

Financial Burden of Families Raising Children with IDD in the US

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Background: Income poverty and children with disabilities

- Children with disabilities are more likely to grow up in poverty than their non-disabled peers (Emerson & Hatton, 2009)
 - The relationship between disability and poverty is likely bi-directional (Elwan, 1999)
- Having a child with a disability is a significant determinant of material hardship (Parish et al, 2008; Emerson & Hatton, 2009)

Background: Elevated costs of care

Families raising children with disabilities incur direct and indirect costs

Direct costs of care:

- Expenses for therapies, rehabilitation, equipment, home modifications, transportation, preventive and emergency services

Indirect costs of care:

- Guardians may need to work fewer hours or give up employment completely to care for the child with a disability

Aim

- There are few current, population-based studies in the US about the costs families incur related to raising their children with intellectual and developmental disabilities
- Our aim: determine the financial burden of such parents

Design & Method

- 2009/10 National Survey of Children with Special Health Care needs
 - Fielded by the National Center for Health Statistics
 - Representative of individual US states with ~ 750 special needs children per state
 - Representative of US
 - Cross-sectional
 - Telephone interviews with knowledgeable adult living in household

Measures & Analysis

- Independent variable: Whether child had ID or other special health care needs
 - ID defined as autism, developmental delay, intellectual disability or mental retardation, cerebral palsy, and Down syndrome
- Dependent measures: annual out-of-pocket costs >\$500; financial problems caused by child's needs; parent stopped work to care for child; parent reduced work to care for child; parent avoided changing jobs because of concerns about child's health insurance
- Covariates: family structure; parental education; income; child's age, race, ethnicity, condition severity and insurance status
- Analysis: Multivariate logistic regression, weighted for complex sampling design

Sample characteristics

Characteristic (% or Mean)	Households with children with ID N = 7951	Households with other CSHCN N = 32,291	Test Statistic
Child's race/ethnicity			3.01*
White	58	60	
Black	15	16	
Latino	18	16	
Other	9	8	
Child's sex is female	32	43	102.23***
Family income <200% FPL ¹	51	42	62.49***
Parent education < high school	13	11	3.70
Single mother family	26	26	0.26
Child has no insurance	3	4	0.47
Child age (years)	9.6	10.0	13.87**

