CHILDREN & YOUTH WITH SPECIAL HEALTH NEEDS

STRATEGIC PLAN
2013-2018

Minnesota Department of Health
Community Family Health Division
Children & Youth with Special Health Needs Section
PO Box 64882
St. Paul, MN 55164-0882
651-201-3650
800-728-5420
www.health.state.mn.us/cyshn

March 8, 2013
# Table of Contents

## Overview

- **Children and Youth with Special Health Needs in Minnesota** ................................................................. 1
- **Minnesota’s Needs Assessment** ................................................................................................................... 3
- **Minnesota’s 2010-2015 Priority Needs** ....................................................................................................... 4
- **Maternal and Child Health Advisory Task Force** ......................................................................................... 4
- **Children & Youth with Special Health Needs Work Group** ....................................................................... 5
- **The Six National Core Outcomes** ............................................................................................................... 6
- **Ten Essential Public Health Services** ......................................................................................................... 6

## CYSHN Strategic Plan 2013

- **Vision** .......................................................................................................................................................... 7
- **Overarching Themes** .................................................................................................................................. 9
  - Vision Element 1: Health Care Home ........................................................................................................... 10
  - Vision Element 2: Insurance and Financing ............................................................................................... 12
  - Vision Element 3: Early and Continuous Screening ................................................................................. 14
  - Vision Element 4: Easy to Access Services ............................................................................................... 16
  - Vision Element 5: Family-Professional Partnerships ................................................................................. 18
  - Vision Element 6: Transitions to Adulthood ............................................................................................... 19
- **First Steps: Implementation** ....................................................................................................................... 20

## Appendix A – Work Group Members

- **Members** .................................................................................................................................................. 21
- **Minnesota Department of Health Staff** .................................................................................................... 21

## Appendix B – Minnesota’s Title V Fact Sheet

## Appendix C

- **Definitions** ............................................................................................................................................... 24
- **Acronyms** ............................................................................................................................................... 27
As early as 1912, 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 strength. It allows states to determine the best use of resources to meet the needs of their communities.

The Omnibus Budget and Reconciliation Act of 1989 (OBRA ’89) amended the Social Security Act and mandated the Title V Maternal and Child Health 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. Objectives called for 1) increasing the proportion of States and territories that have community-based service systems for children with special health care needs; and 2) improving access to a medical home for children and youth with special health care needs. In future years, Healthy People 2010 and Healthy People 2020 expanded to include focus on 4 key goals.

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 an estimated 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. Disabled youth 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 experiences in early childhood (ACEs) create changes in the architecture of the brain that affects 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 ASD were more than three times as likely to be bullied as their peers. CYSHN children 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 works with sister agencies for providing services. MDH’s role is now looking at public health assessment and assurance. Essential public health services to monitor health status, inform and educate the public, mobilize community partnerships and develop policies to assure health promotion and protection.
As part of the collaborative relationship with the 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.

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 identify the priority needs; and
- increase the state’s commitment to addressing the final priorities.
MINNESOTA’S 2010-2015 PRIORITY NEEDS

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 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.

Please refer to Appendix B, Minnesota Title V Fact Sheet, for the national and state performance measures.

MATERNAL AND 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.
As a part of the MCH Task Force’s action plan, a CYSHN Work Group (hereafter referred to as 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.
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 independence.

TEN ESSENTIAL PUBLIC HEALTH SERVICES

HRSA, MCHB, Association of Maternal and Child Health Programs (AMCHP), Association of State and Territorial Health Officials (ASTHO), CityMatCH, and the National Association of County and City Health Officials (NACCHO) together 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.

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 8 of this document.
This strategic plan will guide MDH in supporting the development and coordination of state and local systems for children 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 special needs children and the population as a whole.

The Work Group focused on establishing vision elements based on the six core outcomes - keeping special health needs children 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.

