



Prevalence and economic well-being of families raising multiple children with disabilities

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ABSTRACT

This study estimates the prevalence of households raising more than one child with disabilities, and examines these families' economic well-being. Using pooled data from the 2004 and 2008 Survey of Income and Program Participation we compare households with multiple children with disabilities ($n = 932$) to households with one disabled child ($n = 3457$) and to households with at least one child but none with disabilities ($n = 21,378$) on measures of material hardship. Three percent of U.S. households with children had more than one disabled child. Compared to other households with children, those with multiple children with disabilities were significantly more likely to have income below the federal poverty level and to report material hardships. The number of children with disabilities is an important contextual variable for studying the economic circumstances under which, care is provided to children with disabilities. Its implications for practice and policy are discussed.

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1. Introduction

Households with children with disabilities are more likely to be poor (Emerson & Hatton, 2009; Fujiura & Yamaki, 2000) and experience greater material hardships at all levels of the income distribution (Emerson & Hatton, 2009; Parish, Rose, Grinstein-Weiss, Richman, et al., 2008), than households with nondisabled children. This financial vulnerability has been attributed to the direct and indirect costs of raising children with disabilities (Chen & Newacheck, 2006; Parish, Seltzer, Greenberg, & Floyd, 2004; Perrin, 2002).

Material hardship is the extent to which a household is unable to meet its basic needs (Ouellette, Burstein, Long, & Beecroft, 2004). Emerging evidence suggests that material hardship is a more direct measure of deprivation compared to traditional income poverty measures (Boushey, Brocht, Gundersen, & Bernstein, 2001; Parish, Rose, & Andrews, 2009). Income poverty and material hardships both influence child outcomes, such as education, cognitive development and academic achievement (Gershoff, Aber, Raver, & Lennon, 2007). For children with disabilities, living in poverty and experiencing material hardships likely has deleterious effects on long-term development and may lead to additional co-morbid conditions.

A limitation of the existing research on childhood disability and caregiving is the exclusive focus on a single or focal child with a specific disorder or condition in the household, when it is possible that households can have multiple children with disabilities. Evidence from the 2000 Census (Wang, 2005) showed that of the U.S. households

with children with disabilities, 13% had two or more children with disabilities. However, not much is known about the characteristics of households who have multiple children with disabilities and their experience with income poverty and material well-hardships. The current paper therefore estimates the prevalence of U.S. households that have more than one child with a disability and examines income poverty and material hardship in these households. The findings from this study will have implications for how family caregiving research is conceptualized. It will also provide estimates of the extent of the phenomenon under investigation, and improve our understanding of the material and economic well-being of households with children with disabilities.

1.1. Income poverty and households with children with disabilities

In 2010, an estimated 5.2 million or 8.4% of non-institutionalized U.S. children under age 15 had a disability, and approximately half had severe disabilities (Brault, 2012). Children with disabilities are more likely to grow up in poverty than their non-disabled peers (Emerson & Hatton, 2009; Fujiura & Yamaki, 2000), and the relationship between income poverty and disability is bi-directional (Elwan, 1999; Fujiura & Yamaki, 2000). Income poverty increases the propensity for a child to develop a disability, and high impairment-related costs increase the likelihood that families raising children with disabilities will become impoverished.

Income poverty impacts childhood disability in two ways. First, income poverty is associated with late or no pre-natal care (Alexander & Korenbrot, 1995; Pagnini & Reichman, 2000), which in turn is a risk factor for low-birth weight babies, who are at an increased risk of perinatal and post-natal complications such as developmental delays

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or other chronic conditions (Bradley, Whiteside, Mundfrom, Casey, et al., 1994; Ventura, Martin, Curtin, & Martin, 1997). Second, children born into poor families are more likely to be exposed to hazardous and unsafe living environment, unsafe neighborhoods, are more prone to accidents, and lack access to adequate health care (Brooks-Gunn & Duncan, 1997; Evans, 2004). All of these factors are associated with increased risk of childhood disability.

A child's disability impacts a family's finances in the form of direct and indirect costs of the child's care. Children with disabilities require a range of services such as therapies, rehabilitation services, equipment, home modifications, preventive and emergency services (Perrin, 2002), transportation services and respite care (Newacheck & Kim, 2005; Parish & Cloud, 2006), which are costly and often not fully covered by public or private health insurance (General Accounting Office, 2000). Families therefore incur significant expenditures (Newacheck & Kim, 2005; Parish, Shattuck, & Rose, 2009). Families raising children with disabilities on average spend about \$352 monthly in the form of out-of-pocket expenses, compared to \$174 monthly by families of nondisabled children (Newacheck & Kim, 2005). Families also bear indirect costs because they work fewer hours, lose work time, or must leave employment altogether to care for the child with the disability (Parish et al., 2004; Porterfield, 2002). Parents also spend significant time coordinating care for their child, and arranging therapies, appointments, and rehabilitation services (Perrin, 2002). All these factors contribute to lack of gainful employment, which ultimately reduces lifelong financial security and asset accumulation (Parish, Rose, & Swaine, 2010; Parish et al., 2004).

