

# Material Hardship in US Families Raising Children with Disabilities: Research Summary & Policy Implications



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## Research Brief

**Overview:** *We compared experiences of material hardship, including food insecurity, housing instability, and health care access, in families raising children with and without disabilities. Families of children with disabilities experienced significantly greater hardship than families with nondisabled children. As family income rose above the federal poverty level, hardship declined sharply for families of nondisabled children but not for families of children with disabilities. Thus, the US federal poverty level was found to be a particularly poor predictor of hardship for families whose children have disabilities.*

The United States government defines poverty using an absolute income-based threshold devised in the early 1960s (the poverty level was set at 3 times the annual cost of a basic food budget). Except for adjustments for inflation, the federal poverty level (FPL) has remained unchanged since it was established,<sup>1</sup> despite the fact that housing, child care, and health care inflation in the United States have far outpaced food-cost inflation. Thus, today's families spend less of their income on food and a much greater proportion on housing, health care, and other necessities.<sup>2,3</sup> Furthermore, the FPL fails to account for regional differences in the cost of living, costs of child care and transportation, or receipt of noncash benefits such as Medicaid and food assistance.

Contemporary research focuses on comprehensive approaches to determining American families' basic needs, including the measurement of material hardship. Studies on material hardship examine a family's access to housing and health insurance, adequacy of the food supply, transportation, child care, and the ability to purchase necessities such as personal care products and diapers.

### ***What factors affect material hardship in families raising children with disabilities?***

As compared with 16% of children without disabilities, 28% of US children with disabilities live below the federal poverty threshold.<sup>4</sup> Families of children with disabilities have additional financial expenses related to their child's disabilities, such as therapy costs, specialized day care, and adaptations and modifications of the home.<sup>5,6</sup> Financial concerns are further exacerbated by the fact that mothers frequently must reduce their work hours or quit work altogether to stay home and care for their children with disabilities.<sup>7,8,9</sup>

Although it is critical to understand the effects of disability-related costs on a family's economic well-being, such research is rare. Therefore, the current

# Research Brief

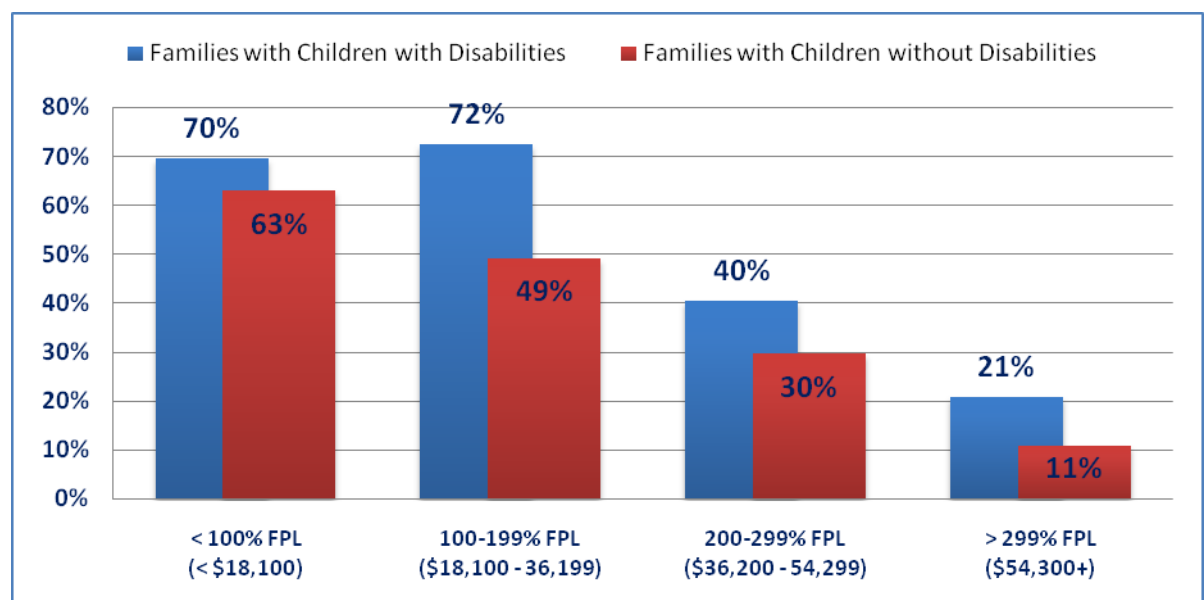
study explored material hardship in US families raising children with disabilities, and examined the adequacy of traditional federal poverty guidelines to satisfactorily measure the experience of these families.<sup>10</sup> The study analyzed the experience of material hardship in 42,000 American households with and without children with disabilities. Material hardship experienced in the past year was measured across four domains: food insecurity, housing stability, telephone disconnection, and health care access. The following sections detail the study findings and policy implications.

