Families Having Children and Youth with Special Healthcare Needs Who Partner in Decision Making Within the Medical Home

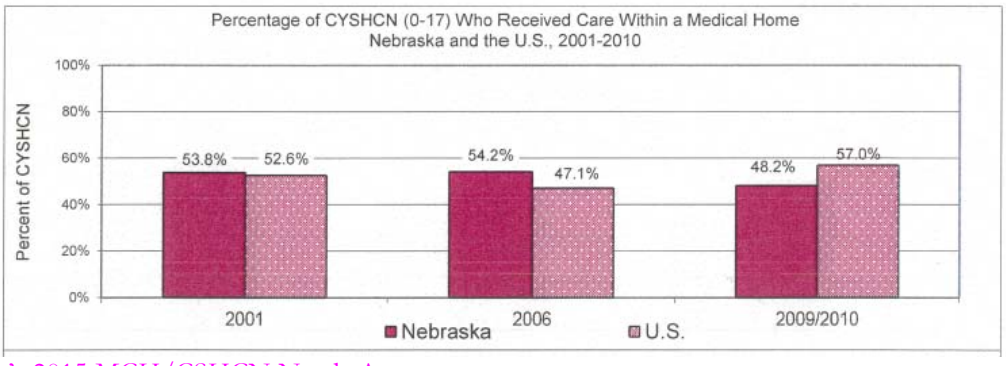
The US Maternal and Child Health Bureau and the American Academy of Pediatrics recommend that all children receive care in a medical home. A medical home is defined as a partnership between a family and a primary health care professional working together with the health care team to manage chronic conditions, coordinate care, access community resources, and continuously work on quality improvement. The concept of a medical home is one of six core outcomes for systems of care reported as performance measures by all state Title V programs and reflected in the Nation's Healthy People 2020 Objectives.[i] Access to a medical home is also a core domain for the Standards for Systems of Care for Children and Youth with Special Health Care Needs (CSHCN). [ii] All Nebraska children should receive comprehensive, coordinated care healthcare to insure that key developmental screenings are provided, needed interventions implemented and that relationships with care providers are developed. Access to this type of care is critical for CSHCN and their families in order to maintain optimal health.

Research has shown that children who do not have a medical home have increased emergency room utilization, miss more days from school and have caregivers who report higher levels of stress and decreased productivity at work.[iii] For CSHCN, this is even more significant as they make up 15% to 20% of the population, yet consume approximately 34% of the medical expenditures attributable to children.[iv] CSHCN are the 'frequent-flyers' of our healthcare system and ultimately, their families coordinate the bulk of their care from numerous different specialists and carryout the day-to-day healthcare needs of their child. Care coordination is an essential component of the medical home and can reduce medical inefficiency. The Catalyst Center, funded by the Maternal Child Health Bureau, maintains that care coordination helps families address unmet needs, has the potential to improve both the quality of care and adherence to treatment. This, in turn, helps providers deliver appropriate care. Care coordination is also a vital asset to state policy makers, particularly Title V programs, who are responsible for promoting statewide systems of quality care for CSHCN.[v]

Criterion 1: The Problem is Worse than the Benchmark or Increasing

According to the 2009/10 National Survey for Children with Special Healthcare Needs, the number and percentage of CSHCN in Nebraska has increased non-significantly since 2001 (12.8% in 2001; 14.6% in 2005/06 and 13.7% in 2009/10). However, the survey data also indicate that the percentage of CSHCN in Nebraska who receive coordinated, ongoing, comprehensive care within a medical home is significantly LOWER than the national average (48.2% in Nebraska versus 57% nationally) and has remained fairly constant (53.8% in 2001 and 54.2% in 2006). See Figure 1.

Given that there has been no significant linear change in the number and percentage of CSHCN who receive care within a medical home over the last 10 years, the projection is that without focused intervention,



approximately half of the estimated 61,000 CSHCN in Nebraska will continue to be unable to access Medical Homes in the future.

