

Children With Chronic Illness and Disabilities

SCOPE OF THE PROBLEM

Roughly 20 million of the Nation's children suffer from at least one chronic health problem. Medical science has made great strides in treating many chronic illnesses and disabilities affecting children, but problems remain.

- Asthma is the most common chronic childhood disease, affecting around 5 million U.S. children.
- In 1995, children were hospitalized for asthma 170,000 times at a cost of \$387 million. In addition, asthma leads to 10 million missed school days each year.
- From 1.7 to 16.1 percent of school-age children have attention deficit-hyperactivity disorder (ADHD), which can adversely affect their ability to learn effectively. Most hyperactive children continue to meet the criteria for ADHD as adolescents and adults.
- Each year there are 313,000 ear tube placements performed on infants and toddlers under the age of 3 for "otitis media with effusion," or OME. Yet there is disagreement as to whether the effects of these ear problems are permanent as well as whether such operations can prevent them.
- Children who have insulin-dependent diabetes are three times more likely than their classmates to be hospitalized.
- Children with special health care needs are less than one-fifth of the U.S. child population overall. But they account for more than four-fifths of children's health care costs.

children a priority population for research. One of AHRQ's main goals in the area of children's health research is to close the knowledge gap about what works—and what does not work—in children's health services in order to inform critical health care decisionmaking by policymakers and other health system leaders.

Impact of AHRQ Research

AHRQ's commitment to research on children's health includes issues relating to the care of children with asthma, diabetes, and other health care conditions affecting large numbers of people under age 18. By supporting such research, AHRQ aims to improve the quality of health care for the Nation's most vulnerable children—the chronically ill, disabled, and those with other special health care needs. Examples of AHRQ's research findings in these areas include the following.

- **Spanish-English scale for asthma in Latino children.** Asthma is the most common chronic illness affecting Latino children. A new Spanish-English scale developed with AHRQ support will help health care workers get information from Latino parents about the level of control over their child's asthma despite language and educational barriers.
- **Quality of care for children with otitis media.** Children who are continuously on Medicaid are far less likely to visit an emergency room for otitis media and are four times more likely to have an assigned primary care doctor than children who are off Medicaid for part of the year. The findings suggest that requiring certification for

Background

The 1999 reauthorization language for the Agency for Healthcare Research and Quality (AHRQ) and AHRQ's own strategic plan make

Medicaid every month may lead to frequent shifts on and off the program and undermine quality care.

- **Out-of-pocket expenses for insulin dependent children.** Families that have an insulin-dependent child have larger health expenses than other families because health plans often do not fully cover the syringes, insulin, and blood testing strips needed for proper diabetes management.
- **Use of specialists in children with special needs on Medicaid.** Medicaid-insured children with chronic diseases receive most of their care from generalist physicians rather than specialists. An AHRQ study found only children who had spina bifida, seizure disorder, congenital heart disease, or cerebral palsy had more than a 50-percent chance of seeing a specialist for their condition during the year.

Tools From AHRQ Research

- **ADHD living guide.** AHRQ researchers have developed an ADHD living guide, a Web-based resource that helps parents of ADHD children coordinate their care with teachers and health professionals. It is available at www1.adhdlivingguide.com.
- **ADHD research for pediatricians.** Using findings from two AHRQ reports, the American Academy of Pediatrics (AAP) developed evidence-based clinical practice guidelines for the diagnosis and treatment of ADHD and distributed them as part of a large-scale implementation initiative.
- **CAHPS.[®]** AHRQ's CAHPS,[®] a kit of survey and report tools with information to help consumers choose a health plan, was recently expanded to include questions on quality of care for children with chronic illnesses.
- **Child Health Toolbox.** AHRQ introduced its "Child Health Toolbox" on the AHRQ Web site in 2001 to help State policymakers assess the quality of their child health programs.

- **Kids' Inpatient Database (KID).** Also in 2001, AHRQ introduced the Kids' Inpatient Database, the first and only publicly available database providing a comprehensive view of in-hospital care for the Nation's children.
- **AHRQ Quality Indicators (QIs)** QIs are measures of health care quality. AHRQ recently released prevention QIs, which include indicators that relate to chronic illness in children—pediatric asthma and low birth weight.

Examples of Current Projects

- **Cost of care for children with special health care needs.** Michigan researchers are comparing patterns of health service use and cost for 12 common chronic conditions in fee-for-service and managed care plans.
- **Children with chronic diseases under managed care.** Investigators in Florida and Washington State are assessing how various structural and quality assurance features of managed care organizations affect care for children with asthma, diabetes, cerebral palsy, and other special health care needs.
- **Asthma case management for Head Start.** Researchers are developing a model to be used by Head Start personnel to help improve asthma management practices of children, their parents and staff.
- **Reducing errors in ADHD care.** A study in three primary care practices is assessing whether a computerized system for laptop use helps improve care for children with ADHD.

For More Information

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U.S. Department
of Health and Human
Services

AHRQ Pub. No.02-M025
March 2002