

Research Article

Parents With and Without Disabilities: Demographics, Material Hardship, and Program Participation

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Abstract: To compare demographics, material hardship, and public benefit program participation among parents with and without disabilities, we analyzed data from the 2008 Survey of Income and Program Participation. Households led by parents with disabilities were significantly more likely to experience hardships despite also being more likely to receive public benefits. Policy recommendations include greater outreach regarding these programs to parents with disabilities and more generous benefit levels.

Keywords: Disability; Parents; Economic Hardship

People with disabilities represent between 12.6% and 18.7% of the US population (Brault, 2012; Kraus, 2015) and face significant economic insecurities throughout the lifespan (Ghosh and Parish 2013; Parish et al. 2008; Parish et al. 2010; Parish, Rose and Swaine 2010, 2010; She & Livermore, 2007; Author et al., 2016a). For example, Peiyun She and Gina Livermore (2007) found that having a work-limiting disability for even less than one year is associated with increased odds of not meeting all expenses, not making rent or mortgage payments, not paying utility bills, not seeking needed medical care, not seeking needed dental care, and being food insecure in the United States. Similarly, having a child with a disability is associated with an increased likelihood of lacking a telephone, not being able to pay rent, postponing medical care, postponing dental care, and being food insecure (Parish et al. 2008; Sonik et al. 2016a).

Notably, these findings persist even when families with disabled household members receive public benefits (Sonik et al. 2016a; Sonik, Parish, and Rosenthal 2016b). These findings indicate that the benefits provided by current programs may not be fully sufficient to meet the complex needs of people with disabilities. This conclusion is supported by evidence from programs such as the Supplemental Nutrition Assistance Program, which has been shown to partially but incompletely alleviate food insecurity (Gregory, Rabbit, & Ribar, 2013; Mabli & Ohls, 2015; National Research Council, 2013; Nord & Golla, 2009; Ratcliff et al., 2011[1] [RS2]; Shaefer & Gutierrez, 2013). Families experience sharp increases in food insecurity prior to initial receipt of benefits, followed by modest but incomplete reductions in

food insecurity after benefits are received (Gregory et al., 2013; National Research Council, 2013). As a result, in cross-sectional analyses, receipt of Supplemental Nutrition Assistance Program benefits is counterintuitively associated with greater levels of material hardship, even after adjusting for income (e.g., Alaimo, Briefel, Frongillo, & Olson, 1998; Cohen, Ohls, Andrews, Ponza, Moreno, Zambrowski, & Cohen, 1999; Jensen, 2002; Ribar & Hamrick, 2003; Wilde & Nord, 2005; Gregory et al., 2013; National Research Council, 2013). Similarly, among low-income families that include children with disabilities, those receiving Supplemental Security Income benefits were more likely to experience food insecurity (Rose-Jacobs et al., 2016[3] [RS4]). In another study, a subpopulation of families including individuals with developmental disabilities had both heightened levels of program participation and widespread moderate—but not extreme—forms of material hardships (Sonik et al. 2016b).

Disability and Parenthood

Despite hardships documented among people with disabilities more broadly, parents with disabilities have received minimal study in terms of demographic and economic descriptions. Social and legal barriers to successful parenthood among people with disabilities are, however, well documented. For example, a review of existing child protection laws across the 50 states and the District of Columbia found that 37 contained language indicating that parental disability is a basis for terminating parental rights (Lightfoot, Hill, & LaLiberte, 2010). Almost all of these statutes specifically identify mental illness and intellectual and developmental disabilities (though often with outmoded language), and several statutes focus on physical disabilities as well (Friesen, Nicholson, Kaplan, & Solomon, 2009; Kaplan, Kottsieper, Scott, Salzer, & Solomon, 2009; Lightfoot et al., 2010). A comprehensive report by the National Council on Disability (2012) found multiple formal and informal challenges to parenting for people with disabilities, ranging from a medical provider culture that discourages fertility for women with disabilities (including encouragement of sterilization, especially among women with psychiatric disabilities), to cultural and statutory biases in the family court and child welfare systems against providing parents with disabilities access to the same parental rights afforded to parents without disabilities.

Consequently, parents with disabilities in general have a heightened risk of losing custody of their children (National Council on Disability, 2012). Individuals with particularly stigmatized disabilities such as mental illness have been reported to experience custody loss at even higher rates, with some estimates of removals occurring 80 percent of the time (Joseph, Joshi, Lewin, & Abrams, 1999). Moreover, children removed from parents with disabilities, as compared to children removed from parents without disabilities, stay in foster care longer and receive fewer formal supports for reunification with their parents (Lightfoot & DeZelar, 2016). Related to this phenomenon, parents with mental illness who lose custody of their children have reported confusion with the process and are, at times, even unclear about where their children live (Sands, Koppelman, & Solomon, 2004).

Given the relationship between poverty and interventions by state child welfare

agencies (Eckenrode, Smith, McCarthy, & Dineen, 2014), poverty and material hardship among parents with disabilities are potentially related to the direct challenges to their parental rights just noted (i.e., cultural and statutory biases). However, few studies have examined the economic well-being of individuals with disabilities, let alone public benefit participation among these parents. The most recently reported nationally representative estimates regarding parents with disabilities found that 6 percent (4.1 million) of parents co-residing with their minor children had disabilities (Kaye, 2012). This study reported that 30 percent of parents with disabilities had income below the federal poverty line and 16 percent of these parents received Supplemental Security Income benefits, a federal means-tested program for low-income, low-asset individuals with work-limiting disabilities (Kaye, 2012). No other measures of material hardship—such as food insecurity and unmet expenses for other essential items—or of public assistance utilization—such as benefits from the Supplemental Nutrition Assistance Program (formerly the Food Stamps Program)—were presented (Kaye, 2012). Also, comparisons to parents without disabilities were not made in this report.

