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Anna Lukemeyer
Syracuse University

Marcia K. Meyers
Columbia University

Timothy M. Smeeding
Syracuse University

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**EXPENSIVE CHILDREN IN POOR FAMILIES:
OUT-OF-POCKET EXPENDITURES FOR THE CARE
OF DISABLED AND CHRONICALLY ILL
CHILDREN AND WELFARE REFORM**

**Anna Lukemeyer, Marcia K. Meyers.
and Timothy M. Smeeding**

**Center for Policy Research
Maxwell School of Citizenship and Public Affairs
Syracuse University
Syracuse, New York 13244-1020**

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Anna Lukemeyer is a Ph.D. candidate in Public Administration at Syracuse University; Marcia K. Meyers is an Assistant Professor at Columbia University School of Social Work; and Timothy M. Smeeding is a Professor of Economics and Public Administration, and Director of the Center for Policy Research at Syracuse University. Support for this research was provided by the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, under Grant #94A5PE263A. The authors would like to thank Judy Wallace, Ann Wicks, and Doug Wolf for assistance, but retain responsibility for all errors of commission and omission.

Abstract

This study explores one aspect of the costs experienced by low-income families with one or more special needs children: direct, out-of-pocket expenses for items related to the child's disability, such as special foods, transportation to medical clinics, or medical costs not covered by insurance. We find that almost half (46 percent) of a sample of California AFDC families with special needs children experienced some special expenses in the preceding month. About 20 percent of these low-income families experienced total costs exceeding \$100. Families with severely disabled children were more likely to experience costs and tended to experience higher costs. While no more likely to experience special expenses, families of children with mental impairments tended to have higher costs than those with physical impairments. The primary impact of special expenses was to increase the percentage of families in deep poverty: those at or below 75 percent of poverty-level income. Taken as a group, however, families with special needs children appeared no more poor than other families. Much of this parity may be due to the Supplemental Security Income (SSI) program. Among families with severely disabled children, only 32 percent of those receiving SSI lived at or below poverty, while three quarters of those without SSI lived at or below poverty. Our findings suggest that out-of-pocket expenses are a substantial burden for some low-income families with special needs children and that the Supplemental Security Income program does a good job of alleviating these extraordinary outlays.

Background and Policy Context

Chronic mental or physical impairments in childhood can impose substantial private costs on families. The cost of special medical care, therapeutic and educational services, transportation, and other special-needs services can be a particularly heavy burden for all poor or near poor families. In addition, the time required for the child's care and the limited availability and/or high cost of specialized child care may reduce parents' ability to sustain paid employment (or raise costs associated with employment). The extent of these costs, their impact on families' economic well-being, and the role of public programs in offsetting them are at the heart of current debates about recent federal reforms to joint federal-state welfare programs such as AFDC and the Supplemental Security Income program.

Although estimates of the prevalence of disabling conditions vary considerably, most suggest that about 5 to 6.5 percent of children experience a condition that results in some impairment or limitation of their ability to engage in the usual activities of a child of that age (Aron, Loprest, and Steurle 1996). These estimates likely undercount mental illnesses and other disabling mental and emotional conditions (Aron, Loprest, and Steurle 1996), and evidence suggests that the number and proportion of children with some limit or impairment is growing (Newacheck and McManus 1988). Thus, a significant and growing minority of families face the challenges of raising a child with a disabling condition.

Disabilities¹ impose both economic and psychosocial costs on families with disabled family members (Hodgson and Meiners 1982). Ethnographic and small sample studies suggest that caring for a child with a severe disability or long-term illness results in a substantial burden to the family in terms of out-of-pocket costs, caregiving time and responsibilities, and emotional stress

(Whyte 1992; Jacobs and McDermott 1989). These studies, however, are limited primarily to the costs of specific, often catastrophic illnesses such as cancer, cerebral palsy, or cystic fibrosis. Less is known about the broader economic impact of other childhood impairments or childhood disabilities in general.

Low-income families seem particularly vulnerable to the costs of chronic childhood illnesses or disabilities. Activity-limiting chronic conditions are more common among children in low-income families (Newacheck, Jameson, and Halfon 1994; Newacheck and McManus 1988), and these families are likely to have fewer resources to meet the challenges of caring for a special needs child. Few studies have addressed the economic impact of childhood disability on low-income families, however. In this era of fiscal constraints, the costs of public programs providing services to disabled children, for instance Medicaid and special education services, are a matter of ongoing concern. Private economic costs, those born solely by the families of special needs children, are given less attention. Nevertheless, these costs affect the well-being of families, and, as Jacobs and McDermott (1989) point out, private costs and public costs are related: “cost-cutting” with respect to public programs may be simply “cost shifting” onto affected families. Effective social policy requires knowledge about both types of costs.

