



KANSAS HEALTH INSTITUTE

CHILDREN'S HEALTH IN ALL POLICIES

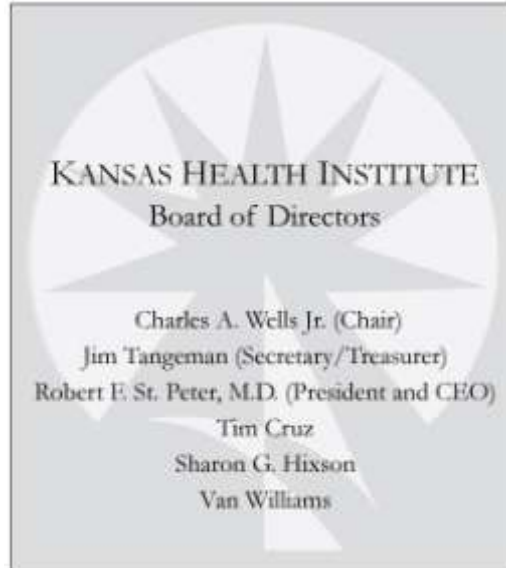
**POLICY OPTIONS FOR ADDRESSING THE
HEALTH OF KANSAS CHILDREN WITH
SPECIAL HEALTH CARE NEEDS**

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February 2, 2010

Noon – 1:30 p.m.




The Kansas Health Institute is an independent, nonprofit health policy and research organization based in Topeka, Kansas.

Established in 1995 with a multi-year 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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KANSAS CHILDREN WITH SPECIAL HEALTH CARE NEEDS: SLIDE I




**POLICY OPTIONS FOR
ADDRESSING THE HEALTH OF
KANSAS CHILDREN WITH SPECIAL
HEALTH CARE NEEDS**

Children's Health in All Policies
February 2, 2010

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KANSAS CHILDREN WITH SPECIAL HEALTH CARE NEEDS: SLIDE 2



WHAT DO STATE LEGISLATORS NEED TO KNOW ABOUT CSHCN?

- About 1 in 5 Kansas children have special health care needs
- CSHCN use more, and more highly specialized health care services
- Families with CSHCN have higher out-of-pocket medical expenses
- Parents often juggle work demands with the needs of their child
- Services are fragmented

SLIDE 2 NOTES:

1. Children with special health care needs (CSHCN) are those children who have a chronic physical, developmental, or emotional health condition and who also require health and health-related services of a type or amount beyond that required by children generally.¹
 - a. This definition captures a broad spectrum of health conditions and disabilities, including chronic conditions such as asthma and diabetes, mental health and behavioral problems, autism, Attention Deficit Hyperactivity Disorder (ADHD), physical disabilities and developmental delays.
2. About one in five Kansas children (20.7 percent) meets the definition of a child with special health care needs.²

¹ United States Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2009). *Maternal and Child Health Research Program Strategic Research Issues: FY 2004-2009*. Retrieved January 25, 2010, from <http://mchb.hrsa.gov/programs/research/issues.htm>.

² National Survey of Children's Health. (2007). *Survey Sections, Kansas, 2007, Health and Functional Status (Survey Section 2), Children with special health care needs (CSHCN)*. Retrieved January 25, 2010, from <http://www.nschdata.org>.

3. Children with special health care needs use more health care services, and more highly specialized services than their peers.³
 - a. In 2003, more than half (55.8 percent) of these children required the services of a medical specialist.
 - b. That same year, more than one-third (36.7 percent) needed specialized support services or equipment.
4. Families with children with special health care needs experience significant financial burdens associated with the needs of their child.⁴
 - a. About 22 percent report spending more than one thousand dollars per year in out-of-pocket medical expenses for their children with special health care needs.
 - b. More than 21 percent reported that their child's condition caused financial problems for the family.
5. Parents of children with special health care needs are often challenged to balance the caregiving needs of their child with work demands.⁵
 - a. One in five families (20.1 percent) reported that family members had been forced to quit a job or reduce working hours in order to care for their child.
6. Services and supports for children with special health care needs are fragmented.
 - a. Accessing needed services frequently involves visits to multiple agencies and providers.
 - i. Eight percent of families with children with special health care needs report that they spend 11 hours or more each week in providing or coordinating health care for their child.⁶
 - b. There is no centralized clearinghouse for information or for seeking assistance.
 - c. In addition to health care professionals, obtaining comprehensive care for children with special health care needs may involve frequent contacts with schools, social service agencies and multiple government assistance programs and agencies.

