

# Family caregiving and employment among parents of children with disabilities on SSI

Kalman Rupp<sup>a,\*</sup> and Steve Ressler<sup>b</sup>

<sup>a</sup>*Social Security Administration, Washington, DC, USA*

<sup>b</sup>*GovLoop.com, Tampa, FL, USA*

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**Abstract.** Parental and family inputs are particularly important for children with disabilities receiving benefits from the Supplemental Security Income (SSI) program. These children often need disability or health-related care, and nonfamily sources provide only limited access. This is the first study to analyze family and nonfamily caregiving for these children with disabilities based on nationally representative quantitative data from the National Survey of SSI Children and Families (NSCF), a survey focusing on SSI recipient children with disabilities. The data suggests substantial variability in the need for caregiving among children on SSI. We find that there is also substantial variation in family inputs related to parental education, living arrangements, the presence of other children of preschool age and other factors that affect the quality and quantity of caregiving. Our analysis confirms that family caregiving is much more substantial for these children than nonfamily caregiving, and that caregiving from both sources is associated with various indicators of the nature and extent of disabilities. We find some – but weaker – evidence of an association between the child’s disabilities and parental employment. Overall, while there is some substitution between parental employment and caregiving there appears to be a substantial net burden on the family arising from the child’s needs for caregiving. We also find that there are significant predictors of family caregiving and parental employment that are unrelated to the child’s disabilities. Most of these show opposite relationships to caregiving and parental employment – negative for one, positive for the other or vice versa. However, better parental education substantially increases the odds of both caregiving and parental employment. Parental disability sharply reduces the odds of parental employment and somewhat increases the odds of reported family caregiving. Overall, the challenges are especially substantial for single mothers who cannot share the extra burden of raising a child with severe disabilities with a spouse.

**Keywords:** Children, caregiving, disabilities, health status, health care utilization, family, labor force participation, home production, parental employment, SSI, SSA

## 1. Introduction

This paper focuses on the role of parental and family inputs in providing the care needed by children with disabilities receiving benefits from the Supplemental Security Income (SSI) program. SSI is a categorical negative income tax program targeting people with low income and assets who are either aged 65 or older or

categorically eligible as “disabled” according to the statutory definition of disability. The rules applying to children with disabilities are somewhat different from those affecting the determination of adult categorical eligibility. This reflects the fact that work is primarily an adult activity in our society. Parents of children play important roles in the lives of the children, and their income and assets may be “deemed” in establishing the child’s eligibility for SSI. For more detail on the SSI rules as they apply to children and their evolution the reader is encouraged to consult Davies, Rupp, and Wittenburg [3]. Depending on the nature and severity of their disabilities, SSI recipient children need caregiving specifically related to their impairments and health

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\* Address for correspondence: Kalman Rupp, Social Security Administration, 500 E Street, SW., 9th Floor ITC Bldg., Washington, DC 20254, USA. Tel.: +1 202 358 6216; Fax: +1 202 358 6187; E-mail: kalman.rupp@ssa.gov.

problems over and beyond the child care need of all children, regardless of disabilities. The need for such care is no less important in determining the quality of life and human capital development of the disabled child than the school environment, access to supportive services such as special education, access to medical care and health insurance coverage, and the added income provided to the family through the SSI program. While there has been speculation among researchers and policy makers that the added cash provided by SSI may allow parents to provide care for their disabled child by substituting SSI benefits for earnings from market work there is a clear gap of empirical knowledge concerning family and nonfamily caregiving. Our study is designed to fill this gap based on data that has been collected by the National Survey of SSI Children and Families (NSCF). The NSCF has a battery of questions specifically related to caregiving provided by the family and others. Our paper provides the first empirical analysis of caregiving using this unique data set. Another paper in this volume [4] focuses on a complementary set of issues related to access to health insurance and medical out of pocket expenditures. The two are related in that both the need for medical care and the need for caregiving services arise from the physical, cognitive and emotional impairments of the SSI recipient child.

In the next section of the paper we provide some background and identify the major research questions of the present study. This is followed by a brief discussion of data and methodology, the presentation of the major empirical findings, and finally the conclusions.

## 2. Background and research questions

Our study fills an important gap in the literature on caring for children with disabilities in general and SSI recipient children specifically. This arises mainly from the fact that previous studies focusing on the relationship between the child's disabilities and parental activities analyzed the relationship between the child's disabilities and parental employment, but did not use any information on the presumed intervening variable, parental caregiving. The failure to look at parental caregiving in past studies had some undesirable consequences. The first major problem is that without explicitly accounting for caregiving there is a substantial danger of incorrectly inferring parental employment effects based on spurious associations. The second problem is that by focusing exclusively on potentially neg-

ative employment effects the attention is diverted from the potentially positive role of parental caregiving in addressing the needs of the child. A third problem is that without data on parental caregiving we cannot address important effects of caregiving on the parents themselves, such as a potential net decrease in parental time available for leisure. In addition to the fact that our study is pioneering by utilizing data on both caregiving and market work by the parents, it also fills a gap by focusing on the subset of children with disabilities who are on SSI, a subgroup facing particularly substantial challenges.

We address three major aspects of the role of parents in caring for the disabled child on SSI:

1. Parental and family inputs;
2. Patterns of family and nonfamily caregiving;
3. Patterns of parental employment and work-related household decisions.

Our first set of research questions focuses on parents and – more broadly – the family environment as inputs to the human capital development of the child. What are the inputs from parents and families that are potentially available to care for the disabled child? We describe the human capital characteristics of the parents themselves (such as education and disability status), labor force participation and earnings, and compare single mothers and mothers and fathers in two-parent families along these dimensions. Parental employment may affect caregiving for the disabled child for two fundamental reasons: earnings of parents affect the financial resources that may be available for child care and other expenses, and employment by the parent reduces the time available for home production, most notably caregiving.<sup>1</sup> This broader view about the role of parents and the family environment in the human capital development of children is further elaborated by Davies, Rupp and Wittenburg [3] in a life-cycle framework.

Second, we look at caregiving patterns from a variety of perspectives: we describe family and nonfamily caregiving and reported childcare arrangements during the parent's work hours as important inputs to the quality of everyday functioning and human capital development of the disabled child. We describe the relationship between family and nonfamily caregiving and various

<sup>1</sup>In turn, the need for devoting time to the disabled child may reduce parental time available for market work and/or reduce income available for other consumption (in case of paid nonfamily caregiving).

dimensions of the child's disabilities and health care utilization. We also estimate logistic models of factors affecting the probability of caregiving.

Third, we address the factors affecting parental employment and work-related household decisions. The fundamental concern here is the tradeoff between parental caregiving and market work. Severe disabilities of the child may increase the need for family caregiving, and therefore reduce time available for market work. Alternatively, nonfamily caregiving can be substituted for family caregiving, or family caregiving reduces the time available for leisure or other home production rather than employment. Thus the presence and magnitude of the relationship between the child's disabilities and parental employment is unclear. Therefore, we need empirical measurement to establish the existence and magnitude of this relationship.

Several pieces of prior research on children and their parents provide useful background for our study, but as previously noted they also indicate gaps. Powers [13] estimates the impact of child disability on maternal employment. She finds a significant negative effect of the child's disability on maternal employment, especially on the employment of single female heads. Her study does not include any direct evidence on parental caregiving, and does not include data on SSI participation status. Powers [14] focuses on the effect of alternative measures of disability on mother's work, and on differences between single mothers' and wives' employment. She finds negative effects of several disability definitions on employment and hours for both groups in a cross-sectional framework. However, when changes in employment and work hours are modeled she finds evidence only for single mothers. Loprest and Davidoff [10] use data on children with special health care needs and analyzes their effect on parent's employment decisions. The authors generally find no significant associations after controlling for differences in demographic and family characteristics. However, they identify a subset of children with special needs whose parents are significantly less likely to work and work fewer hours. The authors conclude that policies to assist low-income single parents of children with disabilities to move into work should target this specific subset of children with special health care needs. Most of the analysis is limited to low-income single parents. The paper does not conduct a separate analysis of SSI recipient children. Karoly and Davies [9] analyze the effect of SSI benefit loss arising from the welfare reform legislation of 1996. They find a substantial drop in the probability that the family mother

and/or father is working for up to 12 months after the loss of SSI benefits for the child. These results are in the opposite direction from prior expectations of a negative relationship between SSI enrollment and parental employment. The authors speculate about the possible causes, such as a relatively short time horizon and possible changes in living arrangements. Other previous studies of the relationship between child health and labor supply among mothers include Salkever [16] and Wolfe and Hill [19].

Two studies by researchers in the United Kingdom provide a very comprehensive analysis of disability, caregiving, employment and poverty among families with children in the UK. McKay and Atkinson [11] look at a cross-section of families with (a) a disabled adult and/or child and (b) a member with a caring responsibility. The authors find an association between the disability status of parents and children. Child disability has a negative estimated effect on paid work for both single mothers and married mothers; this is primarily the result of a negative effect on full-time work. Most fathers work full-time and there is only a small effect of the child's disability depending on type of disability. Substantial caring responsibilities reduce the odds of employment, but those with caring responsibilities less than 20 hours a week were found to be at least as likely to work as others. Atkinson et al. [1] provides a longitudinal analysis of the relationship between health, disability, caring, and employment in families with children. The authors find that similar portions of working and nonworking parents reported longstanding health conditions among their children, but those who were not working were more likely to describe the condition as limiting. The main choice for parents appeared to be whether to work or not, rather than how many hours. Access to appropriate childcare and the cost of child care were of greater concern to parents of children with long-term conditions than to parents with no such health problems.

We have found no prior study focusing on parental caregiving for children with severe disabilities in the United States. However, there is a substantial body of literature on the broader topic of time use among parents. Guryan et al. [6] use data from the 2003–2006 waves of the American Time Use Survey and find that higher-educated parents spend more time with their children, but they also spend more time working outside of the home. Although the study does not separate parental caregiving specifically related to health care or the child's disabilities, their findings are robust across four subcategories of child care: basic, educational,

recreational, and travel related childcare. Comparing the U.S. results with findings from 14 other countries they find that both within and across countries higher income is associated with more time spent with children. Controlling for other variables, the same holds true for parental education. According to Sayer et al. [18] family structure is an important factor driving time spent by parents with their children. While routine child care has decreased over a roughly 30 year period, a steady increase in more developmental activities more than compensated for it. Grogger and Karoly [5] develop a theoretical framework for analyzing the effects of work-conditioned programs on a broader set of parental and child outcomes, and present some evidence concerning effects on marriage, separation, and divorce among parents, and school performance and behavioral outcomes for the child but do not specifically focus on SSI.

