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**THE COST OF CARING: CHILDHOOD
DISABILITY AND POOR FAMILIES**

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and Timothy M. Smeeding**

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Abstract

Children in poor families are at heightened risk for disabilities and chronic health problems, and care for these children can impose substantial costs on families and public programs. Although the prevalence and costs of disabilities among poor children have important policy implications, they have been largely overlooked in research on poverty and welfare and on the costs of childhood disabilities. This paper analyzes the prevalence of childhood disabilities and chronic illness among welfare recipient families in California and the probability families caring for these children experience higher out-of-pocket costs and material hardship than do other similar families.

Introduction

All children require care, but children who have exceptional needs—due to a physical disability, chronic health problem, mental or developmental impairment—often require exceptional levels of care. The costs of this care are borne by families, communities, and public programs. Childhood disabilities and illnesses are not confined by class, race, or income. Nevertheless, poor children living in poor neighborhoods are more likely than others to suffer from these conditions. When poverty and disabilities intersect, the public and private costs associated with children's care have important policy implications.

This study examines this policy intersection directly, by analyzing the prevalence and impact of special needs among children in poor families. Nearly one-fifth of current and recent welfare recipients are found to care for children with disabilities or chronic illnesses. In the short term, care for these exceptional children increased hardship for families as well as use of public services. In the longer term, it may also increase reliance on public assistance and barriers to economic self-sufficiency. Supplemental Security Income (SSI), received by about half of the families with severely disabled children, offset some of the elevated risk of hardship for these families. These findings have implications for federal SSI policy and for states as they develop new cash assistance and welfare-to-work programs in the wake of federal welfare reform.

Background

Estimating the number of children affected by disabilities and chronic illnesses is complicated by differences in reporting categories and definitions. Researchers typically define *chronic* conditions as those that have lasted (or are expected to last) at least three months. As many as 30 percent of children are estimated to have a chronic health condition (Newacheck and Taylor 1992). Only a fraction of these conditions result in significant physical, mental, or

psychosocial impairments. The extent to which conditions are *disabling* is typically measured in terms of functional limitations (e.g., restrictions in daily activities), developmental abnormalities (e.g., educational delays), or the level of pain or discomfort experienced by the child. When researchers restrict their attention to chronic health conditions that are disabling, they estimate that approximately 6 percent of children under age 18 have a limitation due to a chronic health condition or impairment and between 0.5 and 3 percent of children have a severely disabling condition (Newacheck and Taylor 1992; Wenger, Kaye, and LaPlant 1996; McNeil 1993).¹

The Private Costs of Care

Children's disabilities and serious illnesses can impose substantial costs on both families and public services. Most of the costs of caring for these children are private. What are often termed the "subjective" private costs of care relate to deteriorations in the quality of life for the child and caregiving family (e.g., Reinhard and Horwitz 1995; Gerritsen and Van Der Ende 1994; Montgomery, Stull, and Borgatta 1985). Children with disabilities may experience a range of negative psychosocial reactions, including dependency, reduced self-esteem, disrupted development, social isolation, and antisocial behaviors; their families cope with anxiety, grief, family conflict, isolation, and stress (Hodgson and Meiners 1982; Whyte 1992; Benedict, Wulff, and White 1992).

Other dimensions of the private costs of care are financial. The financial costs of caring for children with disabilities and illnesses are typically calculated using a human capital approach that considers the *direct costs* of medical and other rehabilitative or restorative services (including hospitalization, outpatient care, home health care, medications, rehabilitative services and devices) and the *indirect costs* resulting from the loss of productive output by the caregiver (e.g., the loss of earnings due to increases in the extent and intensity of caregiving responsibilities) (Hodgson and Meiners 1982; Jacobs and McDermott 1989). The human capital model is frequently

criticized for failing to capture the emotional, psychological, and interpersonal “costs” associated with disabilities. In categories that are measured, estimates are often incomplete. Most measures of direct costs, for example, fail to capture expenses such as transportation to doctors and therapists, modifications to living quarters, extra costs for specialized child care, and purchases of special food, clothing, and other non-medical items. Likewise, estimates of indirect costs rarely capture losses in spheres such as time for unpaid household work and community activities (Jacobs and McDermott 1989).

Even given these limitations, research suggests that many families incur direct costs caring for disabled children and, for some, these costs are quite high (Newacheck and McManus 1988; Urban Systems Research and Engineering 1979; Jacobs and McDermott 1989). Based on a review of six studies of costs associated with caring for children with specific diseases or disabilities, Jacobs and McDermott (1989) report average annual expenditures ranging from \$334 for children with cystic fibrosis to \$4,012 for children with cancer. For these high-cost cancer victims, direct expenditures associated with the disease consumed 14 to 15 percent of families’ income. Both the probability of any expenses and the average expenditures varied substantially with the type and severity of children’s conditions.

The indirect costs of caring for disabled children may also be substantial. Several small surveys suggest that parents report both additional time spent in care giving and lost employment income as a result of their children’s disabilities (Leonard, Brust, and Sapienza 1992; Lansky et al. 1979; Jacobs and McDermott 1989). In their six-study review, Jacobs and McDermott (1989) report annual time costs (in foregone earnings) averaging \$1,514 to \$4,697. When indirect costs were considered, care for children with cancer was found to consume as much as 37 percent of potential family income.

Studies using larger, nationally representative samples have also found evidence of lower labor force participation among parents (overwhelmingly mothers) who care for disabled children. Salkever (1982) and Breslau, Salkever and Staruch (1982) find that a disabled child had a significantly negative effect on the labor force participation of married mothers, with the impact concentrated among low-income families. Wolfe and Hill (1995) examine labor force participation among a sample of single mothers from the 1984 panel of the Survey of Income and Program Participation; in two of their models the presence of a disabled child significantly reduced the probability of employment. Mauldon (1991) also reports modest but significant reductions in employment for mothers with disabled children, with effects concentrated among low-income women and increasing with the age of the disabled child.