## ***How does hardship differ for children with disabilities and children without disabilities?***

Across income levels, children with disabilities and their families experienced significantly greater levels of material hardship than families whose children had no disabilities. (See Appendix for specific findings for each type of hardship.) Compared to children without disabilities and their families:

- **Children with disabilities and their families were significantly more likely to have experienced food insecurity.** These families were nearly 2 times more likely to report that they had worried food would run out, that food bought did not last, or that they skipped meals because of lack of money. Among families with incomes up to 2 times the FPL (up to \$36,200 for a family of four), children with disabilities and their families were more than twice as likely to have accessed emergency food sources than were other families. As shown below, families raising children with disabilities consistently reported more food hardships than families of nondisabled children, even as income rose to 3 or more times the FPL (\$54,300 or more for a family of four in 2002).

### ***Families Who Experience Food Hardship***

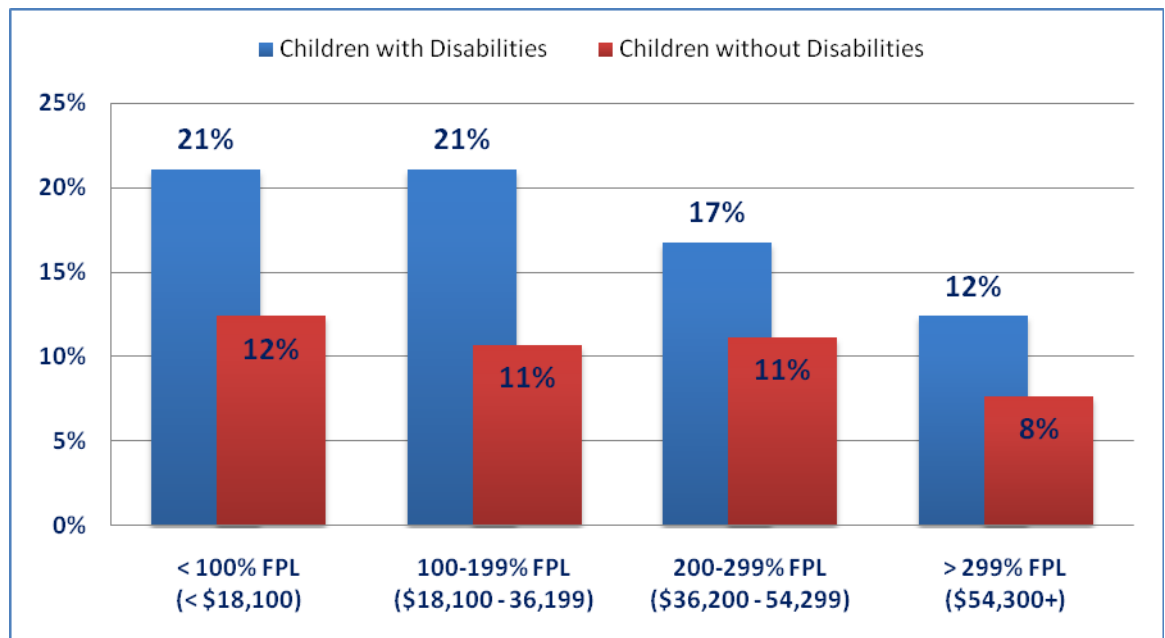


*Note:* In 2002, families of four with annual incomes of \$18,100 or less were considered at or below the FPL. The FPL varies by household size; these figures are used for illustrative purposes.