In summary the few prior studies of the effect of childhood disabilities on parental employment in the United States failed to account for the presumed intervening variable – caregiving – and generally contained limited information (if any) on children with disabilities who receive SSI. Our study fills an important gap in both of these areas. Of course, since our data is limited to SSI recipient children, our results are not necessarily generalizable to other groups of disabled children – to children whose disabilities are less severe and/or who live in families with more substantial economic resources than the families of children receiving means-tested SSI benefits.

### 3. Data and methodology

In this section we describe the (a) sample frame; (b) key variables; and (c) data analysis methodology.

#### 3.1. Sample frame

In developing the sample frame for this study we started out with a nationally representative cross-sectional subsample of the NSCF consisting child SSI recipients aged 0 to 17 at a given point in time: December 2000. We excluded observations where the child's living arrangement was living with a single father, other older relative, other people or missing.<sup>2</sup> This resulted

in a sample of 3,041 unweighted observations representing an estimated 659, 227 children with disabilities, 445,555 of which lived with a single mother, and 231, 672 with both parents.<sup>3</sup> Since the focus of the analysis is the relationship between the characteristics of the child and the mother or father, some of the tables and charts in this article provide 3 panels focusing on the three categories of parents: single mothers, married mothers, and married fathers. However, it is important to keep in mind that the basic unit of analysis is the sampled SSI recipient “reference child.” In effect the characteristics of the parents and families are attributes associated with the sampled reference child. We do not present “family level” statistics where the unit of observation would be the family, not the child.

#### 3.2. Variables

This is the first study analyzing NSCF data on the relationship between the disability characteristics of the SSI recipient children and family and nonfamily caregiving provided to them. In this section we briefly discuss the relevant variables. Other variables will be discussed in the results section as needed; most of these have been discussed by Davies and Rupp [2] and Rupp et al. [15]. The interested reader is also encouraged to consult the extensive NSCF documentation; Davies and Rupp [2] provide the necessary reference to the public use file documentation.

The NSCF contains a large number of variables representing various dimensions of the disabling conditions affecting the child. While we cannot present all of these here we use five indicators of reported disabilities in order to capture the multidimensional nature of disabilities. Three of these are “subjective” in the sense of reflecting the respondent's perception and therefore may be affected by variations in judgment across the respondents (typically parents) in addition to “objective” aspects of the child's health and disability status. These subjective measures include (1) a five item scale of the perceived general health status of the child allowing for classification from “poor” to “excellent”; (2) a ten item scale asking respondents to classify the severity of the child's health condition(s) or problem(s) that we collapsed into three categories (high, moderate, and mild) for purposes of presentation; and (3) a question asking respondents to state whether the child's health

<sup>2</sup>The number of observations in these other living arrangement categories was too small for meaningful comparisons.

<sup>3</sup>2,025 of the 3,041 sampled children lived in a single-mother family, while 1,016 in a two-parent family.

condition or problem affects his/her ability to do things a great deal, some, or very little. We also include two more objective indicators: type of disability and the number of functional limitations.<sup>4</sup> Finally, we include a series of questions capturing various aspects of health care utilization that are also fairly objective measures and closely associated with the child's needs for caregiving. Including this array of nine indicators allows us to: (a) characterize the health and disability challenges facing the child – and by implication the caregiver – in ways that are fairly transparent both for analysts and service providers; (b) assess the empirical association of family and nonfamily caregiving with the various indicators; and (c) analyze the independent contribution of these indicators to caregiving and parental employment outcomes using regression models that control for a large number of factors.

The caregiving variables are contained in the “Disability Status and Functional Limitations” and the “Work/Child Care” modules of the NSCF. First we discuss the home health care information included in the disability module. The relevant questions have been asked from respondents representing all child recipients in our sample. Question B52 of the questionnaire reads as follows:

*“Many families provide health care at home such as changing bandages, care of feeding or breathing equipment, transportation to appointments, and giving medication and therapies. Do any family members provide health care at home for <reference child>?”*

Thus the family caregiving variable in the survey is limited to “health care” provided in the “home” by “family members.” This concept is clearly more limited than the notion of “child care;” it is limited to time spent that is related to a health problem of the child. The wording is narrow in that all of the examples refer to health care needs. Nevertheless many respondents probably interpreted this question quite broadly, partly as a result of the question having followed a long section querying about a wide array of disability and health variables, and as a result of clarifications provided by the interviewer. We note that the question is broad in that it is not limited in terms of calendar time;

<sup>4</sup>The number of functional limitations measure is based on a battery of six “activities of daily living” (ADL) questions. The component variables refer to help needed in getting in and out of bed or chair, getting around inside the home, using or getting to toilet, eating, bathing and showering, and dressing. For very young children the need for help in these areas is closely related to their age-specific developmental needs regardless of disability. Therefore the questions were skipped for children aged 5 years or less.

the question simply uses the present tense. Question B52 is followed by a question on hours per week (again, somewhat vague in terms of timing<sup>5</sup>) asked from those who responded to Question B52 in the affirmative. Finally, a third question asks how the family members providing the care are related to the reference child, allowing, but not prompting for, the listing of more than one person. The instrument did not clarify, however, how to account for hours provided by more than one person, perhaps contemporaneously.

Based on the observation of pretest interviews by the principal author of this article<sup>6</sup> we believe that there was some heterogeneity among respondents in the interpretation of what activities may be counted here. In particular, the questionnaire is not clear about the treatment of caregiving co-occurring with other activities, such as cooking, household chores or even sleeping. There are enormous complexities here that would be difficult to address without much more detail in the questionnaire. For example, a parent may need to be around at all hours to intervene when feeding equipment beeps to signal malfunctioning, an event that can occur fairly randomly and also requires immediate action. Such contingencies would not prevent the parent from engaging in other activities in the home (including even market work or sleep). A few respondents actually reported parental home health care activities occurring “all the time” – 168 hours per week. All in all caution is clearly warranted in interpreting our results.<sup>7</sup>

Finally, this section of the questionnaire is concluded by questions on health care provided by people other

<sup>5</sup>The question is: “How many hours per week do family members spend providing this kind of health care for <NAME>?”

<sup>6</sup>Some respondents – parents of children with behavioral disabilities – had difficulty assigning a specific number of hours of family care. Apparently the reason for this was that the respondent felt that the parent(s) had to provide “supervision” in a vague sense all the time, but this was a presence that rarely required specific action. Upon discussion with the interviewer, an answer of “all the time” evolved, and this was coded as 24/7 (168 hours) of care.

<sup>7</sup>Juster and Stafford [8] compared data based on “stylized time use” questions (when interview subjects are asked to estimate the number of hours spent on an activity during a “typical” period of time) with data based on “time diary” data (when respondents are asked to record each activity for a specific spell of time). They found that the “stylized time use” responses are subject to substantial error, with a tendency towards overestimation. It is not entirely clear whether and to what extent these findings apply to the NSCF questions; while the NSCF also asks for a direct estimate of hours of activity, it does not prompt for giving a “typical” estimate. In any event, time use studies are very expensive, and we did not have access to such data for this study.

than family members,<sup>8</sup> and payments (if any) for such care.

The “Work/Child Care” section of the questionnaire asks about “child care” supplied to the reference child, about the provider(s) of this care (including related and unrelated individuals and institutional providers), the location of the care (home or other), payments, satisfaction with child care arrangements, and hours of care. There are three major differences between this battery of questions and the questions in the disability section discussed above. First, the questions in the “Work/Child Care” section are broader – they refer to “child care” without any health-related qualification. Second, the child care questions here are conditional on the survey respondent reporting to have worked, attended school or participated in a training program. Third, the questions are limited to care provided by others while the respondent was working or in school/training and therefore exclude care provided during non-work hours. We also note that the respondent was not necessarily the parent or guardian, although in most cases it was a female parent or guardian.

### 3.3. Data analysis methodology

The empirical analysis is based on descriptive tabulations and reduced form econometric modeling. The descriptive analysis provides a fairly comprehensive picture of various aspects of family and nonfamily caregiving for the reference child, including summary statistics on the prevalence of reported caregiving and hours of caregiving reported. Likewise, we present a comprehensive array of measures related to parental employment. The analytic modeling focuses on the probability of caregiving, parental work and the perceived effects of the presence of the disabled reference child in the family on various work-related household decisions, but does not attempt to model hours of care and market work. We believe that modeling the probability of caregiving and employment is a first natural step of econometric modeling, and we leave the analysis of hours of care and employment that raise a number of complex issues for subsequent studies. Focusing on the probabilities in this first study is further warranted by the measurement problems associated with estimated hours of these activities.<sup>9</sup>

<sup>8</sup>Here the question refers to “last week.”

<sup>9</sup>Juster and Stafford’s [8] study focuses on the comparison of mean hours. It is not immediately obvious whether the measurement of the incidence of any hours of a certain activity during a given time period would be subject to errors of the same magnitude and direction.

Our logit models are reduced form. We look at the effects of a number of predictors that can be reasonably interpreted as exogenous on the probability of caregiving and employment separately. Thus we are not making assumptions about the causal nature of the relationship between caregiving and parental employment. However, our modeling strategy allows for inferences about the relative importance of the predictor variables in affecting caregiving and parental employment. We present estimated odds ratios from the logistic models.

All descriptive data and models use weighted data thereby providing estimates of population relationships.<sup>10</sup> Standard error and statistical significance estimates account for the complex NSCF survey design using the Balanced Repeated Replication (BRR) weights of the survey file.<sup>11</sup> For descriptive tables we present estimated standard errors, but not the results of t-tests for significant differences. One reason is that many different comparisons can be made, and including all of the results of any combination of tests for differences would be overwhelming. However, the tables contain the data necessary to calculate t-tests. In the text we refer to statistically significant differences if the difference is statistically significant at the 5 percent level. The logit tables contain the p-values testing for the significance of the model parameters. We use STATA “svy” procedures for the data analysis to calculate BRR standard errors [17].

## 4. Results

In order to provide a context for the analysis of we first present some descriptive data on the characteristics of the SSI recipient “reference child”. We focus on disability-related variables here since these are the factors that determine the need for caregiving by parents or others. Table 1 presents the disability and health-care utilization characteristics of SSI recipient children living in single-mother and two-parent families. In general, these characteristics are very similar to

<sup>10</sup>Potter and Diaz-Tena [12] provides the details of the three-step process used by the survey contractor, Mathematica Policy Research, Inc (MPR). First, the MPR statisticians developed sampling weights which are simply the inverse of the probability of selection for each survey member. This was adjusted for two sources of nonresponse. Finally, a post-stratification adjustment was made to derive the final analytic weights. A brief summary is provided by Davies and Rupp [2].

<sup>11</sup>See Davies and Rupp [2] for more detail about alternative approaches to account for the complex NSCF survey design.