Child Disabilities and Poverty

The public and private costs associated with childhood disabilities and health problems have special relevance for family poverty and public welfare policies. Children in low-income families are more likely to suffer from chronic illnesses and disabilities (Newacheck and McManus 1988; McNeil 1993). Newacheck (1988) estimates that children in low-income families face a 40 percent higher risk of being disabled. The causes of this higher prevalence are likely to be multiple and interacting. Children in low-income families are more likely to live in poor neighborhoods where they are exposed to heightened environmental risks. They are more likely to suffer from low birth weight and other complications associated with poor maternal nutrition, health behaviors, and health care. Children in poor families are also less likely to receive the adequate early nutrition, housing, and health care that might help prevent the development of serious disabilities and health conditions.

Low-income families may also be less able than their affluent counterparts to absorb the costs of caring for children with special needs. Researchers who have examined direct medical

expenditures for disabled children find that out-of-pocket expenses for services, equipment and supplies are lower in low-income families (Newacheck and McManus 1988). Lower direct expenditures may reflect more comprehensive coverage for these expenses through Medicaid. They may also reflect budget constraints and lower levels of provision for children in low income families.

The indirect caregiving costs from foregone earnings may also take a particularly heavy toll in families with low human capital and earnings. Estimates of the labor supply reductions associated with care for disabled children have found that the negative impact is greatest on low-income families. Some researchers have concluded that parents in lower-income families may face more extreme choices between the allocation of time to care for a disabled child versus employment (Breslau, Salkever, and Staruch 1982). These families may also incur more devastating financial consequences as a result. As described by Hobbs, Perrin, and Ireys (1985): “For families in poverty, and especially for single-parent families, the presence of a child with a chronic illness may effectively remove any opportunity to earn sufficient money to climb out of poverty. Real income loss is small because income is small in total dollars; opportunity for increasing income, however, may vanish under the demands for care” (p. 184).

Child Disabilities and Public Programs

The intersection of poverty and disabilities is also important for the costs of public welfare programs. Aron, Loprest, and Steuerle (1996) estimate that the total cost of federal, state, and local services for exceptional children was \$44.3 billion in 1993. Less than one-quarter of these costs (an estimated \$10.6 billion) were federal; the majority (\$33.7 billion) were incurred by state and local governments.

The most obvious impact is on means-tested programs targeted at disabled individuals, most notably the Supplemental Security Income (SSI) program. Caseloads and expenditures for

children in the SSI program have grown with better detection and diagnosis of disabilities, and with increasing poverty among families with children. Modifications to federal eligibility rules in the early 1990s exacerbated these trends.² In 1974, shortly after it was first implemented, the program provided benefits to 70,849 children, who made up 2 percent of total SSI beneficiaries. By February 1996, SSI provided \$4.3 billion in benefits to 992,140 children—15 percent of total beneficiaries and more than three times the number of children receiving benefits in 1989 (Aron, Loprest, and Steuerle 1996; Social Security Administration 1996).

The extent and severity of disabilities among poor children also have implications for public programs that are **not** targeted on the disabled. The largest of these programs is Medicaid. Although not targeted on children with disabilities, Medicaid is used to cover medical care, residential care, and some community services for many disabled and handicapped children. By one recent calculation, the cost of Medicaid for an estimated 800,000 disabled children in 1993 was \$3.4 billion in federal and \$2.5 billion in state funds (Aron, Loprest, and Steuerle 1996). In addition to these direct costs, Medicaid has had an unknown impact on participation in Aid to Families with Dependent Children (AFDC) and SSI programs. Until the recent decoupling of Medicaid and welfare eligibility, the only way for some families to access health insurance was by establishing categorical eligibility through participation in welfare or SSI. For families with disabled children, in particular, the higher medical costs associated with disabilities may have increased the value of Medicaid and, in turn, incentives for welfare participation.

Children's disabilities also have a largely unmeasured direct impact on participation in welfare programs. Food Stamps and cash assistance through the AFDC program have (prior to the 1996 federal reforms) been available to all income-eligible families with dependent children. Although not targeted to the disabled, these programs have served large numbers of families with disabled members. Using multiple sources of nationally representative data, Loprest and Acs

(1995) estimate that almost 16 percent of families who received AFDC have a child with some functional limitation. If care for these children causes mothers to leave or reduce paid employment, the duration of their time on welfare may also be quite long. The impact of disabilities on the probability and duration of welfare receipt has received little empirical study. In one of the few studies in this area, Acs and Loprest (1994) estimate the impact of children's disabilities on parents' probability of exiting welfare with and without earnings, and they find no consistent evidence that those with disabled children were less likely to exit AFDC or to exit for work. Brady, Meyers and Luks (1996) however, find that once transitions from AFDC to SSI are controlled, those families caring for disabled children are substantially less likely than families with healthy children to exit welfare for independence.

Outstanding Research and Policy Issues

Although the interaction of child disabilities and poverty has important policy implications, it has been largely overlooked in research that has focused on poverty and welfare program participation (with little attention to child disabilities) or on the public and private costs of childhood disabilities (with scant attention to the impact on public welfare programs). There are few estimates of the number of low-income families caring for disabled and seriously ill children, the direct and indirect impact on families' economic well-being, or the role of income assistance programs in offsetting the extra costs associated with care of exceptional children. The best estimates of the private costs are now over ten years old. These studies do not adequately address the special burdens for low income families, who are more likely to have a chronically ill or disabled child but who may be less able than their more affluent peers to absorb additional costs of care. Nor do they capture the impact of additional resources available through the SSI program.

These gaps in our knowledge take on particular urgency in the wake of the 1996 Personal Responsibility and Work Opportunity Act. The Act requires states to move at least half of their welfare recipient families into work or community service by the end of the decade and to limit lifetime welfare receipt to five years. Changes in federal law will also end Supplemental Security Income (SSI) assistance for as many as 135,000 children who qualified for the program under revised eligibility criteria after 1990 (Social Security Administration 1997). Better information about the prevalence and costs of caring for disabled children is needed to inform decisions about these program changes. As states develop rules for granting hardship exemptions from work requirements, for example, it will be important to understand the magnitude of employment barriers associated with care for disabled children. And as cash assistance through welfare and SSI is reduced, it will be important to consider the impact on those families that incur direct and indirect costs of caring for their exceptional children.