Other studies focusing on subsets of the disability community or with smaller samples have found high levels of hardship beyond income poverty. For example, Alison Luciano, Joanne Nicholson, and Ellen Meara (2014) found that, nationwide, parents with serious mental illnesses were almost twice as likely as parents without any mental illness to have income below the federal poverty level (30% versus 17% for mothers and 17% versus 9% for fathers). In a sample of Supplemental Security Income recipients, parents with mental illness were twice as likely as parents with other disabilities to be unable to pay their rent and 76 percent more likely to experience food insecurity (Sogar, 2016). In addition, qualitative studies involving low-income mothers with disabilities reported severe experiences of material deprivation, even when receiving benefits from social safety-net programs (Magaña, Parish, and Cassiman 2008; Parish, Magaña, and Cassiman 2008). Perhaps relatedly, parents with mental illness were more likely to report having fair or poor health when compared to their counterparts without mental illness (Luciano, Nicholson, & Meara, 2014). Overall, the number of parents with disabilities and their degree of vulnerability indicates that the well-being of this population is a serious public health concern.

Broadly, parenthood is a key life event for which people with disabilities lack full inclusion. Understanding the economic vulnerabilities in this population may be critical to understanding the supports needed to achieve more inclusive policies for parents with disabilities.

Research Questions

The patterns of economic deprivation and program participation observed among the general population of people with disabilities suggest that parents with disabilities may face similar challenges. If so, these hardships may, in unique ways, interact with and exacerbate the social and legal challenges to the rights of parents with disabilities more broadly. Therefore, to better understand the material needs of parents with disabilities, we used data from the nationally representative Survey of Income and Program Participation to pursue the

following research questions: (1) how do parents with and without disabilities of varying severities compare on individual characteristics?, (2) how do parent households compare on measures of material hardships and program participation?, and (3) are there any relationships between parental disability status and material hardships?

Methods

Data

The longitudinal Survey of Income and Program Participation is representative of the non-institutionalized population of the United States (US Census Bureau, n.d.). We utilized data from wave 6 of the 2008 panel of the survey, which was collected between May and August of 2010. In addition to core questions relating to income, demographic information, and program participation, wave 6 contained extensive sets of topical module questions regarding disability status and material hardships. The detailed information provided in these modules allow for differentiation of disabilities into severe and non-severe categories and for examination of multiple domains of material hardship (Brault, 2012; Stoddard, 2014).

The Survey of Income and Program Participation provides several weights that allow for estimation of the number of people or households who are represented by each surveyed person and household (Westat, 2001). Person-weights can be used to calculate descriptive statistics for individual-level variables, such as race and gender. For household-level variables, such as the percentage of households experiencing specific material hardships, household-weights can be used. For variance estimations, the Survey of Income and Program Participation recommends using Fay's modified balanced repeat replication method (Westat, 2001). To prevent respondents from small geographic areas from being identifiable, the Survey of Income and Program Participation alters its primary sample units by combining them into larger variance strata and then splitting each stratum into two variance units. Fay's method is therefore recommended for variance estimation because it is able to account for both halves of the strata that are generated. Resulting variance estimates are nominally conservative (Westat, 2001).

Sample

Parent analysis

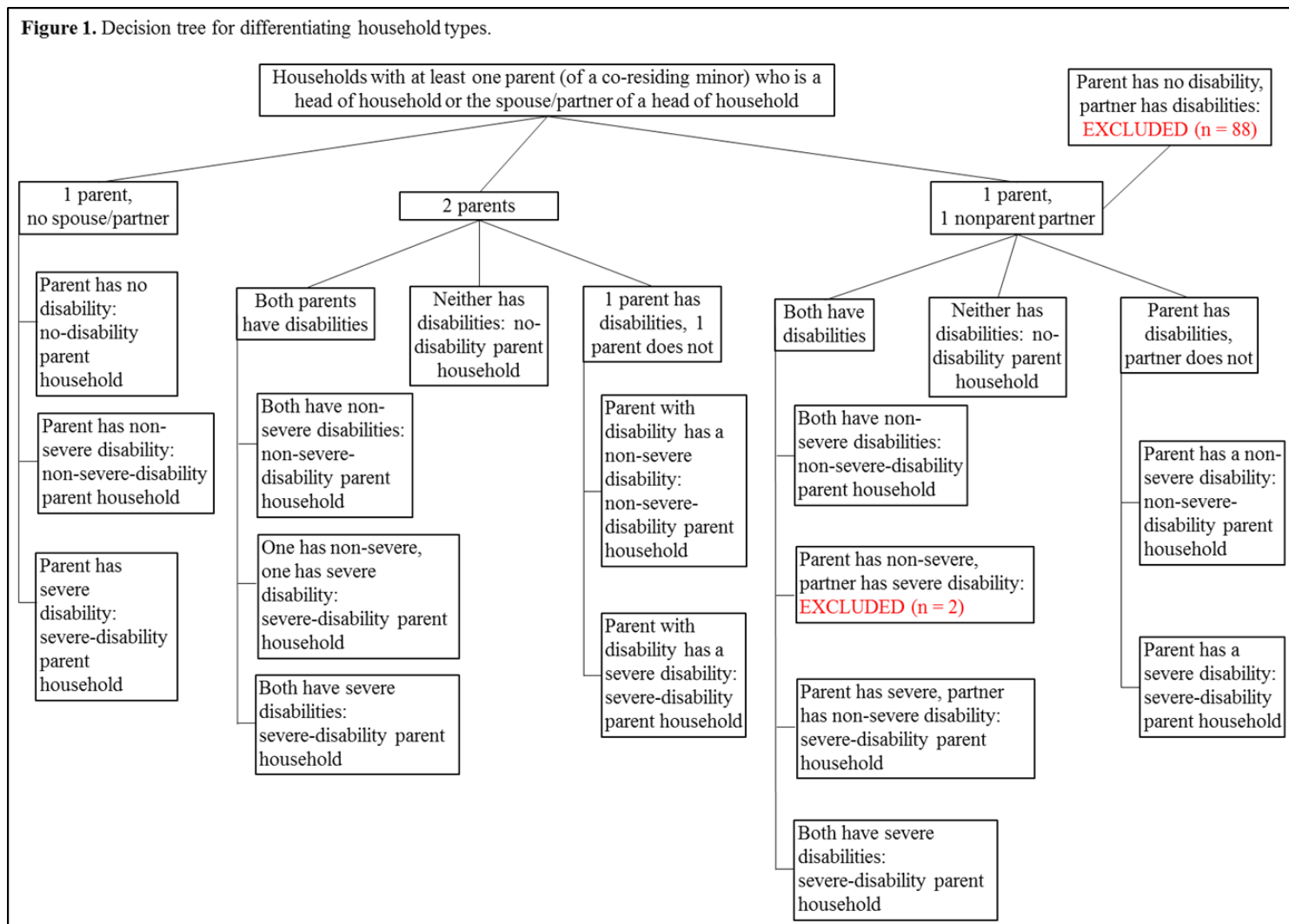
We identified co-residing parents with and without disabilities caring for their minor children (biological, step, or adopted) using several steps. First, we identified individuals who were heads of households or the spouse or partners of heads of households who lived with at least one of their minor children ($n = 17,578$). We limited our sample of parents to those who were heads of households or the spouses or partners of heads of households because of the additional financial responsibilities assumed by individuals in this role and in order to limit data to a maximum of one parent or parenting-pair per household (e.g., if a parent/head of household lived with his or her sibling and sibling's child, the sibling would be excluded). Next, among the parents identified in the first step, we identified those without disabilities (n