<table>
<thead>
<tr>
<th>VISION ELEMENTS</th>
<th>Desired outcomes in 3 – 5 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>STRATEGIES</td>
<td>Activities and initiatives employed to accomplish desired outcomes</td>
</tr>
<tr>
<td>IMPLEMENTATION ACTIVITIES</td>
<td>Identifying first steps toward achievement of strategies</td>
</tr>
</tbody>
</table>
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.
OVERARCHING THEMES

The CYSHN Strategic Plan supports a structure of overarching themes or values which applies 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 to all individual, community and organizational strategies and implementation areas:

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 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 ELEMENT 1: HEALTH CARE HOME

Minnesota children and youth with special health needs and their families have increased access to health care homes as their primary care source. A child’s HCH integrates preventive services, acute illness management, and 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.

Strategy 1-A: Increase demand for quality pediatric health care home services by improving knowledge and understanding of health care home among families, providers and communities.

Possible implementation activities include:

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.

Strategy 1-B: Build capacity of quality pediatric health care homes to work with children and youth with special health needs.

Possible implementation activities include:

1. Partner with physician organizations such as the 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.
Strategy 1-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.

Possible implementation activities include:

1. Incorporate quality of life measures, including developmental and functional status outcome measures within a health care home.

2. Explore a Medical Home Index as a tool for statewide assessment regarding the quality of Health Care Homes for CYSHN across the state.
VISION ELEMENT 2: INSURANCE AND FINANCING

Children and families have flexibility to obtain insurance and financing services 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 2-A: Enhance and improve tools for navigating health insurance and financing options for children and youth with special health needs to maximize use of financing resources.

Possible implementation activities include:

1. Develop 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 2-B: Assure that children and youth with special health needs are a priority in policy-making and allocating resources.

Possible implementation activities include:

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 ELEMENT 3: EARLY AND 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), when appropriate, to improve health outcomes.

Strategy 3-A: Create and promote an infrastructure to support best-practice screening prenatally and birth through adolescence.

Possible implementation activities include:

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 pregnant women, children and youth.
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.

Strategy 3-B: Develop and implement best-practice recommendations for appropriate follow-up from screening prenatally and from birth through adolescence.

Possible implementation activities include:

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 for children 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 Follow Along program and high-risk family home visiting programs.
6. Promote evidence-based or best practice recommendations for follow-up of screening that includes supporting families with next steps.

**Strategy 3-C: Develop policies that ensure cross-organization/cross-stakeholder data sharing to support best practice screening and follow-up.**

_Possible implementation activities include:_

1. Develop policy that allows and encourages data sharing among screening providers.
2. Partner with MDE to create recommendations and provides policies that assure children are referred for medical assessment when appropriate during the Individualized Family Service Plan (IFSP) evaluation.
VISION ELEMENT 4: EASY TO ACCESS 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.

Strategy 4-A: Enhance and improve tools to access and navigate services for children and youth with special health needs.

Possible implementation activities include:

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 allows for common access to child health profile/database to achieve desired child outcomes that includes 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.

Strategy 4-B: Engage appropriate partners to create mechanisms that produce effective access and ease use of services.

Possible implementation activities include:

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.
Strategy 4-C: Promote best practice strategies for underserved populations to improve access to services to eliminate disparities.

Possible implementation activities include:

1. Promote bicultural and bilingual 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 defects trends in order to identify and better focus programs and educational efforts.
VISION ELEMENT 5: 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.

Strategy 5-A: Promote meaningful parent partnerships in program and policy development, implementation and evaluation, and in decision-making at all levels.

Possible implementation activities include:

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, 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.
VISION ELEMENT 6: 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 individuals. The transition process is tracked and evaluated based on guidelines and models from a life course perspective.

Strategy 6-A: Identify and promote models for successful transition among youth, families, providers and community through collaboration.