In this paper we begin to address these gaps in knowledge. Using data from a telephone survey of a random sample of current and recent welfare recipients in California, we address the following questions:

What is the prevalence of disabilities and chronic health problems among children in welfare-recipient households?

How do “caregiving responsibilities” differ across families in terms of the severity of children’s conditions and the number of children affected?

What is the association between the level of “caregiving responsibilities” and the probability that families incur private costs and participate in public welfare programs?

How does the “cost of caring” for exceptional children affect families’ economic well-being and risk of material hardship?

Methods

Sample and Data Sources

This paper uses data from Wave II of the (California) AFDC Household Survey. This is one of several databases constructed through the joint effort of the Department of Social Services of the State of California and the University of California Data Archive and Technical Assistance program. Respondents for the AFDC Household Survey were selected from the California Assistance Payment Demonstration Project (APDP) sample. The APDP sample is a stratified random sample of approximately 15,000 AFDC recipient households selected from four California counties (Los Angeles, Alameda, San Joaquin, and San Bernardino) in November 1992.³ The sample included both single-parent households and two-parent households qualifying for benefits through the AFDC-FG and AFDC-UP programs.⁴

The data analyzed here are from Wave II of a telephone survey of a randomly selected subsample of 2,214 English and Spanish speaking households. The AFDC Household Survey is a panel survey. Initial (Wave I) interviews began in October 1993; follow-up interviews (Wave II) began in May 1995. In both waves, the adult female caretaker for AFDC child(ren) was asked detailed questions about family and household composition, parents' labor market activities, household income, and use of social services. Wave II of the survey also included questions to identify families with chronically ill or disabled children, and to assess the type and severity of the child's disabilities, private expenses resulting from the child's condition, and the impact of the child's disability on parents' labor market participation.

Data are analyzed for 1,696 families containing 3,759 children under the age of 18. A total of 1,764 of the initial respondent families were successfully contacted for the Wave II survey (an 80 percent completion rate). Of these, an additional 68 families were excluded from analyses

because children were no longer living in the household. Data are weighted to adjust for differences in sampling fractions by strata and for survey completion rates.

Defining and Measuring Disabilities and Illnesses

Children with chronic health problems and disabilities were identified by asking mothers whether any of their children:⁵

had a chronic health problem—physical, emotional, or mental—that limited the amount or kinds of things that he or she could do;

had a disability or handicapping condition that limited the amount or kind of things he or she could do; or

received SSI benefits.

We identified a household as including children with chronic conditions if the respondent answered yes to any of these three screening questions. Thus, we screened broadly to include activity-limiting chronic illnesses, as well as emotional, mental, and physical conditions that could produce a functional limitation.

For each child identified as having a limiting condition, respondents were asked to identify up to five specific conditions (diagnoses) causing the child’s impairment. To measure the severity of the condition, respondents were also asked questions regarding functional limitations and use of special health and educational services. These questions were derived from questions in the 1992 National Health Interview Survey, the topical module on children’s disability designed for the Survey of Income and Program Participation, and a 1978 survey of households with SSI children undertaken by Urban Systems Research and Engineering Inc. Figure 1 summarizes our categorization of the severity of children’s conditions. Children who were identified as having a chronic condition but who did not meet tests for “moderate” or “severe” limitations were coded as “mild.”

Defining and Measuring Private and Public Costs

Two categories of private costs are considered. The first is direct out-of-pocket expenditures. This is based on reports from parents with any special needs children regarding any *direct, unreimbursed* expenses incurred in the prior month (and any single expenditures greater than \$100 in the prior year) related specifically to their children's disabilities or illnesses in any of the following categories: special food, diets or clothing, special transportation, modifications to their home, special health care or medicine, or specialized child care.⁶ The second category is *indirect costs*, measured using several survey items relating to mothers' paid employment. Measures include mothers' reported employment in the prior month (any paid work in regular or odd jobs) and active search for employment (among those who were unemployed). Mothers who had any children with special needs were also asked whether those conditions limited their ability to work or the amount or type of work at a job that they could do, and whether they expected these work limitations to continue for one year.

The public costs associated with children's special needs are measured by examining the family's participation in various public programs. Means-tested public assistance programs include cash aid (AFDC and SSI), in-kind programs (Food Stamps and subsidized housing), and public health insurance (Medicaid or Medicare). Specialized services include special education (for children over five) or early intervention programs (for younger children), California Children's Services (providing case management for some developmentally disabled children), and Community Mental Health services.

The economic well-being of families is measured using indicators of income and material hardship. Self-reported income for the family (respondent, spouse, and dependent children) is aggregated for cash transfers, Food Stamps, and earnings; total income is adjusted for family size by dividing by the square root of the total number of resident adults and children. Poverty rates are

also calculated, using 1994 federal poverty guidelines. Respondents were also asked several questions about direct material hardship in the prior year: times when children or adults went hungry due to a lack of money, any evictions or episodes of homelessness, late or nonpayment of rent or mortgage on multiple (three or more) occasions due to a lack of money, and any utility or phone shutoffs. For the final analyses, individual items are combined into an indicator variable for any direct, material hardship in the prior year (if the respondent experienced any one of these hunger or housing problems).

Analyses and Hypotheses

The first analyses are primarily descriptive. We begin with a description of the prevalence and severity of disabilities and illnesses among children and the specific conditions reported by their caretakers.

We then develop a measure of the extra “caregiving responsibility” for families by simultaneously considering the *severity* of these conditions and the *number of affected children*. The first dimension, *severity of children’s limitations*, is measured using the indicators described above and in Figure 1. The second dimension, *number of children affected*, is measured by counting the number of children in the family who are reported to have a disability or chronic illness. These two dimensions are combined into a single scale of caregiving responsibility.

