

A MEDICAL HOME FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN RURAL LOCATIONS

Amy J. McClune, PhD, RN¹

¹Assistant Professor, [Department of Nursing](#), Edinboro University of Pennsylvania, amcclune@edinboro.edu

Key words: Nurse, Rural Health, Children, Special Health Care Needs

ABSTRACT

Children with special health care needs (CSHCN) present a complex challenge to the medical system. The concept of a medical home has been proposed to ensure consistency and continuity of care for CSHCN. Although it seems to be an easy solution in theory, implementation is complicated especially for the child residing in a rural area. This paper will explore the possibilities to ensure that rural CSHCN have access to a medical home. The characteristics of a medical home include continuity, accessibility, coordination and compassion. A comprehensive focus on the family with attention to cultural needs is critical. Geography, transportation, and financial barriers are present in rural families of CSHCN. In a five-year longitudinal study, Adams and colleagues (2006) found unmet dental, visual, and auditory health needs in school-age children in the rural south. Primary care in general was also identified as an unmet need. Nora Pender's model of health promotion (2006) provides a strong framework for assessing and implementing the medical home concept for CSHCN in rural areas. Individual characteristics include the psychological and socio-cultural components of a rural lifestyle. Accessibility issues may prevent optimal health promotion and illness prevention in a CSHCN in a rural area. Using data from the National Survey of CSHCN, Skinner and Slifkin (2007) examined barriers faced by rural families of CSHCN that fit with the behavior specific cognitions and affect described by Pender. Using Pender's model of health promotion (2006) provides a successful template for providing a medical home for CSHCN living in rural areas. Involving health care providers, home health agencies and community resources under the leadership of an advanced practice nurse could provide the chemistry needed for success.

INTRODUCTION

Children with special health care needs (CSHCN) present a complex challenge to the medical system. By definition, these children require healthcare services beyond those of healthy children presenting difficulties with consistency and continuity of care. One solution is the creation of a medical home for each child. Although it seems to be an easy solution in theory, implementation is complicated. Further complications are presented if the child with special health care needs resides in a rural area. This paper will explore the possibilities to ensure that rural CSHCN have access to a medical home.

THE PROBLEM AND ITS CONTEXT

Children with Special Health Care Needs

The term 'children with special health care needs' has been used for the last twenty years to identify infants, children and adolescents who are in need of services due to chronic disability. Over the years, as disabilities have become more complex, the term has undergone redefinition.

The current definition was offered from a collaborative effort by the Maternal and Child Health Bureau and the American Academy of Pediatrics. This definition clears the way for consistent service provision through the various government departments and agencies that serve CSHCN. The definition presented in 1998 because of these efforts is as follows:

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 (McPherson et al., 1998 138).

Children with special health care needs are present in all aspects of society. The National Survey of Children with Special Health Care Needs conducted in 2001 (U.S. Department of Health and Human Services) found that 9.4 million (12.5%) of children under the age of 18 fall under the current definition. These children can be found in one out of five (20%) of U.S. households. CSHCN are found more predominately in the older ages (8% in ages 0-5; 15.8% in adolescents from 12-17 years) due delayed recognition or presentation of symptoms. Fifteen percent (15%) of boys and 10.5% of girls fall within the CSHCN definition. Prevalence rates do not vary significantly between income levels. Concerning race and ethnicity, higher rates are found in Native American/Alaskan Native (16.6%), mixed race (15.1%) and non-Hispanic white children (14.2%). Children with moderate to severe health problems are more likely to be found in rural areas (9% in large rural areas; 8.1% in small rural/isolated areas) than in urban areas (7.7%). (U.S. Department of Health and Human Services, 2005).

Medical Home

The concept of a medical home was introduced by the American Academy of Pediatrics (AAP) in 1967 (as cited in Sia et al., 2004). The medical home was conceptualized as a central place where all information related to the care of a CSHCN could be found. In the late 1970s, the concept of the medical home grew to include more than a repository of information and was retooled to represent a method of community-based primary care focusing on prevention and wellness (Sia et al.). In 1992, the AAP published a definition of a medical home that included six characteristics. A medical home should be “accessible, continuous, comprehensive, family centered, coordinated, and compassionate” (AAP, 774). Culturally effective care was added as a component of the definition in a 2002 update (AAP). Needed healthcare should be available at any time and awareness of available resources assists the child and family meet their healthcare needs. Collaboration between schools, community agencies and providers is important to maintain consistency. Finally, the centralization of the medical record is crucial to seamless provision of care by all parties. A critical measurement of success of the medical home is the partnership between the family and the provider.