Table 1  
 Characteristics of the SSI recipient child by living arrangement

Characteristics of the SSI recipient child	Type of child's family					
	Single mother family		Two-parent family		Single mother or two-parent family	
	Percent	Standard error	Percent	Standard error	Percent	Standard error
<b>Overall</b>	100.0%	0.0%	100.0%	0.0%	100.0%	0.0%
<b>Age group</b>						
0 to 5	16.7%	0.4%	20.8%	0.6%	18.1%	0.3%
6 to 12	43.2%	0.5%	41.4%	0.8%	42.6%	0.4%
13–17	40.0%	0.6%	37.8%	0.6%	39.3%	0.4%
<b>Sex</b>						
Male	65.0%	0.4%	62.6%	0.7%	64.2%	0.2%
Female	35.0%	0.4%	37.4%	0.7%	35.8%	0.2%
<b>Reported general health status</b>						
Poor	10.2%	0.5%	6.4%	0.4%	8.9%	0.4%
Fair	32.1%	0.7%	26.6%	0.8%	30.2%	0.5%
Good	33.4%	0.6%	33.4%	0.9%	33.4%	0.4%
Very good	13.6%	0.4%	19.1%	0.6%	15.5%	0.4%
Excellent	10.3%	0.4%	14.2%	0.6%	11.7%	0.3%
Missing	0.3%	0.1%	0.3%	0.1%	0.3%	0.6%
<b>Severity of health condition</b>						
High	54.9%	0.7%	50.4%	0.8%	53.4%	0.6%
Moderate	32.1%	0.6%	35.2%	0.8%	33.2%	0.5%
Mild	8.9%	0.3%	10.1%	0.6%	9.3%	0.3%
No severity reported or missing	4.1%	0.2%	4.3%	0.4%	4.2%	0.2%
<b>Disability affects ability to do things</b>						
A great deal	34.3%	0.7%	40.2%	0.9%	36.3%	0.6%
Some	43.7%	0.7%	38.7%	0.9%	42.0%	0.6%
Very little	18.9%	0.4%	17.6%	0.6%	18.5%	0.4%
No disability reported or missing	3.1%	0.2%	3.5%	0.3%	3.2%	0.2%
<b>Number of functional limitations<sup>1</sup></b>						
None	71.4%	0.5%	69.7%	1.0%	70.8%	0.4%
1	5.1%	0.3%	4.0%	0.3%	4.8%	0.2%
2	8.7%	0.4%	8.6%	0.6%	8.7%	0.2%
3 to 6	14.7%	0.4%	17.7%	0.7%	15.7%	0.3%
<b>Type of disability</b>						
Physical/non-mental	39.0%	0.5%	44.3%	0.7%	40.8%	0.4%
Mental retardation	6.4%	0.3%	5.0%	0.4%	5.9%	0.3%
Behavioral	2.6%	0.2%	2.5%	0.2%	2.6%	0.1%
Other mental	36.8%	0.6%	32.0%	0.8%	35.2%	0.5%
Other	10.1%	0.3%	11.0%	0.6%	10.4%	0.3%
Missing or no condition reported	5.1%	0.3%	5.3%	0.4%	5.1%	0.3%
<b>Number of doctors visits in the past 12 months</b>						
None	6.2%	0.5%	6.1%	0.4%	6.2%	0.2%
1–2	21.6%	0.5%	20.4%	0.8%	21.2%	0.5%
3–4	20.1%	0.5%	17.1%	0.6%	19.1%	0.4%
5 or more	48.8%	0.6%	52.1%	0.9%	49.9%	0.6%
missing	3.4%	0.2%	4.3%	0.4%	3.7%	0.2%
<b>Number of hospitalizations in the past 12 months</b>						
None	80.8%	0.4%	80.0%	0.7%	80.5%	0.4%
1	8.0%	0.4%	8.1%	0.5%	8.1%	0.3%
2	3.9%	0.2%	3.9%	0.3%	3.9%	0.2%
3 or more	6.8%	0.3%	7.1%	0.4%	7.0%	0.3%
missing	0.4%	0.1%	0.8%	0.2%	0.5%	0.1%
<b>Number of surgeries in the past 12 months</b>						
None	82.9%	0.5%	81.0%	0.8%	82.2%	0.4%
1	11.4%	0.5%	13.2%	0.7%	12.0%	0.3%
2	2.6%	0.2%	2.9%	0.3%	2.7%	0.1%
3 or more	2.8%	0.2%	2.6%	0.3%	2.7%	0.2%
Missing	0.4%	0.1%	0.3%	0.1%	0.4%	0.1%

Table 1, continued

Characteristics of the SSI recipient child	Type of child's family					
	Single mother family		Two-parent family		Single mother or two-parent family	
	Percent	Standard error	Percent	Standard error	Percent	Standard error
<b>Emergency room visits in the past 12 months</b>						
None	53.3%	0.6%	57.3%	0.7%	54.7%	0.5%
1 or more	45.5%	0.6%	41.6%	0.7%	44.1%	0.5%
Missing	1.2%	0.1%	1.1%	0.2%	1.2%	0.1%
N <sup>2</sup>	2,025		1,016		3,041	

<sup>1</sup>Based on survey reports of help needed in performing six activities of daily living (getting in and out of bed or chair, getting around inside home, using or getting to toilet, eating, bathing or showering, and dressing). These questions were skipped for children aged 5 years or less. These younger children are included in the category "None" in this table.

<sup>2</sup>Unweighted number of observations for the base of the estimated statistics.

NOTE: Standard errors have been calculated using the Balanced Repeated Replications (BRR) method to account for the complex NSCF survey design.

the distributions presented by Rupp et al. [15] for the full cross-section of children. The data show substantial heterogeneity on the various disability indicators and on various aspects of health care utilization. The disability characteristics are presumably related to the need of the disabled child for care but do not indicate the extent of this need. On the average, a child with 3 or more functional limitations should need more care than a child with no functional limitations at all, but the extent of this difference is not immediately obvious. We will have to make inferences about these differences, with some caveats, from the actual caregiving patterns to be discussed later. The health care utilization variables give a more direct indication of need in that doctor's visits and hospitalizations are bound to require the allocation of specific blocks of time by parents or other caregivers.

The differences between the characteristics of children living with a single mother are not dramatically different from those living with two parents. Looking at differences that are statistically significant we note that children living with two parents are somewhat more likely to be of pre-school age and tend to have a physical disability. Children living with a single parent are more likely to visit the ER, and less likely to visit the doctor's office 3 or more times than children living with both parents, perhaps because two-parent families may be able to get more preventative care than single moms.

We present major study results in three subsections below on: (a) parental and family inputs; (b) patterns of caregiving; and (c) patterns of parental employment and work-related household decisions.

#### 4.1. Parents and family

Table 2 describes the human capital of parents by living arrangement. The bulk of mothers are in their

thirties; the fathers are a little older (3-year difference in median age). The overwhelming majority of parents are at the peak of the age-earnings profile and for women the peak child-bearing years are included as well. Roughly a third of the parents have less than high school education, and a relatively high proportion reports that either the father or the mother has a disability or health condition, with single mothers displaying the highest proportion. Both characteristics point to constraints on the quantity or quality of parental inputs. The labor force participation patterns are quite different by living arrangement. In two-parent families the fathers are about twice as likely to be employed as the mothers, while single mothers fall somewhere in between. Single mothers are much more likely to be in the labor force compared to married moms. The vast majority of those who have worked during the week prior to the reference week were full-time workers. The differences between single and married mothers are not significant, while married fathers are much more likely to work full-time than either married or single mothers and the differences are highly significant. The differences in mean earnings conditional on positive earnings between single and married mothers are statistically not significant, while married fathers have significantly higher earnings than their spouses. All in all these data show two clear advantages for children living in two-parent families: more parental time potentially available for caregiving, and higher earned income potentially available for purchasing nonfamily caregiving or other disability-related expenses. Note however, that – even among married fathers – the rate of labor force participation is relatively low and the level of earnings tends to be low compared to all working-aged



Table 2  
Characteristic of parents of the SSI recipient child by gender and living arrangement

Characteristic of Parents	Gender and type of living arrangement					
	Single Mother		Married Mother in Two-Parent Family		Married Father in Two-Parent Family	
	Statistics	Standard Error	Statistics	Standard Error	Statistics	Standard Error
Total Percent	100.0%	0.0%	100.0%	0.0%	100.0%	0.0%
Age (Percent Distribution)						
29 or less	22.6%	0.6%	20.0%	0.4%	12.6%	0.5%
30–39	49.9%	0.6%	50.1%	0.9%	42.6%	0.8%
40 or more	27.5%	0.6%	30.0%	0.8%	44.8%	0.8%
Mean age	35.5	0.1	35.8	0.1	39.0	0.1
Median age	35.0	n/a	35.0	n/a	38.0	n/a
Parent's Education (Percent Distribution)						
Less than High School	34.3%	0.7%	37.1%	0.7%	39.0%	0.9%
High School/GED	40.5%	0.7%	37.7%	0.9%	37.4%	1.0%
Some College/Vocational	20.4%	0.6%	20.3%	0.7%	14.9%	0.6%
College/Graduate School	2.7%	0.2%	3.9%	0.4%	4.9%	0.4%
Missing	2.1%	0.2%	1.1%	0.2%	3.8%	0.3%
Mother/Father Reported to Have a Disability or Health Condition (Percent)	22.4%	0.7%	17.2%	0.7%	15.1%	0.5%
Labor Force Status (Percent Distribution)						
Currently Employed	43.9%	0.7%	34.0%	0.8%	66.0%	0.8%
Unemployed	17.7%	0.6%	9.7%	0.5%	11.3%	0.6%
Not in Labor Force	36.5%	0.7%	55.9%	0.9%	20.9%	0.7%
Missing	1.9%	0.2%	0.4%	0.1%	1.9%	0.2%
Hours Per Week Among Those With Positive Hours Reported (Percent Distribution)						
1–19	8.9%	0.5%	10.9%	0.9%	2.1%	0.3%
20–34	27.8%	0.9%	26.6%	1.4%	10.8%	0.7%
35+	63.3%	0.9%	62.6%	1.4%	87.1%	0.7%
Mean	34.6	0.2	34.2	0.3	41.9	0.3
Median Hours Among Those With Positive Hours Reported (Hours)	40.0	n/a	40.0	n/a	40.0	n/a
Monthly Earned Income in Dollars Among Those With Positive Reported Earnings (Percent Distribution)						
1–999	32.8%	1.0%	33.7%	1.3%	11.7%	0.7%
1000–1999	55.8%	1.1%	51.8%	1.5%	52.8%	1.0%
2000–2999	9.9%	0.7%	8.9%	0.9%	24.5%	1.0%
3000 or more	1.5%	0.2%	5.6%	0.8%	11.0%	0.6%
Mean	\$ 1,293.9	\$ 13.6	\$ 1,343.6	\$ 28.0	\$ 1,885.5	\$ 23.4
Median Earnings Among Those With Positive Reported Earnings (\$)	\$ 1,250.8	n/a	\$ 1,260.9	n/a	\$ 1,739.2	n/a
N <sup>1</sup>	2,025		1,016		1,016	

<sup>1</sup>Unweighted number of observations for the base of the estimated statistics.