The second part of the analysis reports bivariate associations between caregiving responsibilities and indicators of private and public costs. We hypothesize that private costs and public costs will all increase along with the extra caregiving responsibility, as suggested in Figure 2.

In the final step, we examine the impact of extra caregiving responsibilities on families’ economic well-being. We compare per capita family income and poverty rates for families with and without disabled and ill children. Because cash income and poverty may not capture the extra direct and indirect costs that families incur caring for exceptional children, we also compare indicators of direct hardship for these groups. We hypothesize that if the extra costs that are associated with caring for disabled children cause families to make tradeoffs between expenditures for the “extra” care of children and other basic necessities, this will be reflected in higher levels of material hardship.

We test the contribution of children’s conditions to families’ economic well-being using logistic regression analysis. We use six dependent variables: the likelihood that the family was

poor at the time of the interview; the likelihood that they had experienced each of four forms of hardship in the prior year (hunger, homelessness/evictions, late payment of rent/mortgage, and utility or phone shutoffs); and the likelihood that they experienced at least one of these problems (“any hardship”). The analysis controls first for family characteristics assumed to increase the likelihood of poverty and hardship: the respondent’s education, marital (cohabitation) status, number of children under age 18, current work status, and race and ethnicity. Because public housing assistance significantly affects income available for other needs, analyses of material hardship also control for whether the respondent was in public housing or receiving Section 8 housing vouchers. (Because receipt of public housing depends on income, this variable is excluded from the poverty regression.) Additional control variables are included to adjust for the sample design (county, program type, and experimental status in the state welfare reform waiver project).

The contribution of the extra caretaking costs to family well-being is measured by adding a dummy variable for whether any child in the family had a severe disability and a second indicator variable for whether there was more than one child in the family with a disability or chronic illness. Because the extra income received through the SSI program may reduce tradeoffs in meeting basic needs, an indicator for whether any child received SSI is included.⁷

The logistic regression coefficients represent the increase in the log of the odds of the outcome given a change in the predictor variable. To interpret these results more directly, the regression coefficients are used in a series of simulations of the contribution of child disabilities to family hardship. The probability of any hardship is first calculated for an “average” family in the sample by setting x values at the mean: the “base case” is a family headed by a white, Anglo, single female respondent who has the average level of education for the sample (10.43 years), cares for the average number of children (2.2), and has no current employment. (The values for

the sample control variables are set to Los Angeles county, “family group” or single parent AFDC case, and experimental group.) The probability of experiencing hardship in the prior year is calculated for this “base case” or average family. A severely disabled child is then “added” to the family (by setting the x value to 1) and the probability of hardship is re-estimated; the family is then “given” SSI and the probability of hardships is estimated once again. A similar process is used to compare probabilities for families with more than one disabled child and for families with more than one disabled child, at least one of whom is severely impaired.

The statistical significance of bivariate comparisons across groups are tested using a Pearson Chi-Square. Because the design effects from a stratified sample may bias inferential statistics (by underestimating standard errors) all statistical tests are reported for unweighted data. Because they do not adjust for design effects these tests are likely to overstate significance and should be interpreted cautiously. These design effects are controlled directly in the regression analysis and simulations by including stratification factors as independent variables.

Generalizability and Limitations

Several important points about the generalizability of this sample should be noted. The sample was designed to represent the AFDC population in four counties in California. While we believe this generalizes well to the welfare population in that state, it may not represent the welfare population elsewhere in the country. Because important groups were not included in this round of surveys, notably immigrants who do not speak either English or Spanish, caution must be used even in drawing conclusions about California. This sample also represents the welfare population prior to recently enacted changes in the federal AFDC and SSI programs.

The sample has another important characteristic. As a point in time sample, it samples the “stock” rather than “flow” of all welfare cases. These findings represent the experiences of families who were receiving welfare at a point in time. As substantial research in this field has

demonstrated, the experience of these families will not represent *all* families who *ever* enter the welfare system. In particular, we would expect this point in time sample to represent the experiences of long-term, more highly disadvantaged welfare recipients (who dominate AFDC caseloads at a point in time) more accurately than the experiences of the larger number of short-term, relatively more advantaged families who cycle through the welfare system more quickly. For the purposes of designing new welfare and SSI policies, conclusions based on this point-in-time sample may be particularly relevant, insofar as it represents existing caseloads.

It is also important to note that this sample represents the experience of only a fraction of SSI recipient and low income families with disabled and ill children. The families represented here, those receiving AFDC as of January 1992, are a small and especially disadvantaged subset of all families who care for exceptional children or who receive SSI. They do represent, however, a population of particular importance for welfare policy. These families are likely to be affected by changes in the AFDC (now TANF) program that set time limits on benefits and increase work requirements. Many will also be affected by changes in the SSI program that now restrict eligibility for various childhood conditions.

Findings

Prevalence and Severity of Special Needs

Table 1 reports the prevalence of special needs at the individual level for all children in the sample (n=3,759 weighted). Mothers reported that 12 percent of all **children** had some form of disability or chronic illness. As would be expected, prevalence increased with children's ages from 6 percent of children under 3 years to 13 to 14 percent of children aged 6 to 14. Severe conditions were much less common in each age group. Among infants and toddlers, 3 percent met our test for a severe condition; among school-aged children, 5 to 6 percent had a severe

condition. Fewer than one-quarter (21.5 percent) of all disabled or ill children, and approximately one-half of those with a “severe” condition, were receiving SSI.

Figure 3 describes the extra “caregiving responsibility” at the household level. Nearly one-fifth (19 percent) of all **families** cared for at least one child with a disability or illness. The level of caregiving responsibility was not the same across these families. Nearly 9 percent of all families reported caring for only one child who had a mild to moderately impairing condition. Over 11 percent, however, cared for more than one mild or moderately involved child (2.6 percent), a severely involved child (6.2 percent), or more than one special needs child at least one of whom had a severe problem (2.4 percent).