According to the National Survey of Children’s Health, 46.1% of all children are reported to have a medical home. The percentages are evenly split between urban (46.4%), small rural/isolated (45.2%) and large rural (44.7%) areas. (U.S. Department of Health and Human Services, 2005).

Benedict (2008) used data from the 2000-2001 National Survey of Children with Special Health Care Needs. Focusing on children requiring therapeutic (n=5,793) and supportive (n=23,376) services, the study evaluated the presence and effectiveness of a medical home.

Occupational, physical and speech therapy and mental and substance abuse services defined therapeutic services. Programs that assist in providing care to the child including specialized equipment, transportation, home health and respite care comprised supportive services. The variable of quality medical home was defined as the components of a medical home defined by the AAP. Unmet therapeutic needs were present in 16.2% of the children while 9.8% lacked needed supportive services. A quality medical home was present for only 23.9% of the children needing therapeutic services and 32.5% those needed supportive services. Additionally it was found that the more severe the condition, the more likely the child was to have unmet needs. Specific components of a quality medical home including access to preventative care, cultural sensitivity of the care provider and the degree of care coordination were found to be associated with lower unmet needs for services. This nationwide survey of a large sample delineates the key issues facing families of CSHCN.

Rural Health Care

Geography can impact the accessibility and consistency of healthcare for all ages. Access to both primary and specialty care has been identified as a concern for rural children. Transportation can be a considerable barrier to accessing the needed care. Additionally financial burdens are consistent with the higher poverty that is often present in rural areas. (Wright, 2006).

A five year longitudinal study focused on school-age children in the rural south identified lack of healthcare in specific areas (Adams et al., 2006). Children (n=2813) were assessed in a health fair format that incorporated health history, vital signs, vision and hearing screenings, a physical examination and an anemia screening. Variables included unmet needs in dental, visual, and auditory health along with referrals based on dental, vision, auditory or primary care needs. Results indicated that uninsured or publically insured children were more likely to experience an unmet health care need and receive a referral for follow-up care. Unmet dental needs were highest among the elementary students; vision needs were highest among junior high students. Unmet auditory needs were highest among middle school students. The findings of this well-designed study with a large sample size can confidently be generalized to other areas suggesting that unmet health care needs can be found throughout the United States.

PENDER'S HEALTH PROMOTION MODEL

Nora Pender's model of health promotion (2006) provides a strong framework for assessing and implementing the medical home concept for CSHCN in rural areas. Pender's model arose from the early nursing philosophy that focused on promoting health and preventing illness. CSHCN require these same interventions – promoting health and preventing illness – to maintain their current level of health and wellbeing. Pender's Health Promotion Model was developed to identify characteristics that result in health promotion. Individual characteristics and experiences impact knowledge and emotions related to a specific behavior. These components result in a behavioral outcome that includes a commitment on the part of the individual to a plan of action focused on a health promoting behavior. (See figure 1).

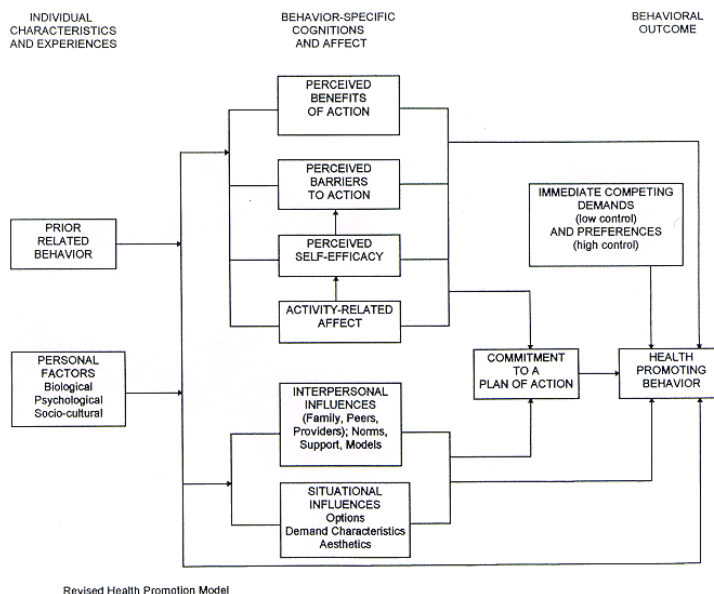


Figure 1. Pender's Health Promotion Model (n.d.)