# Research Brief

- **Children with disabilities were more likely to have access to health care but *less likely* to receive medical services.** Children with disabilities were both significantly more likely to have a usual source of care and less likely to have been uninsured at any time in the prior year. However, despite having better *potential access* to health care, children with disabilities had to delay necessary medical and dental care more often. (See figure below.) Though beyond the scope of this research, future studies should examine the barriers that cause families of children with disabilities to delay needed medical and dental care.

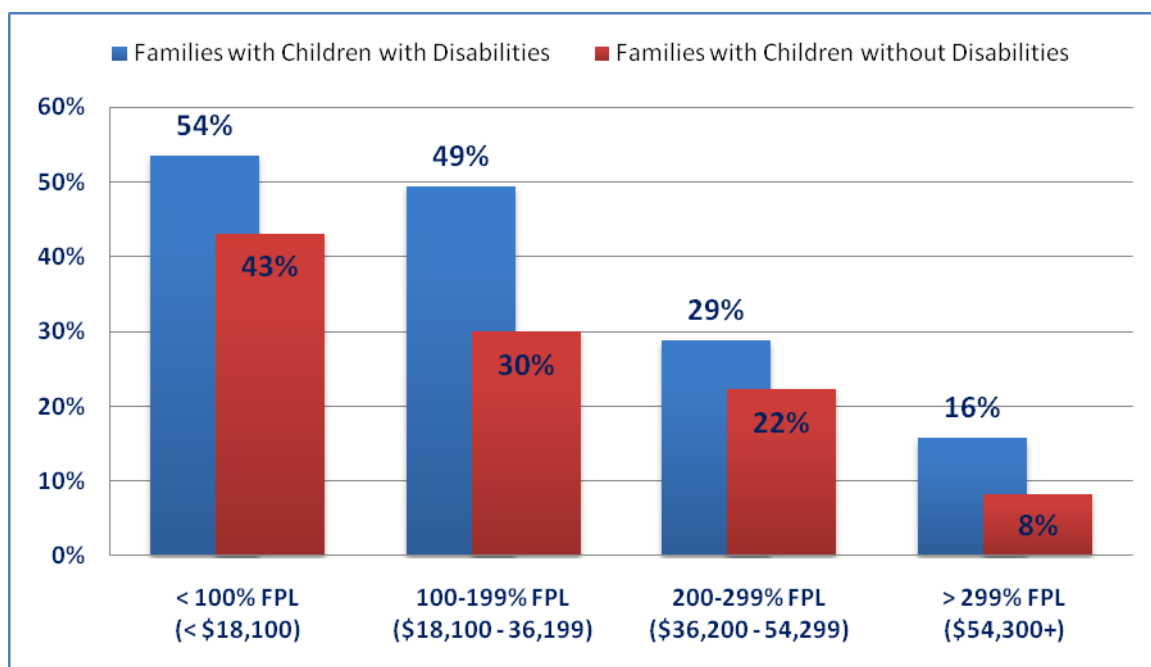
*Children Who Delayed Medical Care*



*Note:* In 2002, families of four with annual incomes of \$18,100 or less were considered at or below the FPL. The FPL varies by household size; these figures are used for illustrative purposes.

- **Families raising children with disabilities reported greater instability with rent and telephone payments.** These families were 72% more likely than other families to have been unable to pay their rent in the prior year. Furthermore, they were 81% more likely to have had phone service disconnected for more than a day during the prior year because of nonpayment. As shown in the figure on the following page, the percentage of families raising children with a disability who experience one or more housing or utility hardships decreases at a much lower rate than other families.

## Families Who Experience Housing or Utility Hardships



*Note:* In 2002, families of four with annual incomes of \$18,100 or less were considered at or below the FPL. The FPL varies by household size; these figures are used for illustrative purposes.