NOTE: Standard errors have been calculated using the Balanced Repeated Replications (BRR) method to account for the complex NSCF survey design.

n/a = not applicable.

adults.<sup>12</sup> On a more optimistic note low employment

rates suggest more parental time potentially available for caregiving.

Table 3 provides information on the family context of the disabled child. Overall we find that children on SSI live in relatively large families. All but a small minority has at least one sibling, and a fairly substantial proportion lives in a family with at least one child aged

<sup>12</sup>Of course this is a selection effect arising primarily from the fact that parental earnings are deemed to children in the SSI financial eligibility determination; children with parents whose earnings are too high to qualify on the SSI means test are not participating in SSI, regardless of disability.

Table 3  
The family context of the disabled child by type of living arrangement

Variable	Type of Living Arrangement					
	Single Mother		Two-Parent		Single Mother or Two-parent Family	
	Percent	Standard Error	Percent	Standard Error	Percent	Standard error
Family Size (Percent Distribution)						
2	16.1%	0.4%	0.0%	0.0%	10.6%	0.3%
3	28.7%	0.5%	12.4%	0.5%	23.1%	0.5%
4	25.3%	0.6%	27.9%	0.9%	26.2%	0.4%
5 or more	29.9%	0.6%	59.8%	0.9%	40.1%	0.6%
Percent with Sibling	78.4%	0.6%	86.1%	0.6%	81.1%	0.4%
Presence of Child Aged 5 or Less						
None	65.9%	0.6%	60.3%	0.9%	64.0%	0.5%
Reference Child Only	10.0%	0.3%	10.7%	0.6%	10.2%	0.2%
Other Child Only	17.4%	0.4%	18.8%	0.8%	17.9%	0.4%
Both	6.8%	0.3%	10.1%	0.4%	7.9%	0.2%
Adults Other Than Parents Present						
Percent with Grandparent	11.2%	0.4%	3.4%	0.3%	8.5%	0.3%
Percent with Adult Other than a Parent or Grandparent Present	20.1%	0.5%	15.4%	0.6%	18.5%	0.4%
Presence of Family Member Other Than Reference Child with Disability or Health Condition (Percent)	46.6%	0.7%	51.1%	0.8%	48.1%	0.5%
Percent with Family Member Other Than the Reference Child Receiving SSI (Percent)	29.3%	0.5%	29.3%	0.8%	29.3%	0.5%
At Least One Parent High School Graduate (Percent)	63.6%	0.8%	75.4%	0.8%	67.7%	0.6%
Family Poverty Status						
Below Poverty Threshold	38.7%	0.7%	19.2%	0.7%	32.0%	0.6%
100–199 Percent of Poverty Threshold	45.8%	0.7%	50.4%	0.8%	47.4%	0.5%
200 Percent of Poverty Threshold or Higher	14.5%	0.6%	29.2%	0.8%	19.5%	0.6%
Missing	0.9%	0.1%	1.3%	0.2%	1.1%	0.1%
Home Ownership (Percent)	26.3%	0.7%	47.9%	0.8%	33.7%	0.6%
N <sup>1</sup>	2,025		1,016		3,041	

<sup>1</sup>Unweighted number of observations for the base of the estimated statistics.

NOTE: Standard errors have been calculated using the Balanced Repeated Replications (BRR) method to account for the complex NSCF survey design.

5 or less. These characteristics suggest that children with disabilities on SSI live in families that have a relatively large need for parental home production, and often may involve child care needs associated with other children. Thus the time budget of the parents available for family caregiving is strained by competing demands. In addition, about half live in a family including at least another disabled person, and many report another SSI recipient in the family. The differences on family variables by living arrangement are significant, with the single exception of the SSI indicator that measures SSI reciprocity by family members other than the reference child. Most of the significant differences are as expected based on differences in family size and composition. The disadvantages of children living in single-mother families in terms of total parental time budget is somewhat mitigated by the lower proportion living in large families with younger siblings, and by the relatively high proportion with a grandparent or

other adult present in the family. Children living in two-parent families are less disadvantaged in terms of the presence of at least one parent who is a high school graduate, higher family income relative to the poverty threshold, and a key indicator of a stable family environment, home ownership.

#### 4.2. Patterns of caregiving

Table 4 describes patterns of family and nonfamily home health care for the disabled SSI recipient child by living arrangement. Our first observation is that home health care is reported only for one third of children living with a single mother, and a significantly higher proportion – not quite reaching half – for children living in two-parent families. Perhaps underreporting contributes to these low rates, but it is likely that even if underreporting bias was to be present a substantial portion of children do not receive any tangible family caregiv-

Table 4  
Patterns of caregiving by living arrangement

Variable	Type of child's family					
	Single mother family		Two-parent family		Single mother or two-parent family	
	Percent	Standard error	Percent	Standard error	Percent	Standard error
Total Percent	100.0%	0.0%	100.0%	0.0%	100.0%	0.0%
Percent reporting positive home health care hours provided by family members last week	34.5%	0.7%	44.7%	1.0%	38.0%	0.6%
Hours per week home health care provided by family members conditional on positive hours reported (Percent distribution)						
1–19	52.5%	1.1%	55.0%	1.4%	53.5%	0.8%
20–34	15.3%	0.9%	14.0%	0.8%	14.8%	0.7%
35 or more	32.1%	1.1%	31.0%	1.3%	31.7%	0.7%
Average hours per week home health care provided by family members among those with positive family caregiving hours (Hours)	36.6	1.1	36.4	1.3	36.5	0.7
Median hours per week home health care provided by family members among those with positive family caregiving hours (Hours)	15	n.a.	14	n.a.	14	n.a.
Mother's reported participation in home health care (Percent distribution)						
Yes	36.3%	0.8%	46.2%	0.9%	39.7%	0.7%
No	63.7%	0.8%	53.8%	0.9%	60.3%	0.7%
Father's reported participation in home health care (Percent distribution)						
Yes	n.a.	n.a.	29.6%	0.8%	n.a.	n.a.
No	n.a.	n.a.	70.4%	0.8%	n.a.	n.a.
Percent reporting positive home health care hours provided by people <i>other than</i> family members last week	11.7%	0.4%	15.5%	0.6%	13.0%	0.3%
Hours per week home health care provided by people <i>other than</i> family members conditional on positive hours reported (Percent distribution)						
1–19	71.4%	1.7%	80.3%	2.3%	75.0%	1.6%
20–34	10.1%	1.0%	7.2%	1.4%	8.9%	0.8%
35 or more	18.5%	1.4%	12.4%	1.9%	16.0%	1.3%
Average hours per week home health care provided by people <i>other than</i> family members among those with positive family caregiving hours (Hours)	17.7	0.9	15.8	1.7	16.9	1.0
Median hours per week home health care provided by people <i>other than</i> family members among those with positive family caregiving hours (Hours)	8	n.a.	5	n.a.	6	n.a.
Pattern of home health care (percent distribution)						
Family care only	27.7%	0.8%	35.6%	0.9%	30.4%	0.6%
Nonfamily care only	4.8%	0.3%	6.4%	0.4%	5.4%	0.2%
Both	6.8%	0.3%	9.1%	0.4%	7.6%	0.2%
Neither	60.7%	0.7%	49.0%	0.9%	56.7%	0.7%
Percent with positive indicator of <i>family payment for nonfamily care</i> provided during previous week	1.4%	0.2%	1.7%	0.2%	1.5%	0.2%
N <sup>1</sup>	2,025		1,016		3,041	

<sup>1</sup>Unweighted number of observations for the base of the estimated statistics.

NOTE: Standard errors have been calculated using the Balanced Repeated Replications (BRR) method to account for the complex NSCF survey design.

ing specifically related to their home health care needs. We also observe that the relatively high prevalence of family caregiving in two-parent families is not only the reflection of caregiving by a minority of fathers, but also that married mothers are more likely to provide more home health care than single mothers. Among those who report positive hours, over half report relatively low hours, but almost a third report care hours essentially equivalent to a full-time job, regardless of living arrangement.<sup>13</sup> Thus caring for the disabled child puts a substantial burden on the time-budget of the families of a nontrivial minority of children on SSI. With respect to home health care provided by people other than family members our major observation is that prevalence is low relative to family care. Again, the prevalence is significantly higher for children in two-parent families. Nonfamily care is dominated by low hours, especially for children in two-parent families, a finding that seems to explain relatively high prevalence in this living arrangement category. Paid care affects only a very small fraction of all children, regardless of living arrangements. Finally, when both family and nonfamily caregiving hours are considered, the prevalence of no reported caregiving is still very high, especially for those living with a single mom. Overall, the data from Table 4 suggest substantial heterogeneity in caregiving hours consumed by children on SSI. Importantly children in two-parent families have a higher probability of receiving both family and nonfamily care. Obviously two adults combined have a time budget twice as large as a single adult; this gives an enormous advantage to children living in two-parent families. The finding also underscores some of the difficult choices single mothers have to make with regards to employment and caregiving.

Forty-seven percent of the respondents for single-mother households report work, school or training during the previous month. The corresponding figure is 38 percent for respondents in two-parent families.<sup>14</sup> The numbers presented here are fairly consistent with the percentages of single and married mothers reporting current employment in Table 2 discussed previously, especially once we account for the fact that a small

fraction of respondents who were “working, attending school or training program” were in school or training – rather than working.

The data presented in Table 5 are all conditional on the respondent “working, attending school or training program.” This table focuses on patterns of care for the disabled child during work hours of the survey respondent. In interpreting the conditional differences we should keep in mind that the proportion of all children with disabilities with a working mother is higher for children living with an unmarried mother than for those living in two-parent families.<sup>15</sup> The vast majority of caregiving provided during the time the respondent was away at work or in school was provided by relatives, with remarkable variation by living arrangement. The reported prevalence of caregiving by unrelated persons (e.g. babysitters) and organized child care facilities combined is 23 percent for children living with a single mother and even lower for children living with both parents. The probability of any childcare provided by others while the respondent is at work is higher among single mothers, while the reverse is true for the conditional mean and median hours. While the overall prevalence of paying for childcare by others during work is fairly small for all children with disabilities, almost one third of children in single-mother families where the respondent was working or in school was subject to paid care. This is interesting, because it sug-

<sup>13</sup>As we noted in the methodology section, some patterns of family caregiving are not neatly amenable to the simple measure of hours of care that was used in this survey. Because of the potential of high outliers of questionable validity that was discussed in that section, the median is clearly a more reliable measure than the mean. We present both.

<sup>14</sup>The 47 and 38 percent figures are based on authors' calculations.