In applying Pender's model to rural CSHCN, many of the issues already discussed fit well. Personal factors that are included in the individual characteristics might include the psychological and socio-cultural components of a rural lifestyle including family make-up, financial issues, and transportation. Perceived benefits of and barriers to action are complicated. Accessibility issues from provider-to-population ratio of both primary and specialty care, insurance coverage, and complexity of medical needs of the child may prevent optimal health promotion and illness prevention.

Using data from the National Survey of CSHCN, Skinner and Slifkin (2007) examined barriers faced by rural families of CSHCN. These barriers fit well with the behavior specific cognitions and affect described by Pender. Rural CSHCN were found to be more likely to seek care from a clinic or health center ($OR=1.44, p<.01$). They are more likely to be cared for by general practitioners ($OR=2.12, p<.01$) than pediatric specialists. These effects remained between urban and rural children after adjustment for poverty, insurance and maternal education. Rural parents delayed seeking care for their CSHCN more than urban parents primarily because the needed care was not provided in the geographic area. Financial issues were also cited as a factor in the delay in seeking care. Unmet healthcare needs in rural CSHCN were more likely a result of transportation or lack of service availability than in urban children. Skinner and Slifkin (2007) reported that rural families bore a greater burden in caring for their CSHCN. Indicators of that burden included providing care in the home, lower financial status, spending more time arranging and providing care for their children. They were also more likely to require additional income to meet the child's healthcare needs.

Collaboration of healthcare providers, family, school, and community can discover ways to alleviate barriers. This collaboration is at the heart of a medical home. Pender believes that nurses are in an ideal position to coordinate this type of collaboration. Advanced practice nurses can extend the benefits of nursing to provide needed primary care.

THE SOLUTION – A MEDICAL HOME FOR RURAL CSHCN

Desired Outcome

The optimal solution for this problem is to develop a program coordinated by a pediatric nurse practitioner that would provide a medical home for CSHCN in rural areas. Outcomes would include a reduction in unmet therapeutic and supportive needs, a satisfaction with accessibility of healthcare and related needed information, and a perception of improved self-efficacy on the part of the parents of CSHCN. This project is being proposed for Erie County, Pennsylvania; a primarily rural county in the northwest corner of the state.

Defensibility and Realism

The literature provides evidence to support the feasibility of the proposed program. In 2001, the Center for Medical Home Improvement was established to promote and support quality primary care medical homes for CSHCN. The Center acknowledges the importance of parental partnerships with professionals in providing healthcare. (Center for Medical Home Improvement, n.d; Cooley & McAllister, 2004). The team members for the Center include a lead pediatrician or primary care provider, key non-physician office staff/care coordinator, and parent partners. Key to success is the investment of time to the needed tasks within a supportive environment.

Farmer and colleagues (2005) explored the feasibility of a rural medical home demonstration project. Participants (n=51 parents of CSHCN) were recruited to take part in a program designed according to the AAPs components of a medical home. A primary care physician, the child and family, a nurse practitioner (NP), office staff, and a parent consultant comprised the healthcare team. Care coordination, information, emotional support and empowerment were the components of the intervention. All participants received a detailed assessment of the needs of the child and family completed by a NP in the home. Individualized health plans were developed for each child with short-term goals that were evaluated at least once during the 12 months of implementation. Upon assessment, children were found to require 4 to 5 health related services. After the completion of the demonstration project, mothers reported better access to mental health services as well as a decrease in visits to their primary and specialty care providers. Significant improvement in satisfaction with care coordination services was reported by mothers. Total family needs were reduced per the mother's reports with less social support, financial and family relationship needs. Family strain was also found to decrease. School attendance for the children involved significantly improved. Of significance for this study is that the "medical home" was not based in one office. The "medical home" was facilitated by the interventions of a project NP who was responsible for making contact with each child's primary care provider to ensure coordination and collaboration. Although this demonstration project was of a smaller scope, it does provide preliminary support for a medical home for rural CSHCN.