Possible implementation activities include:

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:

<table>
<thead>
<tr>
<th>Sequence</th>
<th>Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>5-A Promote meaningful parent partnerships in program and policy development, implementation and evaluation, and in decision-making at the individual level.</td>
</tr>
<tr>
<td>2</td>
<td>4-B. Engage appropriate partners to create mechanisms that produce effective access and ease of use of services</td>
</tr>
<tr>
<td>3</td>
<td>1-B Build capacity of quality pediatric health care homes to work with children and youth with special health needs.</td>
</tr>
<tr>
<td>4</td>
<td>2-B. Assure that CYSHN needs are a priority in policy-making and allocating resources</td>
</tr>
<tr>
<td>5</td>
<td>2-A &amp; 4-A. Enhance and improve tools for navigating health insurance and financing options for CYSHN to maximize use of financing. Enhance and improve tools to access and navigate services for CYSHN</td>
</tr>
<tr>
<td>6</td>
<td>3-A. Create and promote infrastructure to support best-practice screening throughout childhood and adolescence</td>
</tr>
<tr>
<td>7</td>
<td>4-C. Promote best practice strategies for underserved populations to improve access to services to eliminate disparities</td>
</tr>
<tr>
<td>8</td>
<td>3-C. Develop policies that ensure cross-organization/cross-stakeholder data sharing to support best practice screening and follow-up</td>
</tr>
<tr>
<td>9</td>
<td>1-A. Increase demand for quality pediatric health care home services by improving knowledge and understanding of health care home among families, providers and communities</td>
</tr>
<tr>
<td>10</td>
<td>6-A. Identify and promote models for successful transition among youth, families, providers and community through collaboration</td>
</tr>
<tr>
<td>11</td>
<td>3-B. Develop and implement best-practice recommendations for appropriate follow-up from screening throughout childhood and adolescence</td>
</tr>
<tr>
<td>12</td>
<td>1-C. Evaluate and monitor Health Care Homes to determine if families of CYSHN are receiving quality family-centered, coordinated, ongoing, comprehensive and cost-effective care</td>
</tr>
</tbody>
</table>
## APPENDIX A – WORK GROUP MEMBERS

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

## MINNESOTA DEPARTMENT OF HEALTH STAFF

<table>
<thead>
<tr>
<th>Staff</th>
<th>Department/Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nicole Brown</td>
<td>Newborn &amp; Child Follow-up Unit</td>
</tr>
<tr>
<td>Jeanne Carls</td>
<td>CYSHN Section</td>
</tr>
<tr>
<td>Barb Dalbec</td>
<td>CYSHN Section</td>
</tr>
<tr>
<td>Erica Fishman</td>
<td>Birth Defects Monitoring &amp; Analysis Unit</td>
</tr>
<tr>
<td>Shawn Holmes</td>
<td>CYSHN Section</td>
</tr>
<tr>
<td>Barb Lundeen</td>
<td>Health Care Home Section</td>
</tr>
<tr>
<td>Kris Oehlke</td>
<td>Birth Defects Monitoring &amp; Analysis Unit</td>
</tr>
<tr>
<td>Tony Steyermak</td>
<td>Newborn Child Follow-up Unit</td>
</tr>
<tr>
<td>Nancy Vanderburg</td>
<td>Newborn Child Follow-up Unit</td>
</tr>
</tbody>
</table>
About Title V

The federal Maternal and Child Health Bureau (MCHB) 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 inter-relatedness 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 for that priority need, 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/](http://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 (C&TC) visit (EPSDT is known as C&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 (C&TC) visit (EPSDT is known as C&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.

**For more information:**
Susan Castellano, Manager MCH Section
susan.castellano@state.mn.us

Barb Dalbec, Manager CYSHN Section
barb.dalbec@state.mn.us

---

Maternal and Child Health Section
Division of Community and Family Health
Phone: 651/201-3760
http://www.health.state.mn.us/divs/fh/mch/

Children and Youth with Special Health Needs Section
Division of Community and Family Health
Phone: 651/201-3650
http://www.health.state.mn.us/cyshn/
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, development, 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.

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, and 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 give 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 special needs children. Wraparound plans are comprehensive and address multiple life domains across home, school, and community.
ACRONYMS

ACA: Affordable Care Act
ACEs: Adverse Childhood Experiences
ACO: Accountable Care Organization
AMCHP: Association of Maternal and Child Health Programs
C&TC: 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