performance measures for 2011-2015 (see next page).

These state performance measures are not intended to be the only representative measure of all priority needs, but fill a gap in the measures currently available to monitor Minnesota's progress in addressing the priority needs. More information on the Title V (MCH) Block Grant can be found at: www.health.state.mn.us/divs/cfh/na/
National Performance Measures

NPM 1: The percent of screen positive newborns who received timely follow up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs.

NPM 2: The percent of children with special health care needs age 0 to 18 whose families partner in decision-making at all levels and are satisfied with the services they receive.

NPM 3: The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.

NPM 4: The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

NPM 5: The percent of children with special health care needs age 0 to 18 whose families report the community-based service system are organized for easy use.

NPM 6: The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

NPM 7: Percent of 19 to 35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus influenza, Hepatitis B.

NPM 8: The rate of birth (per 1,000) for teenagers aged 15 through 17 years.

NPM 9: Percent of third grade children who have received protective sealants on at least one permanent molar tooth.

NPM 10: The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children.

NPM 11: The percent of mothers who breastfeed their infants at 6 months of age.

NPM 12: Percentage of newborns who have been screened for hearing before hospital discharge.

NPM 13: Percent of children without health insurance.

NPM 14: Percentage of children, ages 2 to 5 years, receiving WIC services that have a Body Mass Index.

NPM 15: Percentage of women who smoke in the last three months of pregnancy.

NPM 16: The rate (per 100,000) of suicide deaths among youths 15-19.

NPM 17: Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.

NPM 18: Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.

State Performance Measures

SPM 1: NEW Percentage of women who did not consume alcohol during the last three months of pregnancy.

SPM 2: REVISED Percentage of children enrolled in Medicaid who receive at least one recommended Child and Teen Checkup (CG-TC) visit (EPSDT is known as CG-TC in Minnesota).

SPM 3: NEW Percentage of Minnesota children birth to 5 enrolled in Medicaid who received a mental health screening using a standardized instrument as part of their Child and Teen Checkup (CG-TC) visit (EPSDT is known as CG-TC in Minnesota).

SPM 4: REVISED Rate of cases of child maltreatment.

SPM 5: NEW The number of children enrolled in the Follow-Along Program.

SPM 6: NEW Percentage of children under the age of one year participating in early intervention through Part C of the Individuals with Disabilities Education Act.

SPM 7: NEW Percentage of participants in Minnesota's family home visiting program referred to community resources that received a family home visitor follow-up on that referral.

SPM 8: NEW Percentage of children and youth with special health care needs that have received all needed health care services.

SPM 9: NEW Percentage of families of children age 0-17 that report costs not covered by insurance are usually or always reasonable.

SPM 10: NEW By 2013, collaborate with other state agencies to identify a state performance measure and benchmark to monitor positive youth development in Minnesota.

Since its inception, Title V has provided a foundation for ensuring the health of Minnesota's mothers and children. Funding from the Title V Block Grant alone cannot fully address all of the needs in the state. However, this funding does support activities at the state and local level that has led to improved outcomes for mothers and children, including children and youth with special health care needs.

More Information

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ACRONYMS

ACA  Affordable Care Act
ACEs  Adverse Childhood Experiences
ACO  Accountable Care Organization
AMCHP  Association of Maternal and Child Health Programs
CGTC  Child & Teen Checkups
CYSHN  Children & Youth with Special Health Needs
DHS  Department of Human Services
GAPS  Guidance for Adolescent Preventive Services
HCH  Health Care Home
HRSA  Health Resources and Services Administration
IEP  Individual Education Plan
IFSP  Individualized Family Service Plan
LPH  Local Public Health
MCH  Maternal & Child Health
MCHATF  Maternal and Child Health Advisory Task Force
MCHB  Maternal & Child Health Bureau
MDE  Minnesota Department of Education
MDH  Minnesota Department of Health
NACCHO  National Association of County and City Health Officials
NBS  Newborn Screening
NS-CSHCN  National Survey of Children with Special Health Care Needs
OBRA  Omnibus Budget and Reconciliation Act of 1989

DEFINITIONS

Best Practices
Health programs, interventions, and policies that have been evaluated, shown to be successful, and have the potential to be adapted, transformed or replicated by others working in the same field.