= 15,636), those with non-severe disabilities ($n = 743$), and those with severe disabilities ($n = 1,199$), using criteria described by the US Census Bureau in its estimates of the prevalence of people with disabilities in the United States (Brault, 2012). The US Census Bureau criteria identifies disabilities relating to various physical tasks, aspects of communication, activities of daily living, instrumental activities of daily living, intellectual and developmental disabilities, mental health conditions, and work-related disabilities (Brault, 2012). The exact definition involves nearly 100 variables, but in general severe disabilities are identified as those involving total functional limitations or leading to a need for assistance from others (Brault, 2012). These initial two steps were used for person-specific estimates, such as demographic information.

Parent-household analysis

Identifying the category of parenting households involved separate steps, depending on whether the identified parent(s) lived (i) without a spouse or partner, (ii) with a spouse or partner who was the biologic, step, or adoptive parent of a child in the household (meaning they were also a parent in the individual analysis), or (iii) with a partner who was not a parent of any kind to any child in the household (meaning they were not a parent in the individual analysis) (Figure 1). In the first scenario, a single parent, the disability status of the parent (none, non-severe, or severe) was also the status for the household. In the second scenario, in which there were two parents, several outcomes were possible: (a) if one parent or both parents had a severe disability, the household was assigned severe disability status; (b) if one parent had a non-severe disability and the other parent had either a non-severe disability or no disability, the household was assigned non-severe disability status; and (c) if neither parent had any disability, the household was assigned a status of no disability. Finally, the third scenario, a parent living with a nonparent partner, had several possible outcomes as well: (a) if the parent had a severe disability, the household was given severe disability status; (b) if the parent had a non-severe disability and the nonparent partner had either a non-severe disability or no disability, the household was given non-severe disability status; (c) if both the parent and the nonparent partner had no disabilities, the household was given a status of no disabilities; (d) if the parent had a non-severe disability and the nonparent partner had a severe disability, the household was excluded ($n = 2$); and (e) if the parent had no disability and the nonparent partner had any type of disability, the household was excluded ($n = 88$). We excluded households in these latter two situations because it was not clear what, if any, caregiving responsibilities the nonparent partners held, making conceivable equally strong arguments for these households to fall into different categories. Ultimately, we identified 8,380 no-disability parent households, 633 non-severe-disability parent households, and 1,116 severe-disability parent households. This approach yielded three mutually exclusive households types, and ensured that there were no duplicated households across categories.

Figure 1. Decision tree for differentiating household types.



Measures

Dependent variables

We explored sociodemographic characteristics, economic and material hardship prevalence, and public benefits program participation. Individual-level sociodemographic factors included, age, gender, race and ethnicity, marital status, health status, and educational attainment, and whether or not any of the children in the parent’s home had any disabilities. As with adult disability, child disability status was also determined based on criteria described by Matthew Brault (2012). Household-level economic factors included income, employment status, food insecurity—identified through methods developed by the United States Department of Agriculture (Nord, 2006), child food insecurity, whether there were any unmet expenses or service needs due to income (including expenses deemed essential, needs to see a doctor, needs to see a dentist, utility expenses, and rent or mortgage payments), whether the telephone or other utility services had been disconnected, whether the family had been evicted because of unpaid rent or mortgage payments, and whether the home had any conditions problems (including malfunctioning plumbing, infestation with pests such as rats or mice,

leaking roof or ceiling, broken windows, cracks in walls or ceiling, holes in the floors, or exposed electrical wires). Finally, we examined household-level receipt of benefits from Supplemental Security Income, the Supplemental Nutrition Assistance Program (both generally and among income-eligible families with income below 185% of the federal poverty level), Temporary Assistance to Needy Families, and unemployment insurance.

Independent variables

For each dependent variable we ran two sets of bivariate analyses: (i) comparing non-disability parents and households to non-severe-disability parents and households, and (ii) comparing non-disability parents and households to severe-disability parents and households. We generated two dummy variables as the independent variables, one for each of these comparisons. For logistic regressions, we used separate dummy variables that were indicators of non-severe-disability household status and severe-disability household status.

Covariates

In logistic regression analyses, we controlled for age, gender, race and ethnicity, marital status, health insurance status, health status, income, education, and employment status. In addition, given the added vulnerability noted in past studies among households including children with disabilities (Parish et al., 2008; Sonik et al., 2016b), we controlled for whether or not any children in the household had a disability. Finally, given evidence that families seek public benefits *after* material hardships arise (Gregory et al., 2013; National Research Council, 2013), we did not adjust for public benefit program receipt as these were likely temporally external to any potential relationships between parental disability status and material hardships. As such, they would be inappropriate to include in cross-sectional models.

Analyses

Stata (Version 14.0) was used to conduct all statistical calculations. We conducted bivariate comparisons on all sociodemographic, economic, and program participation variables. Stata utilizes adjusted Wald tests for weighted mean comparisons and corrected Pearson's χ^2 tests for weighted percentage comparisons, both of which involve F statistics. In addition, we conducted weighted multivariate logistic regressions to examine the relationship between household parental disability status and selected material hardship factors while adjusting for sociodemographic factors.