³ Kansas Health Institute. (2009). *Research Brief: Kansas Children with Special Health Care Needs*. Retrieved January 25, 2010, from <http://www.khi.org/documents/2009/feb/28/kansas-children-special-health-care-needs/>.

⁴ United States Department of Health and Human Services, Health Resources and Services Administration. (2006). *The National Survey of Children with Special Health Care Needs, Kansas Chartbook 2005-2006*. Retrieved January 25, 2010, from <http://mchb.hrsa.gov/cshcn05/SD/kansas.htm>.

⁵ United States Department of Health and Human Services, Health Resources and Services Administration. (2006).

⁶ United States Department of Health and Human Services, Health Resources and Services Administration. (2006).

KANSAS CHILDREN WITH SPECIAL HEALTH CARE NEEDS: SLIDE 3



WHAT CAN STATE LEGISLATORS DO?

- Ensure access to needed medical services
- Improve the coordination of services
- Provide family supports
- Require reasonable accommodation
- Support data collection and research to improve knowledge around the prevalence and needs of CSHCN

SLIDE 3 NOTES:

1. State policymakers can help to optimize the health and growth of Kansas children with special health care needs through many approaches:
 - a. Ensuring access to necessary health care services by insuring adequate health insurance coverage and the availability of sufficient numbers of specialized health professionals in Kansas.
 - b. Improving the coordination of services by encouraging access to medical homes, creating information clearinghouses or centralizing the administrative responsibility for children's services within fewer state departments and programs.
 - c. In 2007, about half of Kansas's children with special health care needs had access to health care that met the definition of a medical home.⁷
 - i. *Medical home*: Primary care that is accessible, comprehensive, coordinated and family-centered.⁸

⁷ National Survey of Children's Health. (2007). *Child Health Measures, Kansas, 2007, Health Care Access and Quality, 4.8 Have a medical home, Special Health Care Need status*. Retrieved January 25, 2010, from <http://nschdata.org/DataQuery/DataQueryResults.aspx>.

⁸ American Academy of Pediatrics, (2009). *Children's Health Topics, Medical Home*. Retrieved January 25, 2010, from <http://www.aap.org/healthtopics/medicalhome.cfm>.

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- d. Providing supports to families with children with special health care needs might come in the form of financial supports such as subsidies or tax credits, case management and advocacy programs or requirements for adequate family leave policies in the workplace.
- e. Some children with disabilities or developmental delays may need accommodation such as ramps, wheelchair seating or communication through sign language or Braille in order to fully participate in their community. Legislation can help to ensure that communities are fully accessible to all children.
- f. Access to complete and reliable data is crucial to understanding the needs of children with chronic health conditions, as well as in planning for supportive services.

KANSAS CHILDREN WITH SPECIAL HEALTH CARE NEEDS: SLIDE 4



WHAT ARE OTHER STATES DOING?

- Title V programs
- Medicaid Home and Community-Based Services (HCBS) waivers
- Early screening and intervention
- Specialized educational services
- Centralized social services
- Enhanced family leave programs
- Data collection & research

SLIDE 4 NOTES:

1. Every state plus the District of Columbia receives federal funding under the Title V Maternal and Child Health Block Grant to provide health-related services to children with special health care needs.
 - a. States have flexibility in defining the financial eligibility requirements and specific health conditions that will be served under their programs. As a result, the populations served by state programs vary considerably.
2. Medicaid Home and Community Based Services (HCBS) waivers are another important source of supports for certain categories of special needs children. For qualifying children, the waiver programs offer Medicaid coverage and funding for other direct support services such as adaptive equipment and respite care.⁹
 - a. States define the eligibility criteria and services to be provided through HCBS waivers and must obtain waiver approval from the Centers for Medicare and Medicaid Services (CMS).