Issues of the economic impact of special needs children on low income families will be even more important as states implement new welfare programs and policies in response to the recently passed Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWO). The PRWO replaces the primary program of income support for families, the Aid to Families with Dependent Children (AFDC) program, with a new, state-managed program of Transitional Aid for Needy Families (TANF). The Act also imposes work requirements and time limits on many recipients. The prevalence of special needs children and the resulting costs to their

families raise issues with respect to eligibility rules, benefit levels, and the applicability of time limits and work requirements in the new TANF programs.

The PRWO also amends the Supplemental Security Income (SSI) program, a federal program providing cash benefits to low income families with severely disabled children. Since 1990, the number of families with disabled children receiving SSI benefits has grown dramatically, and the program has become a lightning rod for controversy. One issue underlying this controversy arises because the cash benefits available through SSI for a disabled child are often substantially greater than the benefits available through other welfare programs such as AFDC. Since SSI provides benefits for both mentally and physically disabled children, some critics have suggested that parents are coaching their children to display symptoms of behavioral disorders (such as attention deficit disorder) in order to obtain the higher SSI benefits. The General Accounting Office (1995, p 18) reports that it “found little evidence of widespread coaching but could not rule it out.”

A traditional explanation for providing SSI’s greater benefits to families with disabled children has been that the child’s disability places a substantial economic burden on the family. The legislative history of Public Law 92-603, which created the SSI program, suggests that Congress enacted a structure allowing families with disabled children access to the greater SSI benefits because it accepted the argument that these families had greater needs than other low-income families.² While the PRWO did not reduce SSI benefit levels, it tightened SSI eligibility requirements for children by imposing a more stringent definition of a qualifying disability. The Social Security Administration (1997) estimates that changes under the PRWO will disqualify approximately 135,000 children receiving benefits under the old standard. The impact of these

changes on family well-being will depend, in part, on the frequency, distribution, and the magnitude of the extra costs incurred by families with disabled children.

Although information about the private costs of children's disabilities is clearly relevant to policy issues with respect to these programs, we know relatively little about the economic impact of a special needs child on a low-income family. This paper investigates one part of the private cost of disability. Specifically, we look at direct economic costs experienced by a sample of current and recent AFDC recipients in California who care for children with special needs. These costs include unreimbursed medical expenses as well as out-of-pocket expenses for non-medical items related to the child's disability such as special diets, specialized child care, or transportation to distant hospitals or clinics. We examine the extent to which these families experience out-of-pocket costs, the impact of these costs on poverty status, and the relationship between out-of-pocket costs and characteristics of the child.

Prior Research

Families with special needs children experience both economic and psychosocial costs (Hodgson and Meiners 1982). Psychosocial costs encompass "a wide variety of deteriorations in the quality of life" resulting from the child's disability (Hodgson and Meiners 1982, p.435). For instance, caregiving tasks (such as daily therapy in the case of a child with cystic fibrosis or coping with disruptive behavior in the case of a child with a mental disability), concern about the child's future, and the financial costs of the child's disability can all lead to emotional stress, disruptions in family relationships, and other psychosocial costs (Reinhard and Horwitz 1995; Baldwin, et al. 1995; Whyte 1992).

Economic costs may be direct or indirect. Indirect economic costs include earnings foregone by the child's parents in order to meet the child's needs as well as the market value of unperformed housekeeping services (Hodgson and Meiners 1982). There is some evidence that parents of children with severe disabilities can spend a substantial amount of each day in caregiving activities and that this can result in indirect economic costs. In a study of Minnesota parents of severely disabled children, Leonard, Brust, and Sapienza (1992) report that the median respondent spent over four hours a day in caregiving activities. Lansky et al. (1979) found that half of the families studied reported lost wages due to the child's condition, with a median of loss of \$68.94 weekly. Salkever (1982) found that the presence of a disabled child had a significantly negative impact on women's labor force participation among white, two-parent families. These studies suggest that for some families with special needs children, the indirect economic costs can be substantial.

Although it is clear that psychosocial and indirect economic costs can be great, we focus on direct economic costs in this paper. Direct costs include out-of-pocket medical expenses associated with the child's condition as well as nonmedical costs directly resulting from the child's disability.³ Nonmedical costs can include transportation and lodging required for travel to distant treatment centers, long distance calls home, structural modifications to the home, special food or clothes for the child, babysitting for other siblings while the parents accompany the child to the doctor, special or more expert child care services while the parents are at work, and numerous other items. In addition to being a direct cost, the child's need for specialized child care can also result in indirect costs by reducing parents' labor force participation.

