

*Editorial***NURSING CARE OF RURAL CHILDREN WITH  
SPECIAL HEALTH CARE NEEDS (CSHCN)**

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VA National Survey of Children with Special health Care Needs conducted in 2001 estimated that there are 9.4 million children who have special health care needs. This represents an estimated 12.8 percent of the children in the United States. The definition of children with special health care needs (CSCHN) was developed by the federal Maternal Child Health Bureau and states that 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 generally (Van Dyck, P., Kogan, M., McPherson, M., Wessman, G., & Newacheck, P., 2004).

In providing nursing care, rural nurses can identify and classify CSHCN by the impact on the child's condition or functional ability. In this classification, nurses can look at whether the special needs a) sometimes affect the child's functional abilities and activities, b) usually or always affect the CSHCN, or c) never affect functional abilities and activities. Nearly 40% of CSHCN never have their activities affected by their special needs – however, 60% of CSHCN have their functional ability affected and as a result are in need of adaptations and services in their community or by referral to a specialty site.

There are specific challenges for nurses who care for these children in rural settings. The first challenge or barrier to care is Access to Care. Accessibility is a great concern, for both primary care and specialty care. The use of a "Medical Home" for coordinated, comprehensive care is highly recommended and endorsed both by the American Academy of Pediatrics (<http://www.aap.org/advocacy/archives/julymedhome.htm>) and also within the objectives of Health People 2010 (Keefe, 2001). In the Medical Home model, the nurse helps to coordinate visit scheduling and communication between families and providers as they use services in primary and specialty care. Another aspect of the Medical Home concept is the use of a portable care plan that lists patient history, treatment plan and goals. Updating and assisting the family as they communicate the care plan to other providers and caregivers is also an aspect of nursing care in the Medical Home model. Transportation issues and availability of services are barriers linked to access to care as the nurse tries to locate and schedule several services.

Another major barrier for the family is the financial and personal demands when caring for a CSHCN. Poverty is common in rural areas and the child with special needs adds financial cost and may also lessen the amount of time available for employment. Awareness and acknowledgement of these issues by the nurse is the first step to accessing

and coordinating available services and dealing with the frustration of the family members.

Another setting for nursing care of the CSHCN is the school system as they progress in their education and make the transition from school to employment and/or residential living. Again, the nurse is essential for helping the young adult to navigate and use medical and community services. This includes the team meetings, such as the 504 or IEP (Individual Educational Plan) within the school setting. The rural nurse needs to educate and advocate for the child and have a good understanding of which community services may provide health care support as the student and teachers work toward meeting educational goals.

Rural nursing provides the opportunity for a close, professional relationship between the nurse, child and the family. The model of family-centered care is the result of a productive, close, professional relationship. The federal Maternal and Child Health Bureau Division of Services for Children with Special Health Needs defines Family Centered Care as:

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 the relationship. Family-Centered Care is the standard of practice which results in high quality services. Each stage of the CSHCN life presents challenges that the rural nurse can help the family navigate, building their decision making ability and their awareness and utilization of services (National Center for Family-Centered Care, 1989).

The nurse assists the providers and families to recognize and provide for the developmental, emotional and recreational needs of the child, rather than focusing only on the episodic difficulties or illnesses. The partnership of family-centered care helps all to work in the child's best interest and foster optimal health and development despite any disability.

The future of rural nursing of CSHCN and their families will include more technology and questions about adult and elder care. Equally important is the need to gather and share information that can be developed into health care policy and evidence based practices so that rural nurses can advocate for CSHCN and work with providers and families to promote family centered-care.

## REFERENCES

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