⁹ Kansas Department of Social and Rehabilitation Services. (2009). *Overview of Medicaid Home & Community Based Services Waivers Operated by DBHS/CSS & MH and KDOA*. Retrieved January 25, 2010, from <http://www.srskansas.org/hcp/css/pdf/WaiverDescription.pdf>.

- b. These programs are not entitlements, and funding levels are capped by the states. Consequently, available services and eligibility criteria vary from state to state, and many states, including Kansas, have waiting lists of qualified individuals.
3. Early screening, identification of health issues and intervention are important in minimizing adverse effects and optimizing health outcomes. In Kansas, KDHE coordinates a network of infant-toddler screening and referral services for developmental delays.
4. Many children with special health care needs will require specialized education and support services to succeed in school.
 - a. The federal Individuals with Disabilities Education Act (IDEA) requires that public schools provide free and appropriate educational services for children with disabilities, in the least restrictive environment and individualized to meet the child's unique needs. The IDEA also mandates that infants and toddlers with disabilities from birth to age three receive early intervention services.
5. Some states, such as Washington, have consolidated early childhood education programs within a single agency.¹⁰
6. Families with children with special health care needs are often challenged to juggle the needs of their child with the demands of a job.
 - a. Caring for a child with special needs often means more frequent appointments for health care services, more frequent illnesses and absences from school and greater difficulty in finding appropriate child care supports.
 - i. Parents in about one in five families report that they have had to reduce work hours or quit a job in order to care for their child with special health care needs.¹¹
 - b. More flexible family leave policies can help these families to balance the needs of their child and their work.
 - i. Some states have extended the provisions of the federal Family Medical Leave Act (FMLA) to allow for additional time off, or for parental time off to attend school functions such as parent-teacher conferences.¹²
 - ii. Three states (Washington, New Jersey and California) have implemented provisions for paid family leave.¹³

¹⁰ Washington State Department of Early Learning. (2008). *About the Department of Early Learning (DEL), What We Do*. Retrieved January 25, 2010, from <http://www.del.wa.gov>.

¹¹ United States Department of Health and Human Services, Health Resources and Services Administration. (2006).

¹² National Conference of State Legislatures. (2008). *State Family and Medical Leave Laws that Differ from the Federal FMLA*. Retrieved January 25, 2010, from <http://www.ncsl.org/Portals/1/Documents/employ/StateFamilyandMedicalLeaveLaws.pdf>

¹³ National Conference of State Legislatures. (2008).

7. Understanding the extent, characteristics and causes of our children's health problems and disabilities is critical to finding ways to effectively reduce adverse effects among children currently faced with chronic health conditions and in preventing health conditions among future generations of children.
 - a. Some states have implemented disease and disability surveillance systems, and some have used state funding to support studies of specific conditions, such as autism.¹⁴

¹⁴ National Conference of State Legislatures. (2010). *NSCL Autism Legislation Database*. Retrieved January 25, 2010, from <http://www.ncsl.org/default.aspx?tabid=14390>.

KANSAS CHILDREN WITH SPECIAL HEALTH CARE NEEDS: SLIDE 5



The slide features a dark blue background with a yellow sunburst logo in the top left corner. The title "KEY QUESTIONS FROM CHAP ROUNDTABLES" is written in yellow, bold, uppercase letters. Below the title, two key questions are listed in white text, each preceded by a yellow square bullet point.

KEY QUESTIONS FROM CHAP ROUNDTABLES


- Should we consolidate services into a single state department?
- How can we provide support and reduce stress and social isolation for families of CSHCN?