Results

Parents With and Without Disabilities

We estimated that 10.3 percent (95% CI: 9.8%, 10.9%) of parents co-residing with their minor children had disabilities; 4.0 percent (95% CI: 3.7%, 4.4%) had non-severe disabilities and 6.3 percent (95% CI: 5.8%, 6.7%) had severe disabilities (Table 1). Socio-demographically, the sample of parents with non-severe disabilities had a similar gender and

racial and ethnic makeup as the parents without disabilities, but these groups differed on all other variables (Table 1). Compared to parents without disabilities, parents with non-severe disabilities were significantly less likely to have ever married (86% versus 90%, $p < 0.001$) or live with a spouse or partner (79% versus 87%, $p < 0.001$). In addition, parents with non-severe disabilities were more than seven times as likely to have fair or poor general health than parents without disabilities (23% versus 3%, $p < 0.001$), they were less likely to have a high school (85% versus 89%, $p < 0.001$) or college degree (25% versus 34%, $p < 0.001$), and they were more likely to have children with disabilities (26% versus 11%, $p < 0.001$) (Table 1). Parents with severe disabilities experienced similar differences when compared to parents without disabilities, though with larger effect sizes (Table 1). In addition, parents with severe disabilities were significantly less likely than parents without disabilities to be men (61% versus 54%, $p < 0.001$), non-Hispanic white (59% versus 63%, $p < 0.001$) or Asian (3% versus 5%, $p = 0.01$), and they were significantly more likely to be non-Hispanic black (16% versus 10%, $p < 0.001$) (Table 1).

Table 1. Parent demographics^a

Variable	Parents without disabilities (<i>n</i> = 15,636)	Parents with non-severe disabilities (<i>n</i> = 743)	<i>F</i> ^b (for comparison to parents without disabilities)	Parents with severe disabilities (<i>n</i> = 1,199)	<i>F</i> (for comparison to parents without disabilities)
% (SE)	89.7 (0.3)	4.0 (0.2)	n/a	6.3 (0.2)	n/a
Age (mean), years (SE)	38.8 (0.1)	40.0** (0.4)	7.9	41.5*** (0.3)	67.5
Women, % (SE)	54.2 (0.2)	58.3 (2.0)	3.8	61.5*** (1.3)	25.8
Race/ethnicity, % (SE)					
Non-Hispanic white	63.0 (0.7)	62.1 (2.0)	0.2	58.9* (1.7)	5.5
Non-Hispanic black	10.4 (0.4)	11.6 (1.4)	0.9	15.9*** (1.2)	26.4
Non-Hispanic Asian	4.6 (0.2)	4.0 (0.7)	0.5	3.0* (0.5)	6.4
Non-Hispanic, other	2.4 (0.2)	2.9 (0.7)	0.6	5.5*** (0.9)	25.0
Hispanic	19.7 (0.5)	19.1 (1.7)	0.0	16.7* (1.3)	4.0
Family status, % (SE)					
Ever married	90.4 (0.3)	86.3*** (1.3)	14.3	83.9*** (1.2)	35.1
Divorced	6.5 (0.2)	10.7*** (1.3)	16.2	12.7*** (1.1)	51.4
Lives with spouse or partner	86.6 (0.3)	79.0*** (1.7)	27.6	72.1*** (1.5)	139.9
Health status, % (SE)					
Excellent	33.6 (0.5)	13.0*** (1.2)	138.6	4.9*** (0.8)	271.6
Very good	40.7 (0.5)	29.0*** (1.9)	32.0	10.6*** (1.0)	354.4
Good	22.5 (0.5)	34.9*** (1.7)	55.1	27.6*** (1.2)	15.5
Fair	2.9 (0.2)	18.2*** (1.6)	381.6	36.1*** (1.8)	1,451.6
Poor	0.2 (0.0)	5.0*** (0.8)	420.1	20.9*** (1.5)	2,850.7
Educational attainment					

High school/GED or m (SE)	89.3 (0.4)	85.4** (1.4)	9.2	79.8*** (1.4)	71.9
Bachelor's degree or m (SE)	33.7 (0.5)	24.6*** (1.9)	20.4	15.2*** (1.1)	163.2
Any children (<18 years) with disabilities in home, % (SE)	11.3 (0.4)	26.1*** (2.0)	99.7	30.4*** (1.7)	264.1
^a All values weighted; ^b For comparisons of weighted means (e.g., income), STATA conducts adjusted Wald tests, and for comparisons of weighted percentages (e.g., gender), STATA conducts corrected Pearson's χ^2 tests. Both produce <i>F</i> statistics; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.					

Parent Households With and Without Disabilities

Among households that included parents co-residing with their minor children, we estimated that 16.2 percent (95% CI: 15.4%, 17.0%) met our definition of a parent-disability household; 6.0 percent (95% CI: 5.5%, 6.7%) were non-severe-disability parent households, and 10.2 percent (95% CI: 9.5%, 10.9%) were severe-disability parent households (Table 2). Economically, non-severe-disability parent households had significantly less income on average than non-disability parent households (\$64,762 versus \$73,874, $p < 0.001$) and were more likely to have income below 100 percent of the federal poverty level (22% versus 18%, $p = 0.04$) (Table 2). Non-severe-disability parent households were also approximately twice as likely to experience any measure of food insecurity (any food insecurity: 23% versus 11%, $p < 0.001$; very low food insecurity: 8% versus 3%, $p < 0.001$; child food insecurity: 8% versus 5%, $p < 0.001$) (Table 2). Non-severe-disability parent households were also two to three times as likely than non-disability parent households to be unable to pay for various critical expenses (such as rent or mortgage payments: 20% versus 10%, $p < 0.001$) and to experience problems with their housing conditions (such as having infestations with rats or mice: 17% versus 7%, $p < 0.001$) (Table 2). These households were also significantly more likely to receive Supplemental Security Income and Supplemental Nutrition Assistance Program benefits (Table 2). Severe-disability parent households also had significantly less income than non-disability parent households (e.g., their mean income was \$46,300, $p < 0.001$), in addition to facing elevated rates of unmet expenses and poor housing conditions (Table 2). Effect sizes were again larger for severe-disability parent households on income, public benefit participation, and most material hardship measures.

