RESEARCH BRIEF

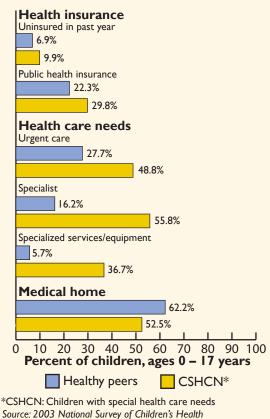


KANSAS CHILDREN WITH SPECIAL HEALTH CARE NEEDS

National Survey of Children's Health finds that more than one in five Kansas children grow up with chronic health conditions and have special health care needs.

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Figure 1. Health care experiences of Kansas children with chronic conditions



Kansas children with chronic health conditions are more likely to need specialized health care than their healthy peers. KHII/09-04 • February 2009 The 2003 National Survey of Children's Health estimated that more than one in four Kansas children were growing up with a chronic health condition or disability, such as Attention Deficit Hyperactivity Disorder, asthma, diabetes, autism or developmental delays. One in five children had special health care needs, which are chronic physical, developmental, behavioral or emotional conditions requiring health care and services beyond those needed by most children.

Children with chronic conditions need specialized treatment and services

Children with special health care needs frequently require more health care services than their peers, and may require specialized treatments, therapies or equipment. Kansas children with special health care needs were almost twice as likely as their healthy peers to have needed urgent care during the previous year. Further, these children were nearly three times as likely to have needed the services of health care specialists, and more than six times more likely to have required special services or equipment (Figure 1).

Accessing specialized health care is challenging

Kansas children with special health care needs also had more difficulty than their healthy peers in accessing the

specialized care that they needed. They were twice as likely to report problems with getting care from specialists, and four times as likely to report problems in accessing necessary specialized therapies, services and equipment.

Navigating the health care system to obtain needed services can be time-consuming, confusing and frustrating. Insurance coverage is one factor that may impact access to health care. Survey findings indicate that Kansas children with special health care needs were not

DEFINITIONS

Children with chronic health conditions have a chronic physical, developmental, behavioral or emotional condition, such as Attention Deficit Hyperactivity Disorder, diabetes, asthma, autism or developmental delays.

Children with special health care needs have certain needs that will last 12 months or longer, such as needing prescription medication, more special therapy, health or educational services than most children of the same age; or are limited in their ability to do things most other children can do.

The Kansas Health Institute is an independent, nonprofit health policy and research organization based in Topeka, Kansas. Established in 1995 with a multiyear grant from the Kansas Health Foundation, the Kansas Health Institute conducts research and policy analysis on issues that affect the health of Kansans.

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Copyright© Kansas Health Institute 2009. Materials may be reprinted with written permission. significantly more likely than their healthy peers to have been uninsured during the previous year, but were significantly more likely to be covered by public programs, such as Medicaid or HealthWave. Other factors that may influence access to care include the availability of qualified providers located within reasonable distance of the child's home, and finding providers that participate in the child's insurance plan and are willing to work with a child with special needs.

Families of children with chronic health problems need coordinated support

Parents of children with special health care needs must juggle the demands of their work and everyday family life with the added challenges of frequent health care appointments, navigating a complex health care system and advocating for the child's needs. They may require extra support and assistance in obtaining the services that their children need. Research studies have shown that children who receive care that is accessible, comprehensive, coordinated, continuous, compassionate, culturally effective and patient-centered — the definition of a medical home — are more likely to obtain the care that they need and have better outcomes in their health status, timeliness of care and improved family functioning.

The survey indicated that in 2003 only one-half of Kansas children with special health care needs received the kind of comprehensive and coordinated care that met the definition of a medical home. Further, children with special health care needs were less likely than their healthy peers to have had a medical home.

Policy implications

Fortunately for most children with chronic health problems, their conditions are mild or moderate in severity and do not have devastating effects. Nevertheless, the high frequency of special health care needs among Kansas children has significant implications for state policymakers.

The most direct policy implication is the impact upon the state's health care system. Children with special health care needs frequently use more health services than their healthy peers and frequently require access to more highly specialized providers, services and equipment. Children with special health care needs, especially those whose conditions are most severe, are more likely to obtain their health insurance coverage through publicly financed sources. However, access to health insurance is not enough. Effectively managing chronic health conditions requires coordination of medical, social and educational services. Care coordination can be improved with access to a medical home, case management and advocacy support.

In addition to having special health care needs, children with chronic health conditions also may require special services at school. Allowing these children to be fully included in the state's educational system will likely require additional resources, coordination of services, and adaptation to support their health needs while maximizing their potential to learn.