SLIDE 5 NOTES:

From the previous CHAP roundtable discussion of children with special health care needs, two themes emerged:

1. A feeling that services for children with special needs are fragmented across too many agencies and organizations.
 - a. Roundtable participants expressed interest in the concept of consolidating all services related to child development within a single state agency or department.
2. Providing support services to families with children with special health care needs. Ideas discussed included specialized case management and parent advocacy support, family mentoring, an information clearinghouse, informational booklets for parents, financial supports and building a sense of community and family social supports to reduce feelings of social isolation.

KANSAS CHILDREN WITH SPECIAL HEALTH CARE NEEDS: SLIDE 6



WHAT ARE PROMISING POLICY SOLUTIONS?

- Consolidate child and family support services
- Create an information clearinghouse
- Provide comprehensive insurance coverage for autism
- Expand family leave options for parents caring for a chronically ill child
- Expand Kansas' Family Caregiver Support Program

SLIDE 6 NOTES:

1. Consolidating services within a single state agency:
 - a. In 2007, the Kansas Legislature passed a bill (HB 2310) which was signed into law (46-1208e).¹⁵ It tasked the Legislative Educational Planning Committee, in conjunction with the 2010 Commission, to study and prepare a plan for the establishment of an office of early childhood education which would consolidate responsibility for all early childhood education services within the Kansas Department of Education by January 1, 2009. As the result of this legislation, the pre-K pilot program was moved from the Children's Cabinet to the Department of Education.
 - b. Because of the broad range of services and support systems potentially required by children with special health care needs (health care, rehabilitative services, mental health services, special education, case management, family supports, etc.), and the equally diverse range of funding sources that support these services, this might prove to be an unwieldy and impractical solution.

¹⁵ Kansas Legislature. (2007). *Early childhood education, study by LEPC and 2010 commission; recommendations and reports*. Retrieved January 25, 2010, from <http://www.kslegislature.org/legsrv-statutes/getStatuteInfo.do>.

2. A children with special health care needs information clearinghouse:
 - a. Could offer information about specific health conditions, treatment options and where families could go to seek assistance.
 - b. Could help to improve efficiencies and coordination of services for both the families with CSHCN and service providers.

3. Insurance coverage:
 - a. Caring for a child with special health care needs can be costly, especially when the child's health insurance provider does not cover necessary diagnostic and treatment services.
 - b. Twenty-eight states have enacted laws regulating insurance coverage for the treatment of autism spectrum disorders. Some specifically require insurers to provide coverage for the treatment of autism, while others have required coverage under laws pertaining to mental health coverage.¹⁶

4. The FMLA provides up to 12 weeks of unpaid leave to eligible employees to care for a newborn or newly-adopted child, or for a close family member with a serious medical condition.¹⁷
 - a. The FMLA applies only to employers with 50 or more employees. Some states have lowered the employer size threshold to expand eligibility to employees in smaller businesses.
 - b. Two states (California and New Jersey) offer paid leave to parents caring for chronically ill children through their employee-funded temporary disability programs.

5. Kansas currently has a Family Caregiver Support program, administered by the Department on Aging. It offers respite care services to caregivers of adults age 60 or older.¹⁸
 - a. This program is funded federally under the Older Americans Act and with state general funds.
 - b. Consideration might be given to offering similar support to parents of children with special health care needs.

¹⁶ National Conference of State Legislatures. (2010). *Insurance Coverage for Autism*. Retrieved January 25, 2010, from <http://www.ncsl.org/default.aspx?tabid=18246>.

¹⁷ National Conference of State Legislatures. (2008).

¹⁸ Link G., Dize V., Folkemer D., & Curran, C. (2006). *Family Caregiver Support: State Facts at a Glance*. Denver: National Conference of State Legislatures.

KANSAS CHILDREN WITH SPECIAL HEALTH CARE NEEDS: SLIDE 7



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Information for policy makers. Health for Kansans.