Table 2. Material hardship and program participation among households of parents with and without disabilities^a

Variable	Parents without disabilities (n = 8,380)	Parents with non-severe disabilities (n = 633)	F ^b (for comparison to parents without disabilities)	Parents with severe disabilities (n = 1,116)	F (for comparison to parents without disabilities)
% (SE)	83.8 (0.4)	6.0 (0.3)	n/a	10.2 (0.3)	n/a
Mean Income, \$ (SE)	73,264 (931)	64,394*** (2,341)	14.1	46,300*** (1,638)	177.3
FPL ^c category, % (SE)					
< 100% FPL	18.2 (0.4)	21.6* (1.7)	4.2	35.2 *** (1.8)	98.9
100-199% FPL	20.5 (0.5)	22.4 (1.7)	1.2	28.2*** (1.4)	34.0
200-299% FPL	17.7 (0.5)	19.3 (1.8)	0.7	16.7 (1.2)	0.5
≥ 300% FPL	43.5 (0.6)	36.6*** (1.9)	12.7	20.0*** (1.3)	178.4
Employed and working % (SE)	80.8 (0.5)	74.9** (1.9)	10.2	35.1*** (1.6)	873.6
Health insurance status, % (SE)					
Uninsured	20.0 (0.5)	18.4 (1.6)	0.9	20.1 (1.4)	0.0
Medicaid and/or Medicare	10.0 (0.4)	16.9*** (1.6)	24.4	38.5*** (1.7)	505.0
Any private	69.9 (0.6)	64.8** (1.9)	7.8	41.5*** (1.8)	204.1
Food security, % (SE)					
Low or very low food security	11.3 (0.4)	23.0*** (1.9)	66.4	29.3*** (1.5)	196.4
Very low food security	3.4 (0.3)	7.9*** (1.1)	31.4	13.3 (1.1)	166.1
Child food insecurity	4.9 (0.3)	8.2*** (1.1)	12.3	11.2*** (1.1)	47.9
Unmet expenses/needs, % (SE)					
Unmet essential expenses	18.6 (0.5)	34.0*** (1.9)	79.8	43.3*** (1.5)	347.3
Unmet need to see doctor	7.0 (0.3)	14.6*** (1.6)	39.4	186.6*** (1.3)	164.9
Unmet need to see dentist	8.9 (0.4)	18.4*** (1.6)	58.9	23.1*** (1.3)	209.2
Unmet utility expenses	12.8 (0.4)	24.3***	63.0	31.4***	215.8

		(1.7)		(1.6)	
Utilities shut off	2.2 (0.2)	4.5*** (0.9)	11.6	6.8*** (0.8)	66.8
Telephone disconnected	4.6 (0.3)	9.3*** (1.0)	29.6	13.1*** (1.3)	74.6
Housing security, % (SE)					
Unpaid housing payments	10.4 (0.4)	20.3*** (1.6)	50.2	22.5*** (1.3)	115.8
Evicted from home	0.5 (0.1)	1.2* (0.4)	4.9	0.9 (0.3)	2.0
Housing conditions, % (SE)					
Plumbing not working	1.5 (0.2)	4.0*** (0.8)	20.2	1.5*** (0.2)	32.9
Pests (rats, mice, etc.)	7.1 (0.3)	16.6*** (1.6)	67.2	12.5*** (1.1)	38.2
Leaking roof or ceiling	4.0 (0.2)	8.2*** (1.1)	23.1	8.8*** (0.8)	60.6
Broken windows	2.8 (0.2)	6.0*** (1.0)	22.8	7.8*** (0.9)	61.9
Cracks in walls or ceiling	2.3 (0.2)	7.3*** (0.9)	61.5	5.8*** (0.6)	52.3
Holes in floor	0.5 (0.1)	1.6** (0.6)	11.3	1.6*** (0.4)	18.7
Exposed electrical wires	0.5 (0.1)	1.0 (0.4)	2.5	2.5*** (0.5)	40.8
Public benefits ^d , % (SE)					
SSI	2.2 (0.2)	5.2*** (1.1)	16.9	17.9*** (1.2)	549.3
SNAP	15.8 (0.5)	23.2*** (1.7)	24.0	40.8*** (1.7)	277.9
SNAP (if < 185% FPL) ^e	39.0 (0.9)	48.3** (3.2)	8.2	60.4*** (1.9)	91.8
TANF	1.9 (0.1)	2.6 (0.7)	1.1	8.3*** (1.0)	140.2
Unemployment	6.5 (0.3)	6.4 (1.1)	0.0	9.9*** (0.9)	16.4
^a All values weighted and at household level; ^b For comparisons of weighted means, STATA conducts adjusted Wald tests, and for comparisons of weighted percentages, STATA conducts corrected Pearson's χ^2 tests. Both produce <i>F</i> statistics; ^c FPL: Federal Poverty Level ^d SSI: Supplemental Security Income; SNAP: Supplemental Nutrition Assistance Program; TANF: Temporary Assistance to Needy Families; ^e Those below 185% FPL are income eligible for SNAP; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.					

Relationships between parental disability status and material and housing hardships

Table 3 and Table 4 present the results of logistic regressions for selected material hardship and housing hardships, respectively. After adjusting for various sociodemographic factors, non-severe and severe-disability household status was significantly associated with each hardship variable except for being evicted. Evictions appeared to be a relatively rare event (0.5% for non-disability households, 1.2% for non-severe-disability households, and 0.9% for severe-disability households). Income was highly associated with all tested hardship variables (Table 3 and Table 4). Counterintuitively, employment status was positively associated with several of the tested hardships, including having an unmet need to see a doctor

(adjusted OR = 1.37 [95% CI 1.12, 1.67]), having utility services terminated (adjusted OR = 1.71 [95% CI 1.22, 2.39), and having unpaid housing rent or mortgage payments (adjusted OR = 1.29 [95% CI 1.08, 1.54]) (Table 3 and Table 4). Finally, the household’s child disability status was associated with all outcomes except for child food insecurity and evictions (Table 3 and Table 4).