To make this proposal a reality would require numerous resources. Funding would need to be secured to provide the NP and other staff members. Primary care and pediatric practices must buy-in to the concept of a medical home for the proposal to succeed. Most importantly, all stakeholders from the healthcare providers to the parents of the CSHCN need to value the possibilities of a medical home.

Although the resources needed to implement a proposal like this seem insurmountable, it would be worth the time and effort. Funding is available from the government and community agencies. With successful grants, funding sources could be found. Starting with a small nucleus of providers who are committed to the project, a marketing campaign could be launched to communicate to primary care and pediatric providers. Collaborating with home health agencies and other community resources would maximize potential. Overall, it could become a reality with the right chemistry of those involved.

CSHCN and their families who live in a rural area are often lacking in the needed services to promote health and prevent illness. The goal for a CSHCN is to maintain or improve their health status as they grow and develop. The stress of caring for a CSHCN can be frustrating and exhausting to families. The implementation of a medical home for rural CSHCN would provide a solution to many of the issues faced by these children and their families.

REFERENCES

- Adams, M.H., Carter, T.M., Judd, A.H., Leeper, J., Yu, J., & Wheat, J.R. (2006). Effectiveness of community efforts to reduce unmet health needs among rural school children. *Southern Online Journal of Nursing Research*, 7(2), 2-21. Retrieved on April 18, 2008, from http://www.snrs.org/publications/SOJNR_articles/iss02vol07.pdf
- American Academy of Pediatrics, Ad Hoc Committee on Definition of the Medical Home. (1992). The medical home. *Pediatrics*, 90, 774. [[MEDLINE](#)]
- American Academy of Pediatrics, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. (2002). The medical home. *Pediatrics*, 110, 184-186. [[MEDLINE](#)]
- Benedict, R.E. (2008). Quality medical homes: Meeting children's needs for therapeutic and supportive services. *Pediatrics*, 121, e127-e134. [[MEDLINE](#)]
- Center for Medical Home Improvement. (n.d.). Retrieved on April 20, 2008, from <http://www.medicalhomeimprovement.org/default.htm>
- Cooley, W.C., & McAllister, J.W. (2004). Building medical homes: Improvement strategies in primary care for children with special health care needs. *Pediatrics*, 113, 1499-1506. [[MEDLINE](#)]
- McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P.W. et al. (1998). A new definition of children with special health care needs. *Pediatrics*, 102, 137-140. [[MEDLINE](#)]
- Pender, N.J. (n.d.). Revised health promotion model. Retrieved on April 20, 2008, from <http://www.nursing.umich.edu/faculty/pender/chart.gif>
- Pender, N.J. (2006). Most frequently asked questions about the Health Promotion Model and my professional work and career. Retrieved on April 20, 2008, from http://www.nursing.umich.edu/faculty/pender/pender_questions.html
- Sia, C., Tonniges, T.F., Osterhus, E., & Taba, S. (2004). History of the medical home concept [Electronic version]. *Pediatrics*, 113, 1473-1478. [[MEDLINE](#)]
- Skinner, A.C., & Slifkin, R.T. (2007). Rural/urban differences in barriers to and burden of care for children with special health care needs. *The Journal of Rural Health*, 23, 150-157. [[MEDLINE](#)]

- U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2005). The national survey of children's health 2003. Rockville, MD: U.S. Department of Health and Human Services. Retrieved on April 18, 2008, from <http://www.mchb.hrsa.gov/ruralhealth/index.htm>
- U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2004). The national survey of children with special health care needs chartbook 2001. Rockville, MD: U.S. Department of Health and Human Services. Retrieved on April 18, 2008, from <http://mchb.hrsa.gov/chscn/index.htm>
- Wright, M.M. (2006). Nursing care of rural children with special health care needs (CSHCN) [Editorial]. *Online Journal of Rural Nursing and Health Care*, 6(2), 5-6. Retrieved on April 18, 2008, from <http://www.rno.org/journal/index.php/online-journal/article/viewFile/16/167>