

'Chilling' hardship rates among families raising disabled children

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Families with disabled children are struggling to keep food on the table, a roof over their heads, and to pay for needed health and dental care. But according to a new study from the University of North Carolina at Chapel Hill, these challenges are now falling on middle-income households and not just on poor families as previous research has found.

These latest findings show that long-held federal standards for identifying the nation's poor are not capturing everyone in need and should be re-evaluated, especially for the financial effects on disabled children, said Susan L. Parish, Ph.D., the study's lead investigator and an assistant professor in the UNC School of Social Work.

"The bottom line is that U.S. families raising children with disabilities are reporting severe hardships at rates that are chilling, including families that are solidly middle-class," she said. "We were shocked to find such high rates of hardship among upper-income families."

The study, which is based on 2002 data from the National Survey of American Families, is being published in this month's journal *Exceptional Children*. The survey analyzed 28,141 households.

The UNC study found that overall, families across all income levels who are raising disabled children are significantly more challenged by food, housing and health issues compared to families without disabled children. Many also struggled to pay their phone bills.

Most surprising, Parish said, was data indicating that a significant percentage of those struggling are higher-income households. Yet based on federal poverty guidelines – which have remained unchanged since the 1960s and are used to determine eligibility for many income, food, health and disability-related programs – those same households would not be classified as "poor," she said. They also would not qualify for assistance, despite the higher costs of raising children with disabilities, Parish noted. In 2002, the federal poverty level for a family of four was \$18,100.

According to the study, 40 percent of the surveyed families with disabled children who earned between two to three times the federal poverty level (between \$36,200 and \$54,300 for a family of four, for example) experienced at least one food hardship, including worrying that food would run out or skipping meals because of a lack of money. Fifteen percent of families with incomes at three or more times the federal poverty level (\$54,300 and up for a family of four) experienced housing instability, meaning they were unable to pay their rent or had to move in with others.

"These results suggest that state and federal policies that are in place to help families with disabled children are not going nearly far enough," Parish said. "They are not eliminating deprivation. And these findings are particularly troubling now when the nation's economy is struggling. Families raising children with disabilities are likely to be hardest hit during this economic downturn."

Though the study found that children with disabilities were more likely to have health insurance and a usual source of care, they were 61 percent more likely than non-disabled children to have postponed necessary medical care and 83 percent more likely to have postponed needed dental care. The study didn't examine the causes for those results, but Parish said they likely are related to the expenses of obtaining care –

even with health insurance – and other issues, such as limited transportation.

The research results offer a compelling reason to expand eligibility standards for federal programs designed to assist families with disabled children, Parish said. Though more study is needed to determine how best to assist these families, UNC researchers suggest that increasing the income limits for food stamps, housing assistance and federal Supplemental Security Income, which assists low-income people with disabilities, would probably be a good start. Raising the asset limit for Supplemental Security Income and Medicaid, the federal insurance program for the poor and disabled, so that families are not penalized for saving money in case of a hardship would also help, Parish said.

"These families struggle to provide adequate care for their disabled children," Parish said, "and stronger supports are vital."

Source: University of North Carolina at Chapel Hill

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