Table 3. Associations between parent disability status and selected material hardships, adjusting for controls^a

	Child food insecurity	Unmet need to see doctor	Unmet need to see dentist	Utilities (gas, electricity, or oil) shut off
Household parent disability status ^b				
Non-severe parent disability	1.5* (1.09, 2.07)	1.97*** (1.46, 2.66)	1.99*** (1.56, 2.53)	1.64* (1, 2.68)
Severe parent disability	1.68** (1.21, 2.34)	2.21*** (1.74, 2.81)	2.07*** (1.63, 2.65)	2.14** (1.37, 3.33)
At least one child with disability	1.2 (0.91, 1.59)	1.5*** (1.26, 1.79)	1.41*** (1.2, 1.65)	1.89*** (1.37, 2.59)
FPL ^c				
< 100% FPL	3.38*** (2.4, 4.75)	2.19*** (1.65, 2.91)	2.25*** (1.73, 2.92)	2.89*** (1.64, 5.1)
100-199% FPL	2.9*** (2.07, 4.06)	1.92*** (1.42, 2.6)	2.33*** (1.79, 3.02)	1.68 (0.99, 2.85)
200-299% FPL	1.86** (1.25, 2.77)	1.81*** (1.35, 2.44)	2.08*** (1.62, 2.67)	1.62 (0.99, 2.64)
Employed and working	1.16 (0.93, 1.44)	1.37** (1.12, 1.67)	1.15 (0.94, 1.39)	1.71** (1.22, 2.39)

^a Weighted logistic regressions were used; odds ratios (95% confidence interval) reported; if two parents were both associated with a household type, the value for the parent head of household was used (see Figure 1); only select covariates are presented (the other covariates were age, gender, race/ethnicity, divorced status, health status, health insurance status, and educational attainment); ^b Reference: no parent disability; ^c FPL: federal poverty level; reference: ≥ 300% FPL; * p<0.05; ** p<0.01; ***p<0.001.

Table 4. Associations between parent disability status and selected housing hardships, adjusting for controls^a

	Unpaid housing payments	Evicted from home	Plumbing not working	Pests (rats, mice, etc.)
Household parent disability status ^b				
Non-severe parent disability	1.86*** (1.46, 2.36)	2.05 (0.93, 4.48)	2.3** (1.38, 3.83)	2.27*** (1.78, 2.89)
Severe parent disability	1.63*** (1.27, 2.08)	1.04 (0.4, 2.74)	1.84* (1.07, 3.18)	1.34* (1.01, 1.77)
At least one child with disability	1.46*** (1.21, 1.77)	1.26 (0.64, 2.51)	1.53* (1.08, 2.16)	1.82*** (1.51, 2.19)
FPL ^d				
< 100% FPL	3.27*** (2.53, 4.23)	9.38*** (3.23, 27.23)	3.29*** (1.9, 5.71)	1.47** (1.16, 1.87)
100-199% FPL	2.43*** (1.99, 2.96)	5.55** (1.96, 15.74)	1.87 (1, 3.52)	1.58*** (1.29, 1.93)
200-299% FPL	1.6*** (1.27, 2.02)	3.12 (0.76, 12.82)	1.53 (0.83, 2.81)	1.15 (0.91, 1.45)
Employed and working	1.29** (1.08, 1.54)	1 (0.52, 1.91)	1.13 (0.78, 1.64)	0.91 (0.73, 1.12)

^a Weighted logistic regressions were used; odds ratios (95% confidence interval) reported; if two parents were both associated with a household type, the value for the parent head of household was used (see Figure 1); only select covariates are presented (the other covariates were age, gender, race/ethnicity, divorced status, health status, health insurance status, and educational attainment); ^b Reference: no parent disability; ^c FPL: federal poverty level; reference: \geq 300% FPL; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Discussion

We present new estimates of the sociodemographic characteristics, material hardship experiences, and level of public benefit program participation among parents with and without disabilities of differing severities and their households. Our estimates for parents with disabilities differ somewhat from those presented by H.S. Kaye (2012). For example, we estimate that 82 percent and 19 percent of parents with disabilities had high school and college degrees, respectively, whereas Kaye (2012) reported these figures to be 77 percent and 13 percent. We also estimated that 10 percent of parents had disabilities, compared to the 6 percent reported by Kaye (2012). One potential explanation for these differences is that Kaye's estimates were derived from analyses of the American Community Survey, which uses a different definition of disabilities than the Survey of Income and Program Participation (Stoddard, 2014). The former defines disability as having serious difficulties in one or more of six areas (hearing, vision, cognitive function, ambulation, self-care, or independent living)

(Stoddard, 2014), whereas the latter uses a more complex algorithm to differentiate disabilities into broader domains (communicative, mental, and physical) and includes both what it considers “severe” and “non-severe” functional impairments (Brault, 2012).

Beyond these initial figures, we found that the households of parents with disabilities—either non-severe or severe—experience poorer health and poorer outcomes regarding a host of economic and material hardships when compared to parents without disabilities. This was true even while controlling for many possible confounders. Moreover, given the correlations found between income and disability status (Table 2) and the relationship between income and economic outcomes (Table 3 and Table 4), income may have captured a significant portion of the variation in the outcome variables originating from disability status.

Also, we found this trend of worse outcomes to persist for the subset of parents with severe disabilities despite the relatively elevated use of public benefits in their households. This trend is consistent with previous findings suggesting that public benefit programs may alleviate hardship, but such benefits do not eliminate hardship (Shaefer & Gutierrez, 2013; Sonik et al., 2016b). We found this to be true for parents with non-severe disabilities as well, despite their being a relatively closer match to parents without disabilities in race, ethnicity, employment status, poverty status, and public benefit program receipt. For example, despite the fact that the households of parents with non-severe disabilities experienced below-poverty income only about 20 percent more frequently than the households of parents without disabilities, they experienced twice the prevalence of food insecurity. This indicates that mechanisms beyond traditionally examined socioeconomic factors are driving at least some of the material hardship differences among these families. Similarly, our finding that being employed was positively associated with certain hardships is unexpected. It is possible that, once controlling for income and health insurance status, being employed versus not implies a greater risk for falling into a gap between eligibility for public benefit programs and having sufficient earned income to avoid hardship.

Given the high direct and indirect health care costs experienced by families including members with disabilities (Mitra, Findley, & Sambamoorthi, 2009; Parish, Shattuck, & Rose, 2009), one potential mechanism leading parents with disabilities to experience excess economic difficulties may be increased health care costs that drain otherwise similar resources. Our findings that households led by parents with disabilities are more likely than those led by parents without disabilities to have unmet medical and dental needs supports this theory. An important caveat to this argument, though, is that data for this study were collected in 2010, before the Affordable Care Act fully came into effect. Future studies should examine whether parents with disabilities—and in particular those with non-severe disabilities—have experienced any reduction in their health care costs in recent years and what effect this may have had on the prevalence of material hardships among these families.

