

Out-of-pocket health care costs for disabled children vary widely by state

July 14 2008

The size of the financial burden on families with disabled children largely depends on which state they live in, according to a new study conducted by the schools of social work at the University of North Carolina at Chapel Hill and Washington University in St. Louis, Mo.

According to researchers, parents in states with higher average incomes face smaller burdens – meaning in contrast, more vulnerable families in poorer states often pay more of their own money to cover their disabled children's health-care costs.

The study found families in Georgia fared the worst, paying an annual average of \$972 out-of-pocket to care for their disabled children. That's nearly \$200 more, on average, than families spend nationwide on children with special health-care needs.

In North Carolina, out-of-pocket costs also exceeded the national average, with families spending \$856 annually.

"These are disturbing findings that highlight the high costs families face in raising their children with disabilities and health conditions, and it shows that the state in which a family lives really does matter," said Susan Parish, an assistant professor at the UNC School of Social Work. Parish co-authored the study with Paul Shattuck, the report's lead investigator and an assistant professor of social work at Washington University in St. Louis, Mo.

The study, which was funded by the National Institute of Child Health and Human Development, appears in the July issue of the *American Academy of Pediatrics Journal*.

Parish said the costs of caring for children with special health-care needs are high, relative to those for typically developing children, because of their greater requirements for both primary and specialty medical care, as well as therapeutic and supportive services such as rehabilitation, assistive devices and mental health, home health and respite care.

"The financial burden associated with raising these children has important clinical and social implications. Understanding that burden is especially pressing, given it's estimated that between about 13 to 16 percent of U.S. children have special health-care needs," Parish said.

Of the nearly 39,000 families included in the research, about 91 percent reported spending some money out-of-pocket on special health-care needs for their children. These expenses ranged from medications to home therapy. The study looked at families with similar household demographics and involved children with a range of disabilities, including mental retardation, asthma and spina bifida, Parish said.

The report, which was based on 2002 data from the National Center for Health Statistics, also looked closely at gross family income to highlight disparities among the states. In North Carolina, for example, a family with a gross income of \$50,000 spent almost \$1,100 annually to care for its disabled children. A family in Louisiana earning the same amount paid about \$1,600 annually.

"What we found was not only was the financial burden higher in some states, it was higher for poor families," Parish said. "We need to understand how state policies are affecting children with disabilities."

Families in Massachusetts felt the least financial pinch. On average, they paid \$562 yearly on health care for their disabled children.

Source: University of North Carolina at Chapel Hill

Citation: Out-of-pocket health care costs for disabled children vary widely by state (2008, July 14) retrieved 27 April 2024 from <https://medicalxpress.com/news/2008-07-out-of-pocket-health-disabled-children-vary.html>

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