These figures suggest that childhood disabilities are considerably more prevalent among current and recent welfare recipients than in the general population. The 12 percent of **children** identified with any limitation in this sample is nearly double the 6 percent identified among all children in the United States using the National Health Interview Survey (Wenger, Kaye, and LaPlante 1996). The 19 percent of families found to care for exceptional children is similar, however, to recent estimates by Loprest and Acs (1995). Using several national data sources, they conclude that 11 to 16 percent of **families** receiving AFDC care for children with some functional limitation.

Private Costs of Care

As expected, families’ direct out-of-pocket expenditures for children’s special needs became more frequent as the number and severity of children’s conditions increased (see Table 2). By definition, families without special needs children did not incur expenses. Among those with any exceptional children, about half incurred expenses for special services, transportation, food or other needs. The probability that they had any expenses rose from 39 percent of those with a single, mild to moderately disabled child to 57 percent of those with multiple and severely

disabled children; the likelihood that they had high expenses (over \$100) in the prior year rose from 11 percent to 21 percent.

Indicators that families incurred indirect costs through reduced earned income also increased significantly with the extra caregiving responsibilities. Sixty one (61) percent of mothers with no disabled children were not employed when contacted. About the same proportion (62 percent) of mothers with a single, mild to moderately disabled child were out of the workforce. Unemployment was significantly higher (79 to 83 percent) for those with more than one or any severely disabled children.

Mothers' self-reports also indicated that care for special needs children depressed employment. One-third (33 percent) of those with only one mild to moderately involved child indicated that care for the child made it difficult to work at present. The percentage of mothers reporting barriers to work increased dramatically with the number and severity of children's special needs, to 65 percent of those with a single severely disabled child and 90 percent of those with multiple and severely disabled children. Mothers were more sanguine about their employment prospects in one year, perhaps because they either expected children's need for care to decline or supportive public or family services to increase. Nevertheless, from 23 to 76 percent expected that caring for special children would cause them to limit their work in 12 months.

Public Costs of Care

As shown in Table 3, the probability that families received services from both targeted and non-targeted programs increased with the level of caregiving responsibility.

The percentage of families with a child in a special education or early intervention program increased from over one-third (39 percent) of those with a single, mild or moderately impaired child to over half (51 percent) of those with a severely disabled child and 83 percent of those with more than one and any severely limited children.⁸ Families were much less likely to be

receiving case management from California Children's Services or mental health services from Community Mental Health programs. Although lower overall, participation rates for these programs also increased significantly with the number and severity of special needs in the family: about 10 percent of families with one severely disabled child, and about 20 percent of those with more than one, were receiving services from at least one of these programs.

It was more surprising to find a similar pattern in non-targeted, means-tested welfare programs. While just under three quarters (74 percent) of families without disabled children were still receiving AFDC when contacted (from 30 to 42 months after the sample was drawn), between 87 and 98 percent of those caring for any severely disabled children remained in the AFDC system. Rates of participation in the Food Stamp program were similar, ranging from 72 percent of those with no special caregiving responsibilities to 82 to 91 percent of those with the highest level of extra responsibility. The percentage of families in subsidized housing (or receiving housing subsidies) varied from a low of 19 percent among those with no special needs children to more than double that percentage (39 percent) among those with multiple and severely disabled children.

Some families with severely disabled adults or children were also eligible to receive SSI, either alone or in combination with AFDC. Nearly 8 percent of families without special needs children were receiving SSI for another household member; 9 percent of families with moderately disabled children were also in the SSI system. In those families with severely disabled children, however, nearly two-thirds (61 to 63 percent) were receiving SSI for an adult and/or one or more children. (Note that children receiving SSI were automatically coded as "severely" disabled on our scale.)

Economic Well-Being

Although families with exceptional children were more likely to receive benefits from public programs, they fared worse than other families on many measures of hardship (Table 4). Family income, adjusted for family size, did not differ significantly with the level of extra caregiving responsibility. Most families in this sample were quite poor, hovering around the federal poverty line when all cash and food stamp income was considered. Families with severely disabled children had slightly greater per capita income and lower average poverty rates, reflecting the more generous SSI benefit received by over half of these families, but differences were not statistically significant. A comparison of per capita family income controls for the number of children in the family; it does not reflect the impact of the extra costs of caring for exceptional children. Even with the extra marginal income provided by SSI, most families with disabled children were living at or below the poverty line. For the one-half or more of more of these families who had incurred direct out-of-pocket expenses caring for their ill or disabled child, even less income was likely to be available to meet other needs.

Direct measures of hardship provide some indication of the impact of care for special needs on families' economic well-being. On several indicators, families with greater caregiving responsibilities for special needs children were consistently more disadvantaged. About 17 percent of families with healthy children reported that children had gone hungry in the prior year because the family lacked money for food; hunger was reported about twice as often (31 to 38 percent) among families with any disabled or chronically ill children. In nearly one quarter of families (22 percent) with healthy children, adults had gone hungry; between 34 and 57 percent of families caring for exceptional children reported hunger among adults. Families with a greater level of extra caregiving responsibility were also two to three times more likely to have

experienced housing instability, in the form of evictions or periods of homelessness, and were more likely to have had phone or utility shutoffs due to a lack of money.

The Costs of Caring

The contribution of children's disabilities and SSI receipt to family hardship is measured more precisely with the multivariate regressions reported in Table 5. The background characteristics of the family have the expected relation to income poverty. The odds that a family had income at or below the poverty line were significantly increased if the mother had fewer years of education, if she was single, if she cared for more children, if she was not employed, and if she was African American or Latina. Marital status, family size, and race/ethnicity had a similar relationship to the individual indicators of hardship (hunger, homelessness/eviction, late rent and mortgage payments, and utility or phone disconnections), and to the summary indicator of any hardship during the prior year. Education and employment, however, had only weak and inconsistent associations with hardship.