Limitations

The Survey of Income and Program Participation relies on self-reported data. Given

biases associated with disability status, and in particular parental disability status (National Council on Disability, 2012), underreporting potentially limited our ability to examine the full population of parents with disabilities. However, because the Survey of Income and Program Participation assesses disability through questions about activity- and function-specific impairments rather than potentially charged labels (Brault, 2012), effects from underreporting are likely to be minimal. In addition, despite moderate to large sample sizes, our analyses may still have lacked adequate power to detect differences between groups in their experiences of low frequency events such as evictions. Finally, we did not explore the potential effects of having one versus two parents with disabilities. Doing so would make identifying appropriate comparisons to single parent households and households with parents without disabilities difficult, and the sample size was insufficient to examine this degree of granularity.

Policy implications

Several public benefit programs are either explicitly provided to people with disabilities, such as the Supplemental Security Income program, or have more flexible program rules for recipients with disabilities, such as the Supplemental Nutrition Assistance Program (SNAP, 2013). Any additional assistance provided by these programs appears insufficient to meet the needs of households that include parents with disabilities. Based on our findings, both uptake levels and the amount of benefits provided appear to be at issue. More than 60 percent of income-eligible households led by parents with severe disabilities receive Supplemental Nutrition Assistance Program benefits. Although uptake for this group was one and half times greater than it was for households led by parents without disabilities, they still experienced two to three times the level of very low food security and child food insecurity. These two factors may be related, as families needing assistance may be less likely to seek benefits that they perceive will only partially alleviate the problem they are trying to solve. A combination of greater outreach to parents with disabilities and more generous benefit levels may be warranted.

Affordable and safe housing policies also appear not to meet the needs of parents with disabilities. We found that parents with disabilities were significantly more likely to experience a host of housing condition problems, such as pest infestations, that are likely detrimental to health and well-being. An associated problem was that one in five of these families—twice the rate for families without parents with disabilities—had unpaid rent or mortgage payments, signifying a likely lack of mobility or options for ensuring improved living conditions. Given the already-vulnerable health status of parents with disabilities, unstable and unsafe living conditions are likely to increase health problems and, ultimately, health care utilization and costs. For these reasons, more robust sustainable housing policies are needed and should contain special considerations for families that include people with disabilities.

Finally, the excess material and housing hardships experienced by parents with disabilities may interact with already-biased social and legal systems with regard to child custody. For example, court systems following inherently biased family law policies are

unlikely to see the harsher living conditions faced by parents with disabilities as anything but confirmation of beliefs that question the appropriateness of parenting with disabilities from the start. Consequently, efforts to reform family policies to make them more accommodating to parents with disability will likely need to be made in concert with efforts to alleviate the hardships experienced by these families if they are to be successful.

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References

- Alaimo, K., Briefel, R. R., Frongillo Jr., E. A., & Olson, C. M. (1998). Food insufficiency exists in the United States: Results from the Third National Health and Nutrition Examination Survey (NHANES III). *American Journal of Public Health*, 88(3), 416–426.
- Brault, M. (2012). Americans with disabilities: 2010 (Current Population Reports, P70-131). Washington, DC: United States Department of Commerce. Retrieved from <http://www.census.gov/prod/2012pubs/p70-131.pdf>.
- Cohen, B., Ohls, J., Andrews, M., Ponza, M., Moreno, L., Zambrowski, A., & Cohen, R. (1999). Food Stamp participants' food security and nutrient availability: Final report. Princeton, NJ: Mathematica Policy Research, Inc.
- Eckenrode, J., Smith, E. G., McCarthy, M. E., & Dineen, M. (2014). Income inequality and child maltreatment in the United States. *Pediatrics*, 133(3), 454–461.
- Friesen, B. J., Nicholson, J., Kaplan, K., & Solomon, P. (2009). Parents with a mental illness and implementation of the adoption and safe families act. In Notkin, S., Weber, K., Golden, O., & Macomber, J. (Eds.), *Intentions and results: A look back at the Adoption and Safe Families Act* (102–114). Washington, D.C.: Urban Institute.
- Ghosh, S., & Parish, S. L. (2013). Prevalence and economic well-being of families raising multiple children with disabilities. *Children and Youth Services Review*, 35(9), 1431–1439.
- Gregory, C., Rabbitt, M. P., & Ribar, D. C. (2013). The supplemental nutrition assistance program and food insecurity (Paper 21). Lexington: University of Kentucky Center for Poverty Research. Retrieved from http://uknowledge.uky.edu/ukcpr_papers/21

- Hollingsworth, L. D. (2004). Child custody loss among women with persistent severe mental illness. *Social Work Research, 28*(4), 199–209.
- Jensen, H. H.. (2002). Food insecurity and the food stamp program. *American Journal of Agricultural Economics, 84*(5), 1215–1228.
- Joseph, J. G., Joshi, S., Lewin, A. B., & Abrams, M. (1999). Characteristics and perceived needs of mothers with serious mental illness. *Psychiatric Services, 50*(10), 1357–1359.
- Kaplan, K., Kottsieper, P., Scott, J., Salzer, M., & Solomon, P. (2009). Adoption and safe families act state statutes regarding parents with mental illness: A review and targeted intervention. *Psychiatric Rehabilitation Journal, 33*(2), 91–94.
- Kaye, H. S. (2012). Current demographics of parents with disabilities in the U.S. Berkeley, CA: Through the Looking Glass. Retrieved from <http://www.lookingglass.org/pdf/States-Data/TLG-Parents-with-Disabilities-US-Demographics.pdf>
- Kraus, L. (2015). “2015 Disability Statistics Annual Report.” Durham, NH: University of New Hampshire. http://www.disabilitycompendium.org/docs/default-source/2015-compendium/annualreport_2015_final.pdf
- Lightfoot, E., & DeZelar, S. (2016). The experiences and outcomes of children in foster care who were removed because of a parental disability. *Children and Youth Services Review, 62*, 22–28.
- Lightfoot, E., Hill, K., & LaLiberte, T. (2010). The inclusion of disability as a condition for termination of parental rights. *Child Abuse & Neglect, 34*, 927–934.
- Luciano, A., Nicholson, J., & Meara, E. (2014). The economic status of parents with serious mental illness in the United States. *Psychiatric Rehabilitation Journal, 37*(3), 242–250.
- Mabli J., & Ohls J. (2015). Supplemental Nutrition Assistance Program participation is associated with an increase in household food security in a national evaluation. *Journal of Nutrition, 145*(2), 344–351.
- Magaña, S., Parish, S. L., & Cassiman, S. A. (2008). Policy lessons from low-income mothers with disabilities: A primer on inadequate incomes, work disincentives, and bureaucratic insensitivity. *Journal of Women, Politics & Policy, 29*, 181–206.
- Mitra, S., Findley, P.A., & Sambamoorthi, U. (2009). Health care expenditures of living with a disability: total expenditures, out-of-pocket expenses, and burden, 1996 to 2004. *Archives of Physical Medicine and Rehabilitation, 90*, 1532–1540.
- National Council on Disability. (2012). *Rocking the cradle: Ensuring the rights of parents with disabilities and their children*. Washington, DC: National Council on Disability.