Figure 1.

Criterion 2: Disparities Exist Related to Health Outcomes

According to the National Survey on CSHCN, the disparity between CYSHCN (ages 0-11 years) and the data for all children (ages 0-11 years) was exceptionally significant. Approximately 60% (2011/2012) of children without special healthcare needs had access to Medical Home care compared to about 50% of CYSHCN (2009/2010).

There are significant disparities within the CSHCN population for those who receive care within a medical home; disparities were noted for children by type of insurance (38.9% for children with public insurance only versus 53.8% for children with private insurance only[vi]), by race/ethnicity (Hispanic 34.7% versus White, non-Hispanic 51.7%[vii]), and poverty (children with families at or greater than 400% of FPL had access averaging 57.1% versus 36% for children below the FPL[viii]). Furthermore, CSHCN with more reported conditions have a lower probability of having a medical home (33.5% of children with 4 or more functional difficulties vs 56.9% to 59.4 % for children with 0 to 3 functional difficulties[ix]).

Criterion 3: Strategies Exist to Address the Problem/An Effective Intervention is Available Criterion

The medical home model was introduced by the American Academy of Pediatrics in 1967 as a standard of primary care provision for CYSHCN. Since then, the model has evolved to be the standard of care for all children and youth.[x] There are many strategies that exist and efforts that are currently underway to help provide coordinated care within a medical home. However, special emphasis is needed for enhancing the coordination of care for children, especially those with special healthcare needs.

After a comprehensive review of the literature, The Association of Maternal and Child Health Programs (AMCHP) described the Overall Systems Standards (Structure and Process) for CYSHCN receiving care within the medical home: "The medical home is ready and willing to provide well, acute and chronic care for all children and youth, including those affected by special health care needs or who hold other risks for compromised health and wellness".[xi] This review also identified several existing national principles and Frameworks supporting the Systems Standards. These include:

- Joint Principles of the Patient Centered Medical Home
- Physician Practice Connections (PPC)-Patient Centered Medical Home (PCMH) Goals and Standards, National Committee for Quality Assurance (NCQA)
- Medical Home Index (Six Domains), Center for Medical Home Improvement
- Family-Centered Care Assessment for Families (FCCA-F), National Center for Family Professional Partnerships
- Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2011

In addition, there are several initiatives that could be supported or expanded in Nebraska to support the medical home. These include:

Medical Home Learning Collaborative

In 2008, the Boys Town Institute for Child Health Improvement was funded by the Maternal Child Health Bureau to develop and implement quality improvement strategies toward increasing chronic condition management, care coordination and early identification of CSHCN. To address these, a

model used in Rhode Island and identified by the MCHB in 2012 as a promising and innovative practice[xii], trains and places parent consultants into pediatric primary and specialty care practices to help families with CSHCN coordinate and access the health system, as well as other services (e.g., social services, education, housing). Trained Parent Consultants, who are parents of CSHCN themselves, assist physicians in providing comprehensive, coordinated medical homes to children with special needs in the state.

Currently, five parent consultants are being supported by the Nebraska Department of Education to assist with early intervention efforts and also supported by the physician's office to help coordinate care for families. Physicians often express interest in making improvements in the way they deliver care to CSHCN but also report that they don't have the time, expertise or resources to implement the changes on their own. This model could be expanded to other practices across the state of Nebraska.