Children's disabilities and SSI made distinctly different contributions to the risk of poverty versus the risk of hardship. Neither the presence of a severely disabled child in the family nor the presence of multiple children with disabilities were significant predictors of income poverty; receipt of SSI for any child, however, reduced the odds of family poverty to nearly zero (odds ratio = .04). In contrast, both child disabilities and SSI were significantly associated with the risk of material hardship. The presence of a severely disabled child was a significant predictor of greater hardship for three of the four discrete measures (hunger, late rent/mortgage, utility shutoffs); the presence of more than one child was significant for one of the three (hunger). On the summary measure of any hardship, the presence of a severely disabled child more than doubled the odds that a family had experienced hardship (odds ratio = 2.53) and the presence of two or more exceptional children increased the odds by over 50 percent (odds ratio = 1.51).

Receipt of SSI for any child significantly reduced the odds on all dimensions of hardship; on the combined measure, SSI reduced the odds by more than half (odds ratio = .42).

A more direct interpretation of the regression results is provided by the simulations in Table 6. This simulation estimates the probability that a family experienced any of the four types of material hardship in the prior year, comparing a “base case” family with healthy children against a family with one or more disabled children. The results are dramatic. Families who reported no disabled or chronically ill children had about a 50 percent probability of having experienced one or more of these forms of material hardship. If they cared for at least one severely disabled child and did not receive SSI, however, their chances of material hardship increased by over 20 percentage points, a 44 percent increase. Families caring for a child with the same level of impairment, but receiving SSI, had about the same probability of hardship (51 percent) as other families. Similar results are obtained for families caring for more than one disabled or ill child. Without SSI, these families have a greater probability of hardship (60 percent); with SSI, their chances of experiencing hardship fall below those of families with healthy children (38 percent). Families with more than one exceptional child, and any severely disabled, paid the highest price in terms of material security. Without SSI, these families were almost certain to have experienced some hardship (probability of 79 percent); even with SSI, their risk of hardship was elevated to 61 percent.

Conclusions and Discussion

The extra caregiving responsibilities of families with disabled and chronically ill children has often been overlooked in the development of public welfare policies. These data suggest that the rate of disabilities and chronic illnesses in children receiving AFDC is about twice that of children in the general population. Nearly one-fifth of low-income, welfare-recipient families

were found to be caring for a disabled or chronically ill child; over 10 percent cared for either a severely disabled child or more than one child with special needs.

The extra caregiving responsibilities resulting from children's disabilities and illness were costly for families. Approximately half of the families in this study incurred direct, out-of-pocket costs for special medical costs, food, transportation or other goods and services related directly to their child's special needs. Mothers caring for special needs children were also much less likely to be working, which suggests that the families were incurring indirect costs in the form of foregone earnings. The probability of incurring both direct and indirect costs increased along with the severity of children's conditions and the number of children affected.

These costs appeared to have a significant impact on the economic well-being of caregiving families. Most families in this study were very poor, hovering around the poverty line even after welfare, food stamp, employment, and SSI income were considered. Families with special needs children did not have lower incomes, on average, than those with healthy children. But they were two to three times more likely to report experiences of hunger and housing instability in the prior year. Multivariate analyses suggest that if the family received SSI, the presence of a severely disabled child did not significantly increase their probability of experiencing some form of hardship. If they did not receive SSI, however, their probability of experiencing hardship increased by 44 percent. This finding—that families caring for disabled and ill children had similar income levels but experienced more direct hardship than other families—suggests that these families may have been forced to make tradeoffs between expenditures for the special needs of children and for other basic needs.

Although families absorbed the majority of costs associated with caring for exceptional children, public programs also absorbed some of the added burden. As would be expected, families with any severely disabled children were much more likely to be receiving services from

special education, mental health, or another targeted public program. About half of families with severely disabled children were also receiving cash assistance through SSI, and this assistance appeared to offset most of their extra financial burden and economic risk. SSI lifted families slightly above the poverty line and reduced their risk of material hardship to about that of the “average” welfare-recipient family.

This suggests that, for this population of AFDC-recipient families, SSI meets its original objectives: the extra income appears to offset the extra expenses that put poor families at risk for extreme hardship. This has important implications for the well-being of families who have not received SSI in the past (nearly half of those in this sample who had children with severe impairments), and for the estimated 135,000 expected to lose SSI after the 1996 Personal Responsibility and Work Opportunity Act is implemented. Families with special needs children were also significantly more likely than others to be receiving benefits through means-tested programs that are *not* targeted on special needs children: AFDC, food stamps, Medicaid, and public housing. This has important policy implications in light of federal welfare changes. These families are part of the larger group of “multi-problem” families that make up a small but disproportionately expensive share of the caseload in many social service and remedial programs. These findings suggest that these families also make up a disproportionately large share of welfare caseloads. They are likely to face greater barriers to self-sufficiency and have longer periods of welfare use. This raises important issues for welfare administrators who are concerned with moving welfare clients out of the system. States that have made the most aggressive efforts to mandate job preparation for a larger share of their welfare caseload have found that, after the most employable welfare recipients leave assistance, the “residual” cases are dominated by longer-term, “harder-to-serve,” multi-problem clients (e.g., Pavetti and Duke 1995). Families

with extra caregiving responsibilities represent one important component of this population of clients.

Relationships among disabilities, poverty and welfare use are complex. For some families in this study, poverty may have contributed to the occurrence or severity of their children's disabilities and illnesses. For others, the special needs of the child—for extra caretaking as well as medicine, goods and services—may have contributed to families' poverty, material hardship, and welfare reliance. For still others, disabilities and poverty may both be traced to other sources. In these “multi-problem” families, a constellation of functional problems and/or severe human capital deficits may increase the risk of poverty, poor health outcomes, and long-term welfare reliance.