<sup>15</sup>An alternative way to look at the data is to calculate the percent of all children in the given living arrangement category subject to the various kinds of child care arrangements used – *while the mother is working or in school or training*. This perspective is relevant in that it gives a sense of the importance of the various arrangements for SSI children (by living arrangement category). These percentages can be obtained by multiplying the percentages presented in the table by 0.47 and 0.38 for children living with a single mother and for children living with both parents, respectively. The patterns will remain the same within living arrangement category but they will be somewhat different across living arrangement categories because of the difference in the scaling factor. In general, the scaled percentages would show that the importance of the various child care arrangements facilitating parental work is smaller when all children are considered. For example, while the percent in a special care facility while the parent is working or in school is low for both living arrangement categories (1.5 and 1.1 percent, respectively), the corresponding number expressed as a percent of all children is even lower (0.7 and 0.4 percent). Likewise, while 31.9 percent of children of single mothers are cared for by a paid provider – a substantial minority – the corresponding estimate is that only 15 percent of children living with a single mother are subject to the use of paid help to facilitate the mother's employment. Nevertheless the percentages expressed relative to all children are somewhat difficult to interpret as a result of the conditioning, and are subject to the criticism of a possible (slight) downward bias since child care by others while the parent is *not* working or in school is unaccounted for.

Table 5  
Patterns of care arrangements during respondent's work and/or participation in school or training program

Variable and value	Percent of Respondents by Type of Living Arrangement Conditional on Reporting Work, School Attendance or Training During Month Prior to Interview			
	Single Mother Family		Two-Parent Family	
	Statistics	Standard Error	Statistics	Standard Error
Respondents Working, Attending School or Training Program Last Month	100.0%	0.0%	100.0%	0.0%
Conditional on Respondent Report of Working, Participating in School or Training Last Month:				
<b>Who took care of reference child?</b>				
Missing	0.3%	0.1%	1.2%	0.3%
Parent/guardian works only during school hours or works at home	15.6%	0.6%	21.9%	1.1%
Mother/female guardian	6.0%	0.5%	17.0%	1.0%
Father/male guardian	2.0%	0.3%	23.2%	1.3%
Self	6.1%	0.4%	4.1%	0.6%
Sibling	11.9%	0.7%	5.5%	0.7%
Grandparent	21.4%	0.7%	4.8%	0.6%
Aunt/uncle	8.0%	0.6%	3.0%	0.5%
Any other relative	5.8%	0.4%	2.8%	0.5%
Unrelated	11.2%	0.6%	9.7%	1.0%
Day Care Center, Day Camp, Care Provided by School and Any Other of which: day care center or day camp specializing for children with disabilities	11.8%	0.6%	6.8%	0.6%
	1.5%	0.3%	1.1%	0.3%
<b>Where was child cared for most often?</b>				
Percent reporting care outside of reference child's home	17.4%	0.7%	9.7%	0.9%
<b>Childcare hours by others during parent is working away from home</b>				
Percent reporting positive childcare hours by others during prior week	68.0%	1.0%	60.8%	1.5%
Hours of care provided <i>conditional</i> report of positive hours <sup>1</sup>				
1–19	48.8%	1.3%	38.3%	2.0%
20–34	25.3%	0.9%	23.1%	1.7%
35 or more	25.9%	1.0%	38.6%	1.8%
Mean hours <i>conditional</i> on positive hours <sup>1</sup>	22.2	0.4	26.6	0.8
Median hours <i>conditional</i> on positive hours <sup>1</sup>	20	n/a	25	n/a
<b>Payment for childcare by others</b>				
Percent reporting that family paid all	23.1%	0.8%	13.6%	1.1%
Percent reporting that family paid for part	10.1%	0.6%	3.0%	0.4%
Percent reporting positive payment amount	31.9%	0.9%	15.3%	1.1%
N <sup>2</sup>	877		363	

<sup>1</sup>The base for these statistics is the unweighted number of observations satisfying the condition (report of positive hours). For observations in the single mother family column the applicable unweighted count is 582. The corresponding count is 214 for the two-parent family column. Note that for all other statistics the appropriate number of counts is as reported in the N row (877 and 363, respectively).

<sup>2</sup>Unweighted number of observations for the base of the estimated statistics.

NOTE: Standard errors have been calculated using the Balanced Repeated Replications (BRR) method to account for the complex NSCF survey design.

gests that in a certain portion of cases the single mother paid a relative – perhaps a sibling – for care.

Table 6 provides a different perspective; our question here is how family and nonfamily caregiving varies by different aspects of the child's disabilities and health care utilization. The outcome of interest in this table is the percent reporting any health care hours. The percent reporting family care is substantially higher in all statistically significant comparisons with nonfamily care within *each* category of *the entire set* of disability/healthcare utilization indicators. Thus, whether chil-

dren have a high severity condition or a low-severity condition, high or low level of health care utilization, physical or mental disability, the family always plays a more important role in caregiving than other providers as measured by the average probability of any caregiving hours.

There is a positive and statistically significant association between severity and the percent reporting family care hours, but the strength of this association substantially differs by disability measure. A relatively high proportion reports positive family care hours for

Table 6  
Family and nonfamily caregiving by characteristics of disabled SSI recipient child

Characteristics of the SSI Recipient Child	N <sup>1</sup>	Positive health care hours last week provided by:			
		Family members		Others	
		Percent	Standard error	Percent	Standard error
<b>Overall</b>	3,041	38.0%	0.6%	13.0%	0.3%
<b>Reported general health status</b>					
Poor	280	40.4%	1.6%	16.6%	1.6%
Fair	933	42.6%	1.1%	12.8%	0.5%
Good	1,034	34.6%	0.8%	12.2%	0.5%
Very good	458	40.1%	1.4%	10.9%	0.9%
Excellent	327	31.2%	1.4%	15.0%	1.2%
Missing	9	...	...	...	...
<b>Severity of health condition</b>					
High	1,632	44.9%	0.8%	16.7%	0.5%
Moderate	1,015	34.8%	0.9%	10.2%	0.5%
Mild	274	21.1%	1.6%	5.5%	0.7%
No severity reported or missing	120	12.3%	1.8%	4.5%	1.1%
<b>Disability affects ability to do things</b>					
A great deal	1,087	51.2%	1.1%	19.0%	0.7%
Some	1,298	35.2%	0.7%	10.6%	0.4%
Very little	556	23.9%	1.1%	7.7%	0.6%
No disability reported or missing	100	6.5%	0.9%	4.7%	1.4%
<b>Number of functional limitations<sup>2</sup></b>					
None	2,219	31.4%	0.6%	11.0%	0.3%
1	151	48.0%	2.3%	13.2%	1.5%
2	255	42.9%	2.0%	10.2%	1.3%
3 to 6	416	61.6%	1.3%	23.1%	1.1%
<b>Type of disability</b>					
Physical/non-mental	1,111	49.0%	1.0%	15.9%	0.5%
Mental retardation	192	30.8%	1.4%	6.9%	0.9%
Behavioral disorders	91	21.4%	2.4%	4.5%	1.4%
Mental disorders nos	1,205	31.6%	0.9%	12.6%	0.6%
Other	290	34.2%	1.5%	12.1%	0.8%
Missing or no condition reported	152	18.1%	1.7%	5.2%	1.1%
<b>Number of doctors visits in the past 12 months</b>					
None	213	16.3%	2.4%	2.2%	0.4%
1-2	678	23.4%	0.9%	5.8%	0.7%
3-4	594	32.2%	1.1%	9.6%	0.7%
5 or more	1,451	49.9%	0.9%	17.7%	0.5%
missing	105	23.8%	2.0%	25.6%	2.3%
<b>Number of hospitalizations in the past 12 months</b>					
None	2,503	34.7%	0.7%	11.2%	0.4%
1	225	50.5%	2.0%	12.6%	1.3%
2	111	51.0%	2.5%	18.4%	1.9%
3 or more	186	56.1%	2.0%	30.6%	1.9%
Missing	16	...	...	...	...
<b>Number of surgeries in the past 12 months</b>					
None	2,547	34.9%	0.7%	11.1%	0.3%
1	334	49.6%	1.7%	18.0%	1.0%
2	78	53.6%	3.4%	34.9%	2.9%
3 or more	72	63.9%	3.0%	25.2%	2.8%
Missing	10	...	...	...	...
<b>Emergency room visits in the past 12 months</b>					
None	1,708	31.3%	0.8%	10.5%	0.5%
1 or more	1,299	46.6%	0.8%	16.0%	0.5%
Missing	34	...	...	...	...

<sup>1</sup>Unweighted number of observations for the base of the estimated statistics.

<sup>2</sup>Based on survey reports of help needed in performing six activities of daily living (getting in and out of bed or chair, getting around inside home, using or getting to toilet, eating, bathing or showering, and dressing. These questions were skipped for children aged 5 years or less. These younger children are included in the category "None" in this table.

Standard errors have been calculated using the Balanced Repeated Replications (BRR) method to account for the complex NSCF survey design. Statistics based on less than 50 observations is not presented. The cell entries in these cases contain a string of dots (...)

children with physical disabilities, and a strikingly low portion for children with behavioral disorders.<sup>16</sup> We find that various measures of health care utilization are strongly associated with the probability of family caregiving. The relationship between the child's disabilities and nonfamily caregiving are fairly similar, except for the generally lower prevalence of nonfamily caregiving and the lack of a clear association between reported general health status and the probability of nonfamily care. Still, nonfamily caregiving is reported for almost a third of children experiencing 3 or more hospitalizations in the last 12 months. Generally, the relationship between disability and health care utilization indicators and the report of family caregiving hours of 35 or more conditional on reporting *any* family caregiving (statistics not shown) is similar to the patterns observed for the prevalence of family caregiving. This is remarkable given that the probability of caregiving and hours conditional on any caregiving are multiplicative: expected caregiving hours are a product of these two.

Table 7 presents the results of logistic models of factors affecting the presence of positive caregiving hours. All three models (Models 1 through 3) in the table give the relative odds of caregiving as a function of the disability and health care utilization variables. We also include indicators of the child being aged 0 to 5 and male in all models. Model 3 also includes parental and family characteristics as predictors.<sup>17</sup> In general, most disability-related odds are expressed relative to a "reference category" (indicating no disability on the specific variables) holding all other variables constant. For example, Model 1 estimates that having 3 or more functional limitations in itself increases the odds of reporting family and/or nonfamily caregiving threefold (odds ratio of 3.06). With respect to type of disability the odds are expressed relative to a child having a physical disability. For example, we estimate that having a "behavioral disability" roughly halves the odds of caregiving relative to having a physical disability (odds ratio of 0.48) holding all other variables constant.