Community Health Workers

One priority of the Public Health Association of Nebraska (PHAN) is to help build the capacity of and identify funding to sustain and expand Community Health Workers. A Community Health Worker (CHW) is a trusted member of/or has a good understanding of the community they serve. They are able to build trusting relationships, and are able to link the individuals with the systems of care in the communities they serve. A CHW also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support, and advocacy. CHW is an umbrella term used to define other professional titles. Other titles may include:

- Promotor
- Lay Health Ambassador
- Patient Health Navigator
- Lay Health Advisor
- Community Health Educator
- Community Outreach Worker
- Peer Counselor

A CHW is an individual who:

- Serves as a link and cultural liaison between public health, health care, behavioral health services, social services, and the community to assist people and communities in adopting healthy behaviors
- Provides Health promotion and disease prevention education for community members
- Conducts outreach and community mobilization that promotes and improves individual and community health
- Assists individuals navigating community resources through case management, care coordination, and advocacy[xiii]

UNMC Munroe-Meyer Institute's Family Trainee

The goal of the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program, funded by the Maternal and Child Health Bureau, is to help improve the health of infants, children, adolescents and young adults with neurodevelopmental and other related disabilities. LEND programs prepare trainees from a wide variety of professional disciplines to assume leadership roles, ensure high levels of interdisciplinary clinical competence, and enhance the ability of clinicians to diagnose, treat, and manage complex disabilities in youth and adolescents. For the last 4 years, the Munroe-Meyer Institute has had Family Trainees who have completed requirements that enhance their knowledge of systems to support CYSHN and their families, enhance their leadership skills and facilitate increased interaction among healthcare providers and families. This traineeship offers the potential to help support both the role of Community Health Workers and the Medical Home model.

Early Childhood Comprehensive Systems (ECCS)

Together for Kids and Families, an Early Childhood Comprehensive Systems Grant Project, is designed to achieve optimum outcomes for Nebraska's young children and their families through comprehensive system planning and collaborative effort among stakeholders. Medical Home is one of the core components identified as part of the early childhood system necessary to achieve positive outcomes.

Criterion 4: Societal Capacity to Address the Problem

There are numerous examples of projects designed to help reform, innovate and transform our healthcare system. Many are based on the "triple-aim" designed to: 1) improve patient outcomes (including quality and patient satisfaction), 2) drive down healthcare costs, and 3) improve population health.[xiv] As one example, The Centers for Medicare and Medicaid Services have offered funding to accomplish these as has other entities.

The following are examples of initiatives occurring in Nebraska.

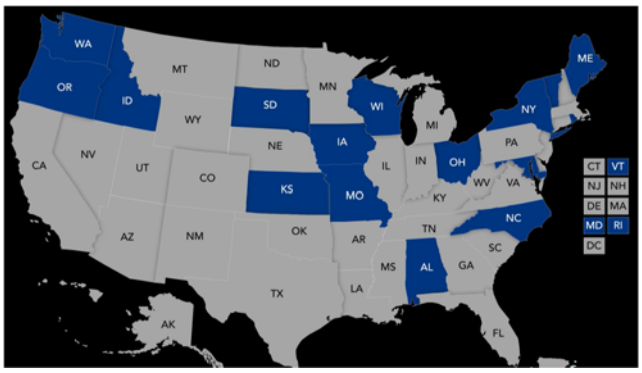
Medical Home

Nebraska has had a Medical Home pilot project with oversight by the Nebraska Legislature from 2012 to 2014. The pilot implemented medical home sites in Kearney, and Lexington. The pilot project measured patient and provider satisfaction, improvements in access and health outcomes and containment of Medicaid expenditures. The pilot also implemented value-based purchasing. Rather than charge for each visit or procedure, providers were paid an initial per-member-per-month (PMPM) payment. The PMPM increased once the practice met Tier 1 Minimum Standards. Practices who met Tier 2 Advanced Standards received an enhanced fee-for-service on selected procedure codes.[xv] While the pilot was discontinued in 2014, bills in the legislature have been introduced to further innovate the healthcare system in Nebraska. Often medical homes, health homes, value-based purchasing and accountable care organizations are mentioned. (Descriptions of these follow)

Health Home

Health homes are designed to be person-centered systems of care that facilitate access to and coordination of the full array of primary and acute physical health services, behavioral health care, and long-term community-based services and supports.