Although we cannot disentangle the poverty and disabilities in this sample of families, these data suggest that they are at very great risk for poverty and material hardship. They face extraordinary costs caring for their children and may have more limited options for employment. Their disabled and chronically ill children may be especially vulnerable to compromises in housing, nutrition, health care, and other living conditions that result. Their children may have exceptional needs for direct care by a parent or other adult. The vulnerability of these families and the care needs of their children justify additional assistance such as has been provided through the SSI program. The special caregiving burden for parents may also justify a special consideration of work requirements and a more careful evaluation of the value—to children and to society—of care provided by mothers to children in their homes. The “tough love” approach of many federal and state welfare changes may simply be too tough for these families, who are likely to need extra support, in the short-term, to achieve greater economic independence and may need continuing help, in the long term, to provide adequate care for their children.

Endnotes

1. Estimates of the prevalence of childhood illnesses are also sensitive to children's ages. Some disabling conditions that occur early in life are not manifested or cannot be easily detected in young children. Other conditions may manifest themselves early in life, but their impact on children's health and functioning cannot be observed until children age. By one estimate, 2.8 of children under age 5 versus 7.5 percent of those aged 5 to 17 have a disabling condition (Wenger, Kaye, and LaPlante 1996).
2. In 1990 in *Sullivan v. Zebly* the Supreme Court required the Social Security Administration (SSA) to provide an individual, functional assessment for children whose disability did not qualify them for benefits under existing criteria. At about this same time, SSA also revised its criteria for evaluating children claiming mental impairments. Both of these changes contributed to substantial growth in the early 1990s in the number of child beneficiaries in the SSI program.
3. Together, these four California counties account for nearly one-half of the AFDC caseload in California.
4. The sample includes a small number of male respondents, but respondents were overwhelmingly women.
5. Respondents were asked screening questions with respect to their biological and step children. A few families were headed by a "caretaker relative" who was not the biological or step parent of the AFDC children. Caretaker relatives were asked the screening questions with respect to their AFDC children.
6. This paper considers only the frequency with which these expenses were incurred. The magnitude of the expenses and impact on family income and poverty status are described in Lukemeyer, Meyers, and Smeeding (1997).
7. To avoid direct correlation between our measures of severity and SSI receipt, variables for the severity of children's conditions were recoded for this analysis on the basis of functional limitations only—i.e., children receiving SSI were not automatically coded as severely impaired. This reduces the number of households with severely disabled children from 148 to 102 for this analysis. This may result in an underestimate of the impact of children's special needs on family hardship.
8. Measures of program participation do not count families in the application process, on waiting lists or under review for services and are therefore conservative estimates.

**Table 1. Special Needs Status of Children: Percentage of all Children by Age and Special Needs
California Families Receiving AFDC in November 1992
(weighted: 3,759 children)**

	Age				Total 18 and Under
	3 and Under	3 to 5	6 to 14	15 to 17	
All Children					
Number	493	826	1,968	472	3,759
Any Disability or Chronic Illness					
Number	29	85	283	60	455
All Children	5.8	10.3	14.4	12.7	12.1
Severe Disability or Chronic Illness					
Number	13	26	108	24	171
All Children	2.6	3.2	5.5	5.1	4.5
Supplemental Security Income (SSI) Receipt					
Number	6	16	64	12	98
All Children	1.2	1.9	3.3	2.5	2.6
Disabled Children	20.7	18.8	22.6	20.0	21.5

Source: California AFDC Household Survey, Wave II.

Table 2. Private Cost of Caring by Child Disabilities/Illness All Families by Number and Severity of Child Conditions: Percent Households California Families Receiving AFDC in November 1992 (weighted: 1,696 Households)

	No Children	Mild or Moderate Severe Condition		Severe Condition	Any Severe Condition	p-Value
		One Child	More than One Child	One Child	More than One Child	
Direct Costs						
Any out-of-pocket expenses last month ^a	n/a	38.9	46.5	51.4	57.1	<0.001
Expenses > \$100 last year	n/a	10.7	2.3	15.9	21.4	<0.001
Indirect Costs						
Mother did not work prior month ^b	61.4	61.5	72.7	79.4	83.3	<0.001
Child(ren)'s condition(s) limit mother's work now	n/a	32.9	40.9	65.4	90.2	<0.001
Limit ability to work at all	n/a	26.2	34.1	34.6	46.3	
Limit hours available for work	n/a	6.7	6.8	30.8	43.9	
Expects child(ren)'s conditions to limit work in 12 months		23.1	30.2	42.3	76.3	<0.001
Limit Ability to work at all	n/a	16.8	25.6	23.7	44.7	
Limit hours available for work	n/a	6.3	4.7	18.6	31.6	

^aExpenses = special expenses for any disabled child in family.

^bWork = at least one hour of work last month.

Source: California AFDC Household Survey, Wave II.

**Table 3. Public Programs by Child Disabilities/Illness, All Families by Number and Severity of Child Conditions: Percent Households
California Families Receiving AFDC in November 1992
(weighted: 1,696 Households)**

	No Children	Mild or Moderate Severe Condition		Severe Condition	Any Severe Condition	p-Value
		One Child	More than One Child	One Child	More than One Child	
Special Services (any child in)						
Special Education or Early Intervention	n/a	38.9	55.8	50.5	82.9	<0.001
California Children's Services	n/a	4.7	2.3	11.2	19.5	<0.001
Community Mental Health Services	n/a	6.7	6.8	9.4	21.4	<0.001
Means-Tested Income^a						
Currently receiving AFDC	73.7	79.2	84.1	86.8	97.6	<0.001
Currently receiving SSI	7.8	8.7	9.3	61.3	63.4	<0.001
Currently Receiving either AFDC or SSI	75.9	79.2	84.1	92.5	100.0	<0.001
Means-Tested in Kind						
Currently receiving Food Stamps	72.1	72.5	77.3	82.1	90.5	0.010
Currently in subsidized housing	19.3	23.3	27.5	33.3	38.5	<0.001
Public Health Insurance						
Medicaid/Medicare (child) ^b	77.6	80.4	86.4	89.6	100.0	<0.001
Medicaid/Medicare (mother)	68.9	72.5	63.6	89.6	85.7	<0.001

^aAFDC/SSI for anyone in household.