1.2. Material hardships and households with children with disabilities

The income poverty threshold is the common U.S. measure of a family's economic well-being, and serves as the criteria for eligibility for many U.S. social welfare programs. Expressed in 2012 dollars, the U.S. poverty threshold for a family of four was roughly \$23,681 (United States Census Bureau, 2012). Developed in the 1960s, the U.S. poverty threshold was based on three times the annual cost of household food budget. It was determined that families spend one-third of their expenses on food. Therefore, individuals living in families with total pre-tax income below this threshold were counted as poor. The formula has remained unchanged (Glennester, 2002), and has since been used to determine eligibility to various assistance and welfare programs for low-income families. Based purely on food budget, the existing measure fails to account for expenses such as housing, child care and health care costs, which now constitutes the majority of household expenses (Citro & Michael, 1995; Porter, 1999), and has been criticized for inadequately identifying households whose basic needs remain unfulfilled (Beverly, 2001b; Boushey et al., 2001). Other supplemental measures such as material hardships have been developed to provide a more nuanced understanding of the extent of families' financial well-being (Ouellette et al., 2004). The two measures, income poverty and material hardships are increasingly being used in conjunction, to fully understand a family's financial wellbeing.

Although, low income households in general experience greater material hardships than higher income households (Beverly, 2001b), Mayer and Jencks (1989) showed that income poverty accounted for less than a quarter of the total variance in material hardship, and factors other than poverty are important determinants of material hardships (Iceland & Bauman, 2004). One such factor is disability. Using material hardships as an outcome measure, Parish et al. (2008) and Emerson and Hatton (2009) showed that families of children with disabilities experienced significantly elevated rates of hardships in comparison to other families. Further, Parish et al. (2008) found that material hardships occurred at all income levels for families of children with disabilities. In other words, the prevailing U.S. poverty threshold did not adequately identify households whose

basic needs remained unfulfilled. Prevalence of material hardship is troubling because growing up in deprivation has deleterious impacts on every aspect of children's development (Ashiabi & O'Neal, 2008; Gershoff et al., 2007; Huang, Oshima, & Kim, 2010). For children with disabilities, deprivation may exacerbate existing conditions, leading to development of secondary conditions and dependency for care and services on family, and public health and social welfare systems.

1.3. Factors associated with higher rates of material hardships

A number of factors have been associated with the experience of higher rates of material hardships. These include, being a single parent, being of racial or ethnic minority and having less than high school education (Boushey et al., 2001). Among households with children with disabilities, Parish et al. (2008) found that single mothers were also more likely than other family types to have experienced higher rates of food insecurity, an inability to pay rent, of phone services being disconnected at least for one day because of non-payment, and to have postponed dental care.

The final variable that has been found to be a significant predictor of material hardship even after controlling for income and socio-economic status, is the presence of an adult with disabilities in the household (She & Livermore, 2007). Similar findings were noted by Parish, Rose, et al. (2009), who found elevated rates of hardship and income poverty among households that included women with disabilities in comparison to other households.

One important limitation of the existing caregiving research is its exclusive focus on one focal child with disabilities in households. For example, studies may exclusively examine children with autism, cerebral palsy, schizophrenia, or any other form of disability and the impact of that one child on the family's wellbeing. In instances where families have multiple children with disabilities, researchers often randomly choose one child for analysis or might select the child with a more severe condition, ignoring any other children with disabilities in the household. Reasons for having multiple children with disabilities could range from shared genetic etiology among first degree relatives, such as siblings and parents (Blacher & Begum, 2011; Crawford, Acuna, & Sherman, 2001; Fombonne, Bolton, Prior, Jordan, & Rutter, 1997; Piven et al., 1990; Stevenson, Asherson, Hay, Levy, et al., 2005; Uher, 2009), such that multiple children in a household could have the same disability, or a disability on the same illness spectrum, to reasons such as shared environmental stressors (Brooks-Gunn & Duncan, 1997; Evans, 2004). However, it is a separate area of research, which warrants further investigation, and is beyond the scope of this study.

There is limited evidence about the prevalence of households with more than one child with a disability. Based on data from the 2000 U.S. Census, Wang (2005) found that of the families who reported having children with disabilities, 87% had one child with disabilities, 11% had two children with disabilities and 2% had three or more children with disabilities. In a study of 325 families of adolescents and adults with autism spectrum disorders, Orsmond, Lin, and Seltzer (2007) found 22% of their sample had more than one child with disabilities.

In terms of household characteristics, Lawton (1998) from a survey in the U.K., found that most households that included multiple children with disabilities were headed by single parents, who were less likely to be employed than parents of one child with disabilities. However, to date, there is no research describing the situation of families with more than one child with disabilities in the U.S.

Having multiple children with disabilities may likely pose significant financial challenges. In general, families may achieve economies of scale in the consumption of private household goods, as the number of household members' increases (Deaton & Paxson, 1998). However, economies of scale in the household consumption of goods are highly

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