

Why GAO Did This Study

On October 8, 2008, the Prenatally and Postnatally Diagnosed Conditions Awareness Act was signed into law, requiring GAO to submit a report concerning the effectiveness of current health care and family support programs for the families of children with disabilities. In this report, GAO focused on Down syndrome because it is a medical condition that is associated with disabilities and occurs frequently enough to yield a sufficient population size for an analysis.

GAO examined (1) what is known about the extent to which children with Down syndrome receive medical care during early childhood and (2) what resources families of children with Down syndrome receive through their health care providers and what barriers families face to using these resources.

GAO analyzed fee-for-service claims data from a very large private health insurance company, for the claims representing its experience with one of the largest national employers, and Medicaid claims data from seven states with high Medicaid enrollment and low percentages of enrollees in Medicaid managed care. GAO also interviewed specialists at six prominent Down syndrome clinics and 12 advocacy groups to examine what resources families receive and to identify barriers they face. GAO also analyzed data from the Health Resources and Services Administration–sponsored 2005-2006 National Survey of Children with Special Health Care Needs on barriers to accessing needed services.

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CHILDREN WITH DOWN SYNDROME

Families Are More Likely to Receive Resources at Time of Diagnosis Than in Early Childhood

What GAO Found

GAO's analysis of data from a very large private health insurance company showed that from birth through early childhood, children with Down syndrome received medical care to address their special health care needs. Specifically, children with Down syndrome received, on average, five times more outpatient care (such as care in an urgent care facility) and over two times more office-based care (such as care in a physician's office) than children without Down syndrome. Overall, both groups received more office-based care than outpatient care. A key difference in the amount of care received by children with Down syndrome was the difference in the amount of therapy services, with a greater percentage of children with Down syndrome receiving physical, occupational, and speech therapy. In addition, children with Down syndrome have an increased risk of certain medical conditions and were hospitalized, on average, nearly twice as often and stayed twice as long as other children. Not surprisingly, differences were also found in medical care expenditures. The total average medical expenditures for children with Down syndrome were an average of five times higher than those for other children. However, both total expenditures and the difference in expenditures decreased substantially as the two groups of children reached 3 years of age. GAO's analysis of Medicaid claims data found similar differences between the two groups.

Down syndrome advocacy groups in selected communities told GAO that families of children with Down syndrome in those communities were more likely to receive the resources recommended for the time of diagnosis than those recommended for early childhood and may face barriers to using available resources. Specifically, advocacy groups reported that families were likely to receive about two-thirds (20 of 32) of the resources that specialists at the six Down syndrome clinics recommended they receive through their health care providers at the time of diagnosis. However, families were likely to receive only about one-quarter (6 of 23) of the resources that specialists recommended they receive through their health care providers after diagnosis and throughout early childhood. In addition, advocacy groups and results from the National Survey of Children with Special Health Care Needs indicate that families may face barriers that can prevent them from using available resources. For example, barriers such as outdated or inaccurate information could lead parents to underestimate their child's potential. Some advocacy groups reported that they and their communities have made efforts to address some of these barriers. For example, to address issues of inaccurate information, one advocacy group initiated an educational outreach program to health care professionals at area hospitals.

GAO provided a draft of this report to the Department of Health and Human Services for comment. It generally agreed with GAO's findings and noted that the report provides a thorough summary of the current practices and the successes and challenges faced by children with Down syndrome and their families.