^bPublic health (child measure) = randomly selected child.

Source: California AFDC Household Survey, Wave II.

Table 4. Family Well-Being and Hardship by Child Disabilities/Illness, All Families by Number and Severity of Child Conditions: Percent Households California Families Receiving AFDC in November 1992 (weighted: 1,696 Households)

	Child Conditions					p-Value
	No Children	Mild or Moderate Severe Condition		Severe Condition	Any Severe Condition	
		One Child	More than One Child	One Child	More than One Child	
Economic Well-Being						
Family Income (adjusted, per individual)	\$652.9	\$665.5	\$515.3	\$699.4	\$738.1	0.159
Poverty level (all income plus Food Stamps)	104.2	106.7	78.4	111.5	114.8	0.121
Material Hardship						
Child(ren) ever hungry	17.0	30.9	34.9	34.9	38.1	<0.001
Adults ever hungry	21.7	33.6	41.9	34.9	57.1	<0.001
Late with rent/mortgage 3 or more times	18.3	18.2	25.6	17.9	31.7	0.505
Evicted or homeless in prior year	6.9	13.4	11.6	6.7	23.8	<0.001
Utility or phone shutoff in prior year ^a	30.4	25.7	48.8	33.6	46.3	0.009

^aIncludes those who never had a phone because they could not afford it.

Source: California AFDC Household Survey, Wave II.

**Table 5. Logistic Regression Results Coefficients (Standard Errors)
California Families Receiving AFDC in November 1992
(weighted: 1,682 Households)**

	At or Below Poverty	Ever Hungry	Ever Homeless or Evicted	Ever Late With Rent	Any Utility/Phone Shutoff	Any Hardship
Respondent education	-0.0937 (0.0268)***	-0.050 (0.021)**	0.023 (0.039)	0.060 (0.021)***	0.025 (0.022)	-0.002 (0.019)
Marital status = married	-1.5595 (0.1598)***	-0.188 (0.143)	-0.595 (0.228)***	-0.365 (0.132)***	-0.309 (0.140)**	-0.476 (0.126)***
Number of children in household	0.2680 (0.0560)***	0.034 (0.047)	0.081 (0.174)	0.037 (0.044)	0.142 (0.046)***	0.115 (0.043)***
Respondent employed	-1.6973 (0.1269)***	-0.153 (0.120)	0.094 (0.185)	0.418 (0.109)***	-0.106 (0.117)	0.031 (0.105)
Ethnicity: African-American	0.3095 (0.1703)*	0.341 (0.165)**	0.345 (0.237)	0.248 (0.151)*	0.567 (0.158)***	0.416 (0.145)***
Latino	0.4571 (0.1621)***	0.291 (0.156)*	-0.381 (0.249)	0.284 (0.141)**	0.236 (0.152)	0.176 (0.135)
County: Alameda	0.1883 (0.1896)	0.190 (0.175)	-0.072 (0.261)	0.049 (0.166)	0.089 (0.175)	0.032 (0.157)
Los Angeles	0.0847 (0.1700)	0.065 (0.156)	-0.311 (0.248)	0.299 (0.145)**	0.075 (0.155)	-0.014 (0.138)
San Bernadino	-0.1516 (0.1875)	-0.153 (0.184)	-0.041 (0.265)	0.136 (0.165)	0.278 (0.173)	-0.005 (0.155)
Program Type	0.7794 (0.1687)	0.013 (0.151)	0.596 (0.228)***	0.160 (0.140)	-0.116 (0.149)	0.208 (0.133)

Table 5. Continued

	At or Below Poverty	Ever Hungry	Ever Homeless or Evicted	Ever Late With Rent	Any Utility/Phone Shutoff	Any Hardship
Experimental Status	0.0705 (0.1279)	0.119 (0.115)	0.079 (0.180)	-0.161 (0.108)	-0.108 (0.114)	-0.038 (0.103)
Any housing subsidy	n/a	0.028 (0.141)	-0.577 (0.244)**	-0.479 (0.137)***	-0.093 (0.139)	-0.230 (0.128)*
Any severely disabled children	0.4783 (0.2992)	1.010 (0.239)***	0.113 (0.382)	0.611 (0.234)***	0.440 (0.245)*	0.930 (0.248)***
More than one child	0.3632 (0.3078)	0.5023 (0.2471)**	0.529 (0.360)	0.203 (0.243)	0.240 (0.254)	0.410 (0.247)*
Child receives SSI	-3.2499 (0.3262)***	-0.6724 (0.2863)**	-0.221 (0.416)	-0.183 (0.257)	-0.996 (0.300)***	-0.860 (0.259)***
Constant	1.254 (0.4530)*	-0.9033 (0.3926)**	-3.277 (0.649)***	-1.543 (0.374)***	-1.388 (0.396)***	-0.417 (0.352)

* p<0.10; ** p<0.05; *** p<0.01.

Source: California AFDC Household Survey, Wave II.

**Table 6. Logistic Regression Simulation Results, Probability of Hardship
California Families Receiving AFDC in November 1992
(weighted: 1,682 Households)**

	Probability of Any Hardship in Prior Year^a
Base Case: assumes respondent has average (10.43 years) education is single has average (2.2) children has no current employment is in the experimental group lives in Los Angeles County is in the FG program type is neither African American or Latino does not receive housing subsidies	0.4928
Add one severely disabled child without SSI	0.7114
Add one severely disabled child with SSI	0.5104
Add more than one child without SSI	0.5943
Add more than one child with SSI	0.3825
Add more than one, with any severely disabled child, without	0.7879
Add more than one, with any severely disabled child, with SSI	0.6111

^aHunger, homelessness or eviction, late payment of housing costs, utility shutoffs.

Source: California AFDC Household Survey, Wave II.

Figure 1 available from the author.

Figure 2 available from the author.

Figure 3 available from the author.

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