The health home model of service delivery expands on the traditional medical home models that many states have developed in their Medicaid programs, by building additional linkages and enhancing coordination and integration of medical and behavioral health care to better meet the needs of people with multiple chronic illnesses. The model aims to improve health care quality and clinical outcomes as well as the patient care experience, while also reducing per capita costs through more cost-effective care.[xvi] As of November 2014, 16 states have a total of 20 approved Medicaid health home models. (Illustrated in the map below)[xvii]



The Catalyst Center, who researches best practices and policy for CYSHN, has identified

the health home as one important strategy in being able to coordinate care for CYSHN who are eligible for Medicaid. This model would pay for:

- Comprehensive care management
- Care Coordination
- Health promotion;
- Comprehensive transitional care/follow-up;
- Patient and family support; and
- Referral to community and social support services.

In addition, the state can obtain a 90% match for the first 2 years the Health Home is implemented.[xviii] Last year, there was a proposal to fund health homes by the Nebraska Legislature[xix] and this year there is a bill introduced to do the same[xx]. In addition, this fits within Nebraska's vision to transform the healthcare delivery system identified through Legislative Resolution LR422.[xxi]

System of Care (SOC)

In 2014, the Nebraska Division of Behavioral Health held many stakeholder meetings to obtain data on the needs for wrap around services for children, and adolescents with behavioral health issues and their families.

"*Nebraska's child and family serving system of care will improve access to appropriate and timely community-based care that is family-driven and youth-guided; embodies the cultural and linguistic values of the individuals and families being served and improves their clinical, behavioral, social, and educational outcomes; and eliminates fragmented approaches to meeting need. Child and family-serving systems will achieve this change through transparent system collaboration with partnerships and shared ownership involving individuals and families as full partners.*"[xxii]

Currently, the decision to build a statewide system of care to insure wrap around services being provided is awaiting the approval of the new leadership within DHHS and Behavioral Health. However, a March 2015 letter that was sent to stakeholders indicate that the Division of Behavioral Health is committed to providing these services.[xxiii]

Criterion 5: Severity of Consequences Criterion

The data indicate CSHCN utilize medical services at increased rates, including 4 times the number of hospitalizations, twice as many doctor visits and 1.5 times as many emergency room visits, and receive 5 times the number of prescriptions[xxiv]. The anticipated outcomes of these circumstances can also include increased stress on families with CSHCN and increased potential for maltreatment.[xxv]

CSHCN in Nebraska have difficulty accessing needed health care services. There is a lack of primary care physicians in many areas of the state as well as an overall lack of pediatric specialists. In 2008, 96.7% (90/93) of Nebraska counties had a shortage of pediatricians.[xxvi] Diminished access to pediatric subspecialty care harms children and their families and creates costly inefficiencies for the health care system.

Furthermore, despite the widely acknowledged value of care coordination, lack of financing makes it unavailable to most CYSHCN and their families. Studies consistently find that the lack of care coordination is an important area of unmet need for families. Over one fifth of families (22%) spend more than two hours per week of their own time coordinating care for their child and 4% spend more than ten hours per week coordinating care.[xxvii]

There are many documented benefits of a medical home for CSHCN, including streamlined care for the child and family; efficient use of limited resources; decreased out-of-pocket expenditures; expanded expertise and competence for the involved providers; establishment of a forum for problem solving; and improved satisfaction for the patient, family, and provider[xxviii].

Furthermore, a recent study by Fiks (2012)[xxix] found that increased Shared Decision Making (SDM; families and clinicians participate together in decision making, exchange information, and determine a treatment plan) resulted in decreased costs and utilization of services for CSHCN.

Most people often believe that access to clinical care is the most important variable in determining health outcomes. Yet, according to the University of Wisconsin Population Health Institute, which analyzes public health data and issues an annual report called, "Community Health Rankings[xxx]," access to social and economic factors has a greater impact on health.

The medical home is a model that can help families access and coordinate clinical care, and identify community resources, both which have shown to impact health outcomes for both the child receiving them and the family member who is caring for the child.

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