Looking at Model 1 which focuses on the probability of any caregiving regardless of source (i.e. considering both family and nonfamily caregiving) our major observation is that most of the estimates are highly

significant, and have the expected sign. Controlling for other factors the odds of positive caregiving are especially high for children with 3 or more ADLs, for children whose functioning is perceived to be affected "a great deal" and for those with 5 or more doctors' visits. Children with mental disabilities consistently experience lower odds of caregiving than children with physical disabilities. The one important exception to our prior expectations is that children who are reported to be in "poor health" are significantly less likely to receive caregiving than otherwise similar children who are not reported to be in poor health. This finding qualitatively differs from the gross association reported in Table 6. The main reason, we think, is that reported general health status is a highly subjective indicator. Also, the findings are consistent with the notion that it is not simply "poor health" but the various functional limitations or health care utilization needs of the child in poor health that drive the need for caregiving.

The next two models in Table 7 present the results for family (Model 3) and nonfamily (Model 2) caregiving separately. The family and nonfamily caregiving models are similar in most respects, but there are some notable differences. In particular, the relative odds of caregiving for a child with "other mental disability" is opposite for the two caregiving sources, both estimates being highly significant. Another marked contrast involves the variable measuring the parent's perception concerning the degree to which the disability affects the child's functioning. This appears to have a strong positive association with family caregiving, but not with nonfamily caregiving. A possible reason may be that this variable picks up the parent's taste for caregiving, but it is also conceivable that it picks up aspects of everyday *family* caregiving needs that are not captured by other severity indicators. Finally, 3 or more hospitalizations increase the odds of nonfamily caregiving substantially, while it has only a modest effect on family caregiving. This also makes sense since the model includes other indicators affecting the need for family care, while the round-the-clock care provided by hospitals to some extent acts as a substitute of caregiving in the family setting.

Finally, Model 3 adds parent and family variables that *are not* inherently tied to caregiving "need" – in contrast to the child disability and health care utilization variables that *are* – but may in fact affect the supply of family caregiving for other reasons. First, we find that the addition of these variables has virtually no effect on the disability and health care utilization coefficients. Second, we find some strong relationships – all

<sup>16</sup>Hemmeter, Kauff and Wittenburg [7] find that children with behavioral disorders are more likely to get into trouble than other children on SSI. Our finding here provides a possible reason – insufficient attention at home.

<sup>17</sup>Note that the coefficients on the disability and health care utilization variables are robust to the addition of these predictors.

Table 7  
Estimated odds ratios from logistic regressions on factors affecting caregiving

Characteristics	Estimated odds ratios from logit regressions of probability of reporting positive caregiving hours					
	Model 1		Model 2		Model 3	
	Family and/or nonfamily care		Nonfamily care		Family care	
	Odds Ratio	P >  t	Odds Ratio	P >  t	Odds Ratio	P >  t
<i>SSI recipient child demographic characteristics</i>						
Reference child aged 0 to 5	1.96	0.000	2.11	0.000	1.62	0.000
Male reference child	1.08	0.071	1.09	0.123	1.03	0.452
<i>Disability indicators of SSI recipient child</i>						
Mental retardation	0.60	0.000	0.61	0.005	0.64	0.000
Behavioral disability	0.48	0.000	0.44	0.039	0.42	0.000
Other mental disability	0.76	0.000	1.19	0.017	0.66	0.000
Other condition	0.62	0.000	0.88	0.160	0.59	0.000
Missing or no condition	0.72	0.029	0.51	0.003	0.73	0.028
1 adl limitation <sup>1</sup>	1.91	0.000	1.38	0.027	2.12	0.000
2 adl limitations <sup>1</sup>	1.65	0.000	0.98	0.874	1.70	0.000
3 or more adl limitations <sup>1</sup>	3.06	0.000	2.05	0.000	2.71	0.000
High severity reported	1.16	0.018	1.30	0.000	1.19	0.005
Always limited	2.13	0.000	2.09	0.000	1.80	0.000
Usually limited	1.97	0.000	1.88	0.001	1.55	0.000
Sometimes limited	1.57	0.000	1.46	0.022	1.45	0.001
Disability affects great deal	3.88	0.000	0.96	0.915	4.99	0.000
Disability affects some	2.85	0.000	0.76	0.492	3.87	0.000
Disability affects very little	1.85	0.016	0.60	0.215	2.52	0.000
Poor health	0.72	0.000	0.79	0.071	0.68	0.000
<i>Health care utilization by SSI recipient child</i>						
1 or 2 doctors visits	0.96	0.566	0.51	0.000	1.31	0.014
3 or 4 doctors visits	1.38	0.000	0.79	0.131	1.73	0.000
5 or more doctors visits	2.29	0.000	1.16	0.178	2.68	0.000
1 hospitalization	1.13	0.219	0.77	0.091	1.26	0.022
2 hospitalizations	1.04	0.748	0.93	0.696	1.10	0.407
3 or more hospitalizations	1.57	0.000	1.97	0.000	1.20	0.040
1 surgery	1.22	0.007	1.28	0.013	1.16	0.056
2 surgeries	1.32	0.096	2.64	0.000	0.97	0.840
3 or more surgeries	1.71	0.001	1.20	0.300	1.63	0.001
Any emergency room visit	1.15	0.007	1.00	0.953	1.31	0.000
<i>Parental and family characteristics</i>						
Two-parent family	×	×	×	×	1.44	0.000
Grandparent present	×	×	×	×	1.04	0.599
Other adult present	×	×	×	×	1.28	0.000
Other child aged 0 to 5	×	×	×	×	0.89	0.078
Other child aged 13 or over	×	×	×	×	0.96	0.429
High school graduate parent	×	×	×	×	1.22	0.001
College (at least some) educated parent	×	×	×	×	1.78	0.000
Disabled parent	×	×	×	×	1.29	0.000
Other disabled person in family	×	×	×	×	0.95	0.453

<sup>1</sup>Since the functional limitations questions were skipped for children aged 0 to 5 the activities of daily living (adl) variable value of "1" (yes) is conditional on the child being 6 to 17 years of age.

NOTE: Standard errors have been calculated using the Balanced Repeated Replications (BRR) method to account for the complex NSCF survey design.

highlighting the importance of the family environment. Better parental education is a key variable here: the odds of family caregiving are about 80 percent higher for children with at least one parent who has post-high-school education when compared to parent(s) who did not graduate from high school (the reference category). Importantly, living in a two-parent family increases the odds of family caregiving by almost 50 percent. We

also find that the presence of an adult other than the parent(s) or a grandparent increases the odds of caregiving. In contrast – as expected – having another child who is aged 0 to 5 or another disabled person in the family reduces the odds of caregiving. These variables indicate the importance of parental and family inputs and competing needs for caregiving. Finally, the presence of a disabled parent increases the odds of



Table 8  
Parental employment by the characteristics of disabled SSI recipient child

Characteristics of the SSI Recipient Child	Percent reporting any employment hours					
	Single mother		Two-parent family			
	Percent	Standard error	Mother		Father	
Percent			Standard error	Percent	Standard error	
<b>Overall</b>	43.2%	0.7%	30.6%	0.8%	63.1%	0.7%
<b>Reported general health status</b>						
Poor	32.6%	1.9%	19.6%	2.8%	57.4%	2.5%
Fair	41.4%	1.1%	28.8%	1.5%	57.3%	1.6%
Good	42.8%	1.0%	32.0%	1.2%	63.2%	1.4%
Very good	51.2%	2.0%	33.3%	1.6%	69.7%	2.0%
Excellent	51.0%	2.0%	32.9%	2.4%	67.9%	2.1%
Missing	...	...	...	...	...	...
<b>Severity of health condition</b>						
High	42.1%	1.0%	32.6%	1.2%	61.6%	1.0%
Moderate	47.7%	1.2%	29.5%	1.4%	65.3%	1.4%
Mild	34.9%	2.0%	30.4%	2.4%	63.1%	2.6%
No severity reported or missing	41.8%	3.3%	...	...	...	...
<b>Disability affects ability to do things</b>						
A great deal	43.5%	1.0%	34.3%	1.2%	65.7%	1.3%
Some	44.1%	1.0%	30.3%	1.3%	61.7%	1.2%
Very little	40.9%	1.4%	25.4%	2.1%	60.8%	2.1%
No disability reported or missing	41.5%	4.0%	...	...	...	...
<b>Number of functional limitations<sup>1</sup></b>						
None	43.3%	0.7%	31.2%	0.9%	62.4%	1.0%
1	45.1%	3.0%	...	...	...	...
2	40.1%	2.5%	32.4%	2.8%	57.7%	2.9%
3 to 6	44.1%	1.4%	27.5%	2.5%	66.6%	2.3%
<b>Type of disability</b>						
Physical/non-mental	45.2%	0.9%	33.3%	1.5%	67.7%	1.1%
Mental retardation	46.1%	2.2%	21.0%	3.7%	52.4%	4.4%
Behavioral	39.3%	3.7%	...	...	...	...
Other mental	41.0%	1.0%	31.4%	1.4%	57.3%	1.7%
Other	46.2%	2.0%	24.6%	2.4%	65.1%	2.8%
Missing or no condition reported	36.2%	3.1%	22.3%	3.5%	72.1%	4.3%
<b>Number of doctors visits in the past 12 months</b>						
None	44.7%	2.4%	29.4%	2.8%	56.8%	3.9%
1–2	41.6%	1.3%	24.4%	1.5%	59.7%	1.8%
3–4	45.8%	1.3%	29.1%	1.8%	65.6%	2.2%
5 or more	43.7%	1.1%	34.1%	1.3%	64.2%	1.0%
missing	29.1%	2.5%	...	...	...	...
<b>Number of hospitalizations in the past 12 months</b>						
None	43.5%	0.7%	30.5%	0.7%	62.4%	0.9%
1	45.3%	2.3%	33.6%	3.4%	64.8%	2.7%
2	39.9%	3.4%	...	...	...	...
3 or more	40.4%	2.7%	28.9%	2.6%	70.3%	2.9%
missing	...	...	...	...	...	...
<b>Number of surgeries in the past 12 months</b>						
None	43.1%	0.7%	30.3%	0.9%	62.7%	0.8%
1	41.9%	2.0%	33.5%	2.5%	66.0%	2.0%
2	57.2%	3.7%	...	...	...	...
3 or more	...	...	...	...	...	...
Missing	...	...	...	...	...	...
<b>Emergency room visits in the past 12 months</b>						
None	43.6%	0.9%	31.3%	0.9%	65.5%	1.1%
1 or more	43.6%	1.0%	29.8%	1.3%	59.4%	1.1%
Missing	...	...	...	...	...	...

<sup>1</sup>Based on survey reports of help needed in performing six activities of daily living (getting in and out of bed or chair, getting around inside home, using or getting to toilet, eating, bathing or showering, and dressing. These questions were skipped for children aged 5 years or less. These younger children are included in the category "None" in this table.

NOTE #1: Standard errors have been calculated using the Balanced Repeated Replications (BRR) method to account for the complex NSCF survey design.

