

FAMILY VOICES



THE FAMILY PARTNERS PROJECT:

The Health Care Experiences of Families of Children with Special Health Care Needs

FAMILY IMPACTS

A Fact Sheet on Findings

What types of impacts did mothers who participated in the survey report as the result of having a child with special health care needs?

Methods: Families were asked about three impacts that might result from having a child with special health care needs: impacts on parents' time (in the form of providing home health care to their children), impacts on employment, and impacts on their family's finances. The analyses reported here include only mothers (88% of the 2,220 respondents), who typically have primary responsibility for providing care to their children. The probability of experiencing these impacts on time, employment, and family finances were analyzed to examine associations with child health status, family and child demographics, mothers' characteristics, and receipt of formal supports.

Findings:

- 81% of the mothers reported experiencing an impact either on their employment status, their family's finances, or on their time with respect to the provision of in home health care.
- Just over half of mothers (55%) provided some health care at home for their child each week, such as physical therapy, dressing changes, or care of feeding or breathing equipment.
- Some mothers spent large amounts of time on these tasks, essentially working a part-time or full-time job to provide such care: 18% reported that they spent 20 or more hours per week performing home health care for their children.
- Children who received home health care from their mothers were more likely to have poor or fair health, have unstable and severe conditions, be technology dependent, and also receive home health care from professionals. They were also more likely to live in a family with higher income, and to have a sibling with special needs.
- In addition to the time mothers spend providing home health care, many also spend time arranging or coordinating their children's care. *Among the mothers who provided some health care to their children*, we found that 27% spent less than one hour per week coordinating care, 47% spent one to four hours coordinating care, and 26% spent five or more hours coordinating their children's care.
- 60% of mothers agreed that their child's condition had an impact on their employment: 33% had cut down their hours but were still working, and 27% stopped working altogether because of their child's health conditions.
- At the time of the survey, 48 percent of mothers were at home full-time, 26% were employed part-time, and 26% were employed full-time.
- Mothers who reported an impact on their employment were more likely to have children with unstable and more severe conditions, and were more likely to have a college degree, and work part-time. Their children were more likely to receive home health care from professionals.
- The majority of families incurred out of pocket costs associated with caring for their child's special health care needs in the 12 months prior to the survey: 32% paid less than \$500, 23% paid \$500-\$999, 24% paid \$1,000-\$2,999, and 20% paid more than \$3,000 for extra expenses. These costs included medical bills, transportation, special food, and adaptive clothing.

- 56% of the mothers reported financial problems related to their child's condition, or needed more income to cover their child's medical expenses.
- Poorer families were more likely to report an impact on family finances. So were families who paid for medical services out of pocket, and those who had children with more severe conditions.
- Families whose children had Medicaid as their primary health care plan were less likely to report a financial impact.
- More than half of the families (58%) experienced multiple impacts: 27% experienced two of the three impacts, and 31% experienced all three impacts as the result of having a child with special health care needs.
- Families who experienced all three impacts were more likely to have children with unstable conditions, more severe conditions, and technical dependency. These children were more likely to receive professional home health care. The mothers were more likely to be college graduates, and were less likely to be working full-time. These families were poorer, and incurred greater out of pocket expenses for their children's care.

Additional information about the survey and its results can be obtained from:

www.familyvoices.org

or by contacting:

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