Care Coordination
A patient- and family-centered approach that provides health care designed for individuals that have multiple needs that cannot be met by a single clinician or by a single clinical organization, while enhancing the caregiving capabilities of families. Information is shared between providers, patients, types and levels of service with a goal of information being shared between providers and other sources of service, as well as reaching out to connect and link services in meaningful ways so that information is communicated appropriately and consistently to achieve optimal health and wellness outcomes.

Children and Youth with Special Health Care Needs
Individuals who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Cultural Competence
Culturally competent organizations and individuals have a defined set of values and principles, and demonstrate behaviors, attitudes, policies and structures that enable them to work effectively cross-culturally. Cultural competence refers to an ability to relate respectfully and effectively with people of all cultures, in a manner that affirms the worth and preserves the dignity of individuals, families and communities.

Cultural Responsiveness
The ability to be responsive to the needs of individuals and their families as they make choices and plans, which are often based on a framework influenced by their cultural background.
APPENDIX C: Acronyms Definitions

**Family-Centered Care**
Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Families are provided all best-practice information and options in a clear manner, are recognized as the experts on their child and family, and as principle caregivers and centers of strength for their children.

**Family-Professional Partnerships**
Family-professional partnerships assures that all are working together collaboratively with a sense of shared ownership, responsibility, success, power and respect for each other’s collective knowledge and expertise.

**Health Care Home/ Medical Home**
A “health care home,” also called a “medical home,” is not a building, house, or hospital – but rather an approach to providing comprehensive primary care in which primary care providers, families and patients work in partnership to improve health outcomes and quality of life for individuals with chronic health conditions and disabilities. Through this partnership, the primary health care professional can help the family and patient access and coordinate specialty care, other health care services, educational services, in and out of home care, family support, and other public and private community services that are important to the overall health of the child and family. Providing a medical home means addressing the medical and non-medical needs of the child and family.

For this document, the terms “health care home” and “medical home” are synonymous and used interchangeably.

**Policy (internal & external)**
A set of rules, procedures or protocols that serve to guide actions of individuals that establishes uniform criteria, methods, processes and practices within an agency or organization. Policy is a rule or principle that serves to guide decisions and achieve outcomes.

**Policy (legislative & systems)**
The basic principles or laws by which a government or organization is guided, the declared objectives that a government or party seeks to achieve and preserve in the interest of communities or individuals. Public policy is a system of laws, regulatory measures, courses of action and funding priorities concerning a given topic. Individuals and groups often attempt to shape public policy through education, advocacy, or mobilization of interest groups.

**Preventive Care**
Preventive care means disease prevention and health maintenance. It includes screening, early identification, counseling, treatment, and education to prevent health problems.

**Primary Care**
Primary care means overall and ongoing medical responsibility for a patient's comprehensive care and for preventive care and a full range of acute and chronic conditions, including end-of-life care when appropriate.

**Transition**
Transition can be characterized by looking back to childhood years while looking forward to being an adult. Health transition looks to maximize lifelong functioning and well-being for all youth, ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood.

**Underserved**
Children, adolescents or adults who are provided with inadequate or insufficient services that creates a vulnerability or risk for poor health outcomes due to difficulty accessing the necessary resources for optimal health, or difficulty accessing quality health care.

**Wraparound**
Wraparound is a philosophy of care with a defined planning process used to build relationships, support and services for youth with special health needs and their families. Wraparound service is community-based, culturally relevant, individualized, strength-based and family-centered — used to guide service planning for children with special health needs. Wraparound plans are comprehensive and address multiple life domains across home, school, and community.
Early identification and intervention provided the opportunity for our daughters with hearing loss to learn language during those critical first years of life, getting them off to an amazing start.

- Many parents do not know that it is critical for their baby to have a newborn hearing screening at birth.
- Many don’t know how important it is to follow-up if their child does not pass the hearing screening.
- Many don’t know that hearing loss is often invisible until age two.
- Many don’t know that time is critical because a child’s brain is programmed to learn language during the first few years of life.

In Minnesota, too many children are falling through the cracks.

*Parent of two children that are deaf*
Strategic coordinated planning efforts across home, school and community have a big impact on the success of children and youth with disabilities and their families.

*The Minnesota State Interagency Committee*