Table 8, continued

NOTE #2: For the number of unweighted cases forming the basis of the percentages presented in this table the reader may want to consult Appendix Table 1. Statistics based on less than 50 observations not presented. The cell entries in these cases contain a string of dots (...).

positive family care hours reported. Whether this is the result of lower labor supply among disabled parents or other factors is not immediately obvious. All in all parental and family inputs and competing needs substantially affect the probability of family caregiving, and thus the quality of the disabled child's life.

#### 4.3. Factors affecting parental employment and work-related household decisions

In the previous section we have seen that in general, the severity of the child's disabilities is positively associated with family and nonfamily caregiving, and a substantial minority of children on SSI receive family care that is equivalent to full-time work. Is there a similar relationship between severity of the child's disability and parental employment? This is an important question, since family caregiving may be provided at the expense of parental employment. Alternatively, family caregiving (a form of nonmarket work) may just add to the total burden on the parent's time budget. There are an infinite number of possible combinations of these extreme scenarios. Since the gross time budget available for mothers and fathers in two-parent families is always larger than the time available for single parents, in Table 8 we present data on parental employment for single mothers, married mothers, and married fathers separately. The table provides information on the association between various indicators of the severity of the child's disability, living arrangements, and the probability of parental employment. When we compare the probability of parental employment by living arrangement and gender within categories formed by our array of child disability and health care utilization variables, fairly straightforward and strong patterns emerge. Single mothers are more likely to be employed than married mothers, while married fathers are more likely to be employed than either their spouses or single mothers regardless of the disability-health care utilization category. When we restrict ourselves to the probability of full-time employment conditional on working (data not shown) we no longer find consistent and statistically significant differences among single and married mothers, but married fathers are clearly more likely to work full-time than either married mothers or single mothers across the board.

In contrast to these straightforward differences by living arrangement and gender, we find only weak ev-

idence of consistent and statistically significant differences in the probability of employment of the mother and/or father by the severity of the child's disabilities and health care utilization variables. The only severity indicator that shows a clear pattern of the expected negative association with the probability of parental employment is the reported general health status of the child. Mothers and/or fathers are significantly more likely to be employed if the child is reported to be in "excellent health" compared to "poor health." However, we fail to observe a clear and consistent pattern of differences in the probability of parental employment and the other severity indicators. Nor do we find a clear relationship between health care utilization variables and parental employment.<sup>18</sup>

Table 9 presents the results of multivariate models of factors affecting the probability of parental employment. In general, compared to the caregiving models, a relatively small number of *disability related variables* are statistically significant, and some of them indicate a counterintuitive direction. For single mothers (Model 1), the estimates for two subjective indicators – reported degree of the effect of the child's disability on his/her ability to do things and his/her poor health – reduce the probability of maternal employment. But the more objective indicators do not show a clear pattern. The patterns for married mothers (Model 2) and married fathers (Model 3) are more complex.<sup>19</sup> What is most clear from this table is that the probability of parental employment seems to be driven by variables essentially *unrelated to the severity of the child's disability*: presence of a child (the reference child or a sibling) who is aged 0 to 5, parental education, the presence of a disabled parent or other family member, and the presence of a grandparent. Most of these variables have opposite relationships to family caregiving and the probability of maternal employment (negative

<sup>18</sup>Interestingly when we look at full-time employment conditional on any employment (data not shown), we find a clear negative relationship with the severity of the child's disabilities for single mothers, a finding suggesting the challenges arising from the lack of a spouse to share the burdens of childcare and employment.

<sup>19</sup>In several cases the direction of odds ratios show the opposite pattern for married mothers and married fathers (one is larger than 1, while the other is smaller). This may be the result of a certain degree of complementarity in the way married parents adjust to having a disabled child.

Table 9  
Estimated odds ratios from logit regressions of probability of reporting parental employment

Characteristics	Estimated odds ratios from logit regressions of probability of reporting parental employment							
	Model 1		Model 2		Model 3		Model 4	
	Single mother		Married mother		Married father		Either mother or father (two-parent family)	
	Odds Ratio	P >  t	Odds Ratio	P >  t	Odds Ratio	P >  t	Odds Ratio	P >  t
<i>SSI recipient child demographic characteristics</i>								
Reference child aged 0 to 5	0.75	0.001	0.96	0.726	1.39	0.002	1.14	0.210
Male reference child	0.90	0.128	1.15	0.258	0.87	0.126	0.95	0.615
<i>Disability indicators of SSI recipient child</i>								
Mental retardation	1.09	0.456	0.84	0.542	0.76	0.209	0.97	0.856
Behavioral disability	0.93	0.661	1.71	0.135	0.62	0.053	1.22	0.533
Other mental disability	0.85	0.031	1.05	0.642	0.87	0.259	0.90	0.424
Other condition	1.03	0.786	0.62	0.009	1.06	0.720	0.99	0.970
Missing or no condition	0.38	0.000	0.62	0.042	2.36	0.003	1.61	0.127
1 adl limitation <sup>1</sup>	1.26	0.109	0.70	0.057	1.00	0.993	0.67	0.106
2 adl limitations <sup>1</sup>	0.75	0.021	0.85	0.321	0.69	0.019	0.97	0.868
3 or more adl limitations <sup>1</sup>	0.92	0.306	0.61	0.000	1.00	0.984	0.89	0.469
High severity reported	0.95	0.468	0.99	0.940	0.82	0.021	0.96	0.734
Always limited	1.05	0.733	1.90	0.000	1.07	0.780	1.33	0.240
Usually limited	1.11	0.472	0.81	0.143	0.87	0.481	1.01	0.963
Sometimes limited	0.97	0.815	0.92	0.594	0.81	0.240	0.96	0.814
Disability affects great deal	0.52	0.010	1.50	0.116	4.73	0.000	5.04	0.000
Disability affects some	0.56	0.014	1.78	0.028	4.48	0.000	4.88	0.000
Disability affects very little	0.50	0.002	1.53	0.075	3.72	0.000	3.59	0.001
Poor health	0.73	0.006	0.47	0.002	1.02	0.897	0.71	0.006
<i>Health care utilization by SSI recipient child</i>								
1 or 2 doctors visits	0.92	0.417	0.71	0.059	1.19	0.402	1.12	0.575
3 or 4 doctors visits	1.07	0.575	0.90	0.476	1.59	0.017	1.58	0.005
5 or more doctors visits	1.04	0.716	1.29	0.086	1.38	0.026	1.45	0.009
1 hospitalization	1.01	0.963	1.27	0.126	1.18	0.393	1.58	0.018
2 hospitalizations	0.64	0.010	0.97	0.911	0.98	0.939	0.58	0.008
3 or more hospitalizations	0.76	0.070	0.80	0.239	1.16	0.406	0.99	0.934
1 surgery	0.99	0.917	1.00	0.977	0.99	0.958	0.98	0.870
2 surgeries	1.81	0.001	1.52	0.113	0.87	0.557	1.01	0.978
3 or more surgeries	1.31	0.154	0.22	0.000	0.96	0.854	0.81	0.390
Any emergency room visit	1.11	0.084	0.88	0.131	0.64	0.000	0.66	0.000
<i>Parental and family characteristics</i>								
Grandparent present	0.94	0.526	0.24	0.000	2.19	0.010	1.35	0.330
Other adult present	0.92	0.275	0.97	0.810	0.69	0.003	0.72	0.022
Other child aged 0 to 5	0.65	0.000	0.70	0.001	1.08	0.416	0.91	0.325
Other child aged 13 or over	1.09	0.266	1.37	0.002	1.16	0.149	1.07	0.483
High school graduate mother <sup>2</sup>	2.38	0.000	1.50	0.000	1.48	0.000	2.28	0.000
College (at least some) educated mother <sup>3</sup>	3.53	0.000	2.09	0.000	1.71	0.000	2.91	0.000
High school graduate father	×	×	2.17	0.000	1.47	0.001	×	×
College (at least some) educated father	×	×	1.57	0.001	1.91	0.000	×	×
Disabled mother <sup>4</sup>	0.12	0.000	0.18	0.000	0.92	0.524	0.18	0.000
Disabled father	×	×	0.88	0.384	0.10	0.000	×	×
Other disabled person in family	0.60	0.000	0.54	0.000	0.74	0.008	0.55	0.000

NOTE: Standard errors have been calculated using the Balanced Repeated Replications (BRR) method to account for the complex NSCF survey design.

<sup>1</sup>Since the functional limitations questions were skipped for children aged 0 to 5 the activities of daily living (adl) variable value of "1" (yes) is conditional on the child being 6 to 17 years of age.

<sup>2</sup>In Model 4 variable refers to presence of high school graduate mother and/or father.

<sup>3</sup>In Model 4 variable refers to presence of college (at least some) educated mother and/or father.

<sup>4</sup>In Model 4 variable refers to presence of disabled mother and/or father.

for one, positive for the other), but there is a notable exception. Parent's *education* is positively associated with both family *caregiving* and parental *employment*. This is a strong relationship. For children liv-

ing with a single mother, the mother having at least some college education increases the odds of maternal employment 3.5 times compared to the mother being a high-school dropout. For children living in two-parent

families (using the indicator of at least one parent having at least some college education) the comparable relationship is somewhat weaker (odds ratio = 2.91) but still highly significant. This suggests a substantially stronger relationship between parental employment and education than was estimated in the family caregiving model (odds ratio = 1.78, Table 7) applied to all children (recipients living either with a mother or in a two-parent family combined). The parent's reported disability substantially reduces the probability of employment. Importantly, having another disabled person in the family is associated with reduced employment probabilities across the board. There are some notable differences in the results for single mothers (Model 1) and for parents in two-parent families (Models 2 and 3). For example, having a reference child aged 0 to 5 significantly reduces the odds of employment among single mothers. The corresponding estimate is not significant for married mothers, but there is a highly significant positive relationship with the probability of paternal employment. In general, two-parent families have more flexibility.

All in all the results show only a modest and occasionally inconsistent association between the severity of the child's disabilities and parental employment, while clearly indicate the importance of variables that are unrelated to the child's disabilities as determinants of the probability of parental employment.

Finally, Table 10 presents the results of multivariate models of the perceived role of the child's disability on work-related household decisions. The NSCF survey contains a battery of questions querying whether for "reasons related to (REFERENCE CHILD'S) health has **anyone** in the household **ever**" made various presumably negative work related decisions, including not taking a job, quit working, changing jobs, changing work hours and turning down a better job.<sup>20</sup> Overall, a fairly high proportion of respondents had an affirmative answer on these questions.<sup>21</sup> The responses may reflect subjective perceptions about causation as opposed to hard facts. Our multivariate analysis was designed to address two aspects of this concern:

- First, is there a clear association between various indicators of the severity of the child's disabilities and health care utilization and the response to these five questions?
- Second, can we identify factors that seem to affect the answer to the five questions, but reflect factors not intrinsically related to the child's disabilities?