Retrieved from

https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf

- National Research Council. (2013). Research opportunities concerning the causes and consequences of child food insecurity and hunger: Workshop summary. Washington, DC: National Academy of Sciences. Retrieved from <http://www.nap.edu/catalog/18504/research-opportunities-concerning-the-causes-and-consequences-of-child-foodinsecurity-and-hunger>
- Nord, M. (2006). Survey of income and program participation 2001 wave 8 food security data file technical documentation and user notes. Washington, DC: U.S. Department of Agriculture. Retrieved from http://www.nber.org/sipp/food_security/2001.pdf
- Nord, M., & Golla, A. M. (2009). Does SNAP decrease food insecurity: untangling the self-selection effect. Retrieved February 21, 2016, from https://www.ers.usda.gov/webdocs/publications/err85/10977_err85_1_.pdf?v=42317
- Parish, S. L., Grinstein-Weiss, M., Yeo, Y., Rose, R. A., & Rimmerman, A. (2010). Assets and income: Evidence of disability-based disparities in the U. S. *Social Work Research*, 34, 71–82.
- Parish, S. L., Magaña, S., & Cassiman, S. A. (2008). It's just that much harder: Multilayered hardship experiences of low-income mothers with disabilities raising their children. *The Journal of Women and Social Work*, 23(1), 51–65.
- Parish, S. L., Rose, R. A., Grinstein-Weiss, M., Richman, E. L., & Andrews, M. E. (2008). Material hardship in U.S. families raising children with disabilities. *Exceptional Children*, 75(1), 71–92.
- Parish, S.L., Rose, R.A., & Swaine, J.G. (2010). Financial well-being of US parents caring for co-resident children and adults with developmental disabilities: An age-cohort analysis. *Journal of Intellectual & Developmental Disabilities*, 35, 235–243.
- Parish, S. L., Shattuck, P. T., & Rose, R. A. (2009). Financial burden of raising CSHCN: Association with state policy choices. *Pediatrics*, 124(Supplement 4):S435-S442.
- Park, J. M., Solomon, P., & Mandell, D. S. (2006). Involvement in the child welfare system among mothers with serious mental illness. *Psychiatric Services*, 75(4), 493–497.
- Ratcliffe, C., McKernan, S.-M., & Zhang, S. (2011). How much does the supplemental nutrition assistance program reduce food insecurity?. *American Journal of Agricultural Economics*, 93(4), 1082–1098.
- Ribar, D. C., & Hamrick, K. S. (2003). Dynamics of poverty and food sufficiency. Washington, DC: United States Department of Agriculture, Food and Nutrition Research Report No. 36.

- Rose-Jacobs, R., Fiore, J. G., de Cuba, S. E., Black, M., Cutts, D. B., Coleman, S. M., ... Frank, D. A. (2016). Children with special health care needs, Supplemental Security Income, and food insecurity. *Journal of Developmental and Behavioral Pediatrics*, 37(2), 140–147.
- Sands, R. G., Koppelman, N., & Solomon, P. (2004). Maternal custody status and living arrangements of children of women with severe mental illness. *Health & Social Work*, 29(4), 317–325.
- Shaefer, H. L., & Gutierrez, I. A. (2013). The supplemental nutrition assistance program and material hardships among low-income households with children. *Social Services Review*, 87, 753–779.
- She, P., & Livermore, G. A. (2007). Material hardship, poverty, and disability among working-age adults. *Social Science Quarterly*, 88(4), 970–989.
- Supplemental Nutrition Assistance Program (SNAP). (2013). SNAP special rules for the elderly or disabled. Washington, DC: U.S. Department of Agriculture. Retrieved from <http://www.fns.usda.gov/snap/snap-special-rules-elderly-or-disabled>
- Sogar, C. A. (2016). The relationship between parents' physical and mental health symptoms and parenting and material limitations: Results from interviews with parents who receive Supplemental Security Income. *American International Journal of Humanities and Social Science*, 2(2), 36–44.
- Sonik, R. A., Parish, S. L., Ghosh, S., & Igdalsky, L. (2016a). Food insecurity in U.S. households that include children with disabilities. *Exceptional Children*, 83(1), 42–57.
- Sonik, R. A., Parish, S. L., & Rosenthal, E. S. (2016b). Sibling caregivers of people with intellectual and developmental disabilities: Sociodemographic characteristics and material hardship prevalence. *Intellectual and Developmental Disabilities*, 54(5), 332–341.
- Stoddard, S. (2014). 2014 Disability Statistics Annual Report. Durham, NH: University of New Hampshire. Retrieved from <http://www.disabilitycompendium.org/docs/default-source/2014-compendium/annual-report.pdf>
- US Census Bureau. (n.d.). Survey of Income and Program Participation: Methodology. Retrieved from <http://www.census.gov/programs-surveys/sipp/methodology/sampling.html>
- Westat. (2001). Survey of Income and Program Participation user guide. Washington, DC: U.S. Census Bureau. Retrieved from https://www.census.gov/content/dam/Census/programs-surveys/sipp/methodology/SIPP_USERS_Guide_Third_Edition_2001.pdf
- Wilde, P., & Nord, M. (2005). The effect of food stamps on food security: A panel data

approach. *Review of Agricultural Economics*, 27(3), 425–432.



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