Note: ¹ federal poverty level

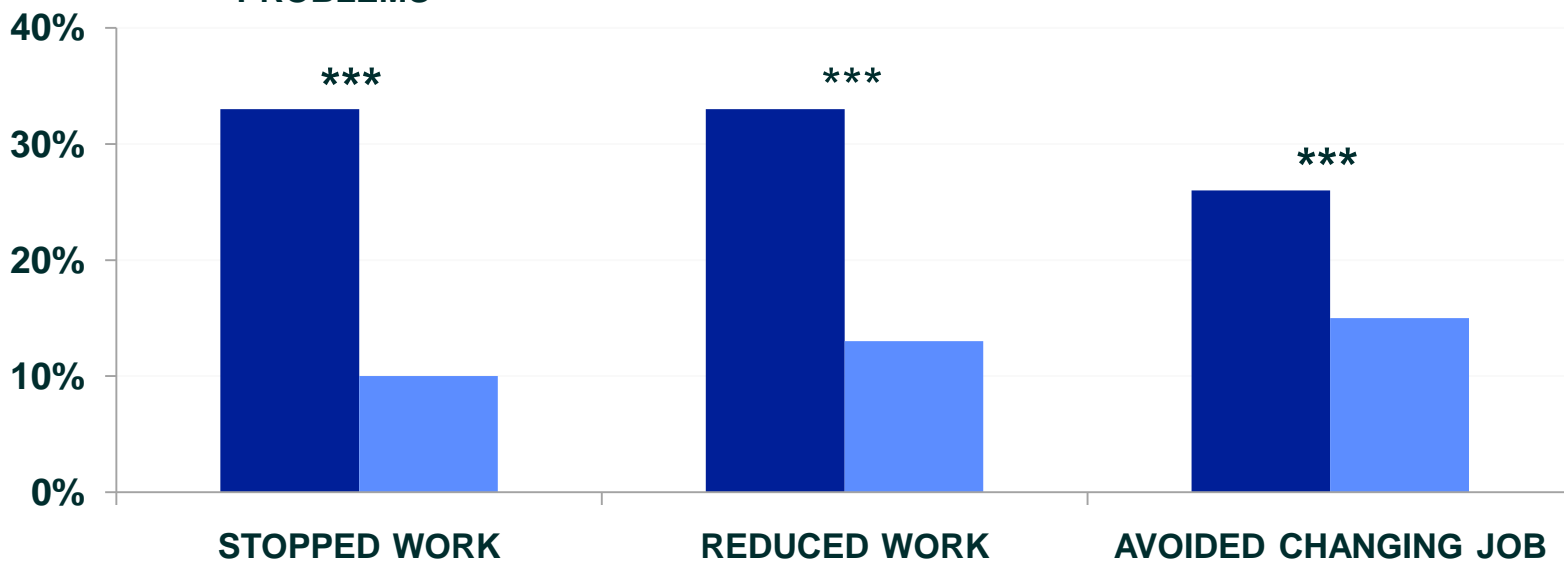
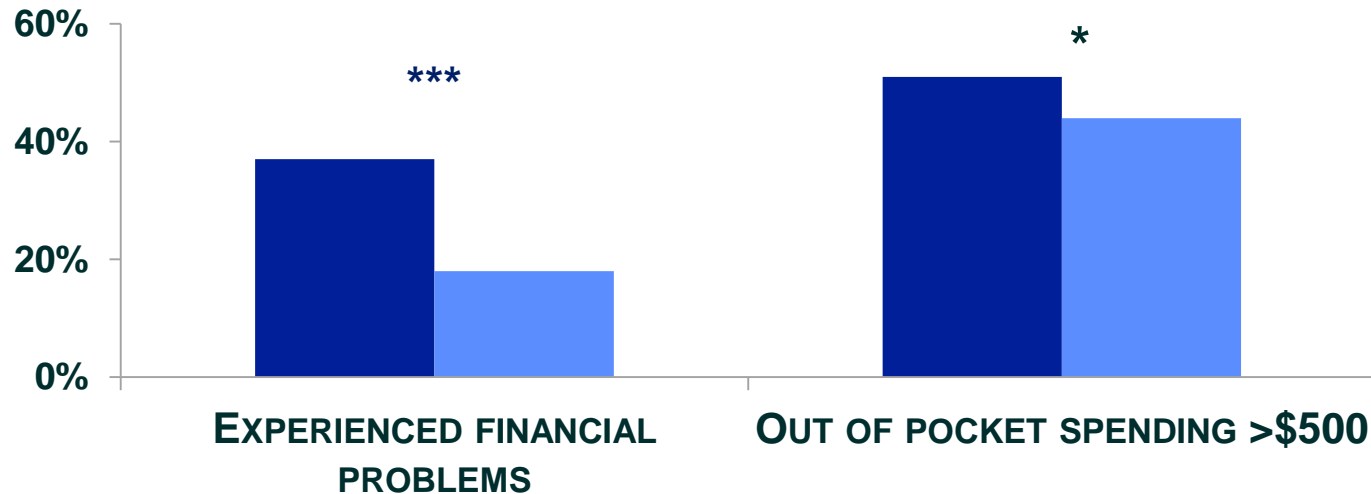


Results

Children with IDD



Children with other SHCN



Limitations

- Specific disability-related costs of care were unavailable
- Lack of data on the types of services used
- Data are cross-sectional
- No measures of hardship or deprivation, even though these are important indicators of well-being

Conclusions

- The US safety net for families raising children with ID appears inadequate
- Households with children with ID incur significant financial burden, even in comparison to children with other special health care needs
- Employment-related burdens are a concern since it is nearly impossible to avoid poverty in the US without employment
- More effective policies are needed to buffer the costs these families incur, and to ensure their financial well-being

Thank You

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