There is some variability by the specific question (e.g. quit working versus changed work hours) and the predictor variable, but the overall patterns are fairly consistent (most of the significant estimates make sense and have similar patterns across the different questions), and pretty straightforward answers emerge with respect to our two questions. With respect to the first question our main finding is that there is indeed a clear association between many of the severity and health care utilization predictors – both subjective and more objective indicators – and the predicted work-related decision in the expected direction (more severity  $\Rightarrow$  higher reported incidence of "negative" work-related decisions). Interestingly, the child having mental retardation, behavioral or other mental disability reduces the reported incidence of most negative work-related decisions compared to the physical disabilities reference category. Surprisingly, one of our most subjective predictors (poor health) is not statistically significantly associated with any of the work-related indicators except turning down a job offer. The gist of our findings here is that they provide some face validity to the work-related decision questions. However, in our judgment the results are far from providing strong evidence for a causal effect – especially given the seemingly weaker relationships between severity of the child's disability and the probability of parental employment and the probability of full-time work. With respect to the second question the overall finding is that the responses to the work-related questions are clearly influenced by factors that are not intrinsically related to the reference child's disabilities. Having a college-educated parent, for example, clearly increases the odds of an affirmative answer on all of the work-related indicators.<sup>22</sup> In contrast, having a disabled parent reduces the odds of reporting a work-related decision.<sup>23</sup> These findings

<sup>20</sup>The exact wording of the questions was: For reasons related to (NAME's) health, has anyone in the household ever: A. Not taken a job in order to care for (NAME)? B. Quit working other than normal maternity leave? C. Changed jobs? D. Changed work hours to a different time of the day? E. Turned down a better job or promotion?

<sup>21</sup>Overall, 36.6 percent reported that someone in the household had not taken a job for reasons related to the child's health. The corresponding percentages for quit working, changing jobs, changing hours, and turning down a better job were 27.0, 19.1, 31.6 and 16.4.

<sup>22</sup>This should not be surprising, but the exact reasons are unclear. For example, college educated parents are more likely to be employed to start with than others. They may have more, and more complex, work-related options, and so on. But perceptions may also be highly correlated with education in ways that seem difficult to predict.

<sup>23</sup>There are a variety of possible explanations for this finding. Perhaps the most plausible is that disabled parents have lower employment probabilities to start with.

Table 10

Estimated odds ratios from logistic regressions on factors affecting the perceived role of the child's disability and other parental and family variables on work-related household decisions

Characteristics	Odds ratios from logit regressions of probability of various work-related (parental <sup>2</sup> ) decisions arising from the child's disability status and other variables									
	not taken job		quit working		changed jobs		changed work hours		turned down job	
	Odds Ratio	P >  t	Odds Ratio	P >  t	Odds Ratio	P >  t	Odds Ratio	P >  t	Odds Ratio	P >  t
<i>SSI recipient child demographic characteristics</i>										
Reference child aged 0 to 5	1.53	0.000	1.20	0.012	0.97	0.773	0.99	0.935	1.11	0.170
Male reference child	1.01	0.888	1.10	0.030	1.04	0.519	0.93	0.167	1.01	0.861
<i>Disability indicators of SSI recipient child</i>										
Mental retardation	0.82	0.076	0.81	0.037	0.69	0.023	0.88	0.178	0.73	0.032
Behavioral disability	0.49	0.000	0.44	0.000	0.67	0.087	0.77	0.109	0.78	0.313
Other mental disability	0.70	0.000	0.78	0.000	0.92	0.271	1.26	0.000	1.00	0.970
Other condition	0.85	0.059	0.81	0.012	0.63	0.000	0.97	0.656	1.13	0.290
Missing or no condition	0.99	0.973	0.70	0.068	0.93	0.731	0.96	0.813	0.64	0.063
1 adl limitation <sup>1</sup>	1.09	0.285	1.46	0.005	1.23	0.058	1.33	0.006	1.50	0.000
2 adl limitations <sup>1</sup>	1.66	0.000	1.69	0.000	1.06	0.522	1.07	0.461	0.93	0.506
3 or more adl limitations <sup>1</sup>	2.12	0.000	1.68	0.000	1.30	0.002	1.33	0.000	1.76	0.000
High severity reported	1.15	0.009	1.18	0.006	1.22	0.002	1.16	0.006	1.40	0.000
Always limited	1.75	0.000	1.91	0.000	1.94	0.000	2.69	0.000	2.57	0.000
Usually limited	1.90	0.000	2.36	0.000	1.84	0.000	2.32	0.000	2.73	0.000
Sometimes limited	1.14	0.169	1.59	0.001	1.45	0.008	1.67	0.000	1.83	0.002
Disability affects great deal	2.17	0.003	1.18	0.533	0.92	0.784	1.11	0.642	3.19	0.035
Disability affects some	1.95	0.009	1.02	0.930	1.06	0.833	1.16	0.511	2.90	0.051
Disability affects very little	1.35	0.248	0.75	0.268	0.57	0.080	0.93	0.735	2.26	0.109
Poor health	1.08	0.266	1.09	0.330	1.05	0.626	0.91	0.320	1.24	0.045
<i>Health care utilization by SSI recipient child</i>										
1 or 2 doctors visits	1.46	0.000	1.16	0.179	1.05	0.634	1.13	0.288	0.85	0.136
3 or 4 doctors visits	1.70	0.000	1.51	0.001	1.40	0.005	1.40	0.004	0.86	0.265
5 or more doctors visits	2.23	0.000	1.94	0.000	1.43	0.001	1.54	0.000	1.10	0.358
1 hospitalization	1.01	0.908	1.06	0.480	1.16	0.049	1.10	0.268	1.10	0.413
2 hospitalizations	1.31	0.014	0.99	0.961	1.01	0.908	1.17	0.327	1.23	0.095
3 or more hospitalizations	1.13	0.220	1.05	0.586	0.97	0.720	1.34	0.002	1.76	0.000
1 surgery	1.00	0.989	1.04	0.642	0.84	0.022	1.21	0.007	1.11	0.202
2 surgeries	1.04	0.808	1.10	0.529	1.53	0.004	1.76	0.000	1.72	0.002
3 or more surgeries	1.68	0.001	1.92	0.000	1.11	0.469	0.87	0.329	1.25	0.207
Any emergency room visit	0.90	0.034	1.17	0.006	1.17	0.026	1.06	0.391	1.03	0.705
<i>Parental and family characteristics</i>										
Two-parent family	1.36	0.000	1.13	0.039	0.91	0.179	0.73	0.000	0.76	0.000
Grandparent present	1.07	0.478	0.80	0.042	0.82	0.051	0.92	0.357	0.78	0.028
Other adult present	1.06	0.313	1.02	0.766	0.96	0.518	0.93	0.211	0.87	0.129
Other child aged 0 to 5	1.14	0.008	1.18	0.006	1.05	0.408	0.91	0.027	0.82	0.012
Other child aged 13 or over	1.05	0.440	0.76	0.000	0.82	0.001	0.93	0.098	0.94	0.332
High school graduate parent	1.12	0.050	1.27	0.000	1.72	0.000	1.79	0.000	1.38	0.000
College (at least some) educated parent	1.64	0.000	1.93	0.000	2.58	0.000	2.76	0.000	2.63	0.000
Disabled parent	0.88	0.010	0.77	0.001	0.72	0.000	0.62	0.000	0.80	0.001
Other disabled person in family	1.46	0.000	1.20	0.001	0.95	0.391	1.11	0.122	0.92	0.283

NOTE: Standard errors have been calculated using the Balanced Repeated Replications (BRR) method to account for the complex NSCF survey design.

<sup>1</sup>Since the functional limitations questions were skipped for children aged 0 to 5 the activities of daily living (adl) variable value of "1" (yes) is conditional on the child being 6 to 17 years of age.

<sup>2</sup>Strictly speaking, the questionnaire asks about "household" decisions, but in most cases this refers to a parental decision.

suggest that measurement error and/or complex interactions may substantially affect survey responses concerning work-related decisions.

## 5. Conclusions

In this paper we present empirical evidence concerning parental and family inputs that may facilitate or hinder family caregiving, patterns of family and nonfamily caregiving and the role of the child's disabilities and other factors in shaping the probability of employment among parents. We summarize key findings here.

Parental and family inputs show substantial variation that may affect the availability and quality of family caregiving. Factors such as low parental education, disability of a parent or others in the family, single parenting, and the presence of other pre-school age children in the family affect many children on SSI, and reduce the quality and/or amount of time available for family caregiving. Variation in family caregiving is substantial, with no family caregiving reported for a large portion of children, while 35 or more hours per week are reported for a nontrivial minority of children. Overall the role of the family in providing needed care for children with disabilities is clearly larger than the role of nonfamily providers, with a negligible involvement of providers specializing in the care of children with disabilities. The probability of both family and nonfamily caregiving is clearly associated with the nature and severity of the child's disabilities. Nevertheless, controlling for the child's disabilities, family caregiving is substantially affected by other factors, such as parental education, living arrangements, the presence of pre-school age siblings, parental disabilities, and the presence of other potential caregivers, such as a grandparent. This suggests that the family's need for support programs is affected not only by the child's disabilities, but also by these other circumstances.

We also explored the relationship of the child's disabilities and other factors with parental employment. In general, we found some relationship between the child's disabilities and parental employment, but this relationship was not entirely consistent, and was clearly much weaker than the relationship between the child's disabilities and family caregiving. This suggests that there may be some substitution between parental employment and caregiving, especially among parents of children with substantial care needs, but caring for a disabled child puts an extra burden on the parents that is not – or not entirely – offset by reduced employment.

We also find that parental and family characteristics unrelated to the child's disabilities (such as parental education or caring for another young child) are very strong predictors of parental employment patterns. While some of these factors have opposite effects on family caregiving, other factors – most notably parental education – is positively associated both with family caregiving and with employment. This suggests that the recent finding by Guryan et al. [6] concerning the strong and positive relationship between parental education and both time spent with children and employment among parents in general may also apply for the subgroup of families with children with disabilities on SSI.

We found strong relationships between indicators of the child's disability and self-reported negative labor market decisions by family members. Given the relatively weak findings concerning the factors affecting the odds of parental employment, this might reflect, at least to some extent, perceptions rather than underlying reality. We did find some positive evidence of measurement bias in these subjective indicators as a result of strong estimated relationships between these perceptions and parental and family variables that are independent of the child's disabilities. This warrants some further caution in interpreting these subjective measures.

Finally, we identify several potentially fruitful areas of future research. Perhaps the most natural extension would involve a closer look at the factors affecting family caregiving hours and parental employment hours. This should shed substantial light on the question of substitution between parental employment and caregiving hours and on the overall role of the child's disabilities in affecting parental market and home production. The second line of research would look at the relationship between family and nonfamily caregiving and long-term outcomes for the children themselves. This would be a similarly intriguing and challenging extension. Finally, methodological research on the measurement of caregiving hours is also called for.

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