### ***How well does the US federal poverty level represent families with children living with material hardship?***

We analyzed the percentage of families experiencing various levels of hardship within four income groups: poor (below 100% of the FPL); near-poor (income between 1–2 times the FPL); those with income 2–3 times the FPL; and those with income  $\geq 3$  times the FPL. The results were telling: the two lowest income groups of families raising children with disabilities—those earning less than the FPL and those with incomes up to 2 times the FPL—followed the same trend on food, housing, and telephone service hardships. Consequently, near-poor families (i.e., income up to 2 *times above* the FPL, or \$36,200 for a family of four) generally were no better off than poor families. When considering health care access, families of children with disabilities who earned up to 3 *times above* the FPL still experienced similar levels of medical hardships as did poor families raising children with disabilities.

When the numbers of hardships were compared by income level and child's disability status, families experienced less hardship when their incomes were 2 times greater than the FPL, regardless of their child's disability status. However, within each income group, families of children with disabilities experienced overall greater hardship. In addition, as the family income increased for families of nondisabled children, the number of hardships they experienced declined significantly; in contrast, the rate of decline was significantly slower for families of children with disabilities.

### ***What are the policy implications?***

Families raising children with disabilities were more likely to experience

# Research Brief

material hardship than families of nondisabled children. Most compelling is the finding that substantial hardship was found among families with incomes well above the US government's definition of poverty.

Essentially, a substantial proportion of middle-class and low-income families raising children with disabilities experience significant material hardship. These data provide a strong argument against use of the FPL as a primary means of determining need or controlling the eligibility of children with disabilities for support services such as like Medicaid and Supplemental Security Income (SSI). Rather, this study suggests that families raising children with disabilities could benefit from an increase in the SSI payment level as well as from an increase in the threshold limit of parental income that determines if children with disabilities qualify for SSI and Medicaid. Further, given that families of children with disabilities are more likely to report difficulty maintaining telephone services, providing free or low-cost cell phones to these low-income families could assist them in managing and meeting their children's needs. As more American families face financial difficulties, it is imperative to create policies that protect children and families at greatest risk of material hardship.

## References

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**Appendix: Percentages of Families Who Experienced Medical, Food,  
or Housing/Utility Hardship, 2002**

<b>Level and Type of Hardship</b>	<b>&lt; 100% FPL</b>		<b>100-199% FPL</b>		<b>200-299% FPL</b>		<b>&gt; 299% FPL</b>	
	Families with Children with Disabilities	Families with Children without Disabilities	Families with Children with Disabilities	Families with Children without Disabilities	Families with Children with Disabilities	Families with Children without Disabilities	Families with Children with Disabilities	Families with Children without Disabilities
Experienced any type of hardship	83.73	80.96	86.27	72.52	68.90	56.22	44.84	30.91
Experienced food, housing/utility and medical hardships	26.30	21.62	29.23	14.35	13.42	8.04	7.30	2.58
Worried that food would run out	61.56	56.10	65.21	42.15	33.40	25.92	18.07	8.92
Cut/skip meals because of lack of money	37.26	28.27	37.04	18.92	19.40	12.91	9.83	3.44
Food did not last	56.75	47.47	55.07	33.48	25.87	20.33	14.52	6.27
Received emergency food	35.73	21.51	30.96	13.68	22.48	6.30	10.95	5.50
Dental care postponed	27.56	19.39	34.09	21.80	33.28	19.65	21.71	13.18
Medical care postponed	21.07	12.42	21.11	10.69	16.74	11.15	12.40	7.65
Uninsured at any time	14.28	24.21	17.64	25.29	12.32	14.56	6.56	6.11
Did not have usual source of health care	11.63	13.28	7.90	8.73	4.24	4.77	2.02	2.49
No phone for >1 day	31.86	23.20	24.87	13.76	9.32	7.92	6.30	2.05
Unable to pay rent	44.51	34.71	41.86	24.04	25.29	18.76	14.54	7.43
Moved in with others	12.16	14.94	8.97	6.61	3.00	7.71	15.26	2.36

**For more information or to request a reprint of the original study, please contact Susan Parish, School of Social Work, University of North Carolina at Chapel Hill, 325 Pittsboro Street – CB 3550, Chapel Hill, NC 27599-3550; [parish@unc.edu](mailto:parish@unc.edu) or 919-962-6434.**