Newacheck and McManus (1988) report that disabled children on average used more medical and health care services and incurred health care expenditures nearly three times as great

as non-disabled children.⁴ Expenditures were comparatively low or nonexistent for most and very high for a minority. Most disabled children have public or private medical insurance (Congressional Research Service 1988), but this insurance does not necessarily cover all health care expenses. Newacheck and McManus (1988) also found that families with disabled children experienced uncovered, out-of-pocket expenses substantially higher than those of families with no disabled children.⁵ Out-of-pocket expenditures were distributed like medical expenditures in general: relatively low for many disabled children but high for some.⁶ Overall, out-of-pocket expenses were lower for disabled children in low-income families, reflecting perhaps the more comprehensive coverage provided by Medicaid (Newacheck and McManus 1988) and/or budget constraints in these families.

Newacheck and McManus (1988) apparently included only health care costs in their calculation of out-of-pocket expenses. Studies using smaller, more limited samples have looked at other, nonmedical out-of-pocket costs. Jacobs and McDermott (1989) reviewed six studies published between 1971 and 1985 which looked at the costs associated with caring for children with specific, very disabling diseases. Looking at home costs, travel costs, and equipment costs,⁷ these studies reported average annual expenditures ranging from \$334 for children with cystic fibrosis to \$4,012 for children with cancer.

Urban Systems Research and Engineering (1979) investigated extra expenditures incurred by families with children eligible for federal Supplemental Security Income (SSI) program benefits. Due to the eligibility restrictions of the SSI program, these are low-income families with a relatively severely disabled child. These SSI families averaged \$28 per month in out-of-pocket expenses related to the child's disability in 1978. The most commonly reported categories of additional costs were transportation, clothes, and medical care items and services not covered by

Medicaid. Again, these costs were not evenly distributed across families; some families experienced no costs while others experienced substantial costs.

Although the number of studies is small and many are dated, this research suggests some tentative conclusions. First, many families of disabled children experience out-of-pocket costs resulting from the child's disability, and for some families these costs can be a very substantial burden. Jacobs and McDermott (1989) were able to compute the proportion of family income consumed by out-of-pocket costs for two of the cancer studies. The results were quite high: 14 and 15 percent. Newacheck and McManus (1988) report that 15 percent of families experiencing high costs had incomes below poverty. Among Urban System's sample of low-income families, 22 percent reported making at least one special purchase or incurring one major expense of greater than \$100 in the past year due to the child's disability.

Second, these studies consistently report considerable variability in the amount of costs. This is true even with respect to those studies limited to a single category of disease. Although researchers have begun to identify factors associated with high costs, much work remains to be done in identifying causal relationships among the wealth of variables potentially affecting costs (Leonard, Brust, and Sapienza 1992; Jacobs and McDermott 1989).

Finally, out-of-pocket expenses can contribute substantially to the psychosocial costs of disability. In a study of childhood cancer, Lansky and colleagues (1979) report that, after the disease itself, financial burdens are the primary source of stress for patients' families. Because they generally must be paid out-of-pocket immediately, nonmedical costs cause the most worry.

Research Questions

The out-of-pocket costs associated with childhood disabilities vary widely across types of disabilities and types of families affected. The best studies for measuring these costs are now more than 15 years old, and we still know little about the factors that determine the distribution of those costs. While low-income families are more likely to include a special needs child, they are less likely to have the resources to absorb private, disability-related costs. Nevertheless, information about the magnitude, distribution, and impact of out-of-pocket expenses on low-income families is particularly scarce. These issues have particular urgency in light of federal legislation affecting the primary programs of cash assistance to poor families with disabled children, AFDC and SSI.

This paper addresses these gaps in our knowledge. We address four research questions that have bearing on current policy debates:

- ! What is the prevalence of special needs among welfare recipient families?
- ! What is the distribution of out-of-pocket costs across welfare families with special needs children?
- ! What is the impact of those costs on poverty status?
- ! How is the occurrence and amount of out-of-pocket costs related to individual and family characteristics, including the type and functional severity of the child's condition?

Methods

Data

This paper analyzes data from Wave II of the (California) AFDC Household Survey, 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. An initial stratified random sample of AFDC recipient families was selected from four California counties: Los Angeles, Alameda, San Joaquin, and San Bernardino. The sample included both single-parent households and two-parent households qualifying for benefits through the AFDC-UP program.⁸ The data analyzed here are from Wave II of a telephone survey of a subsample of 2,250 English and Spanish speaking households randomly selected from the initial sample. The AFDC Household Survey is a panel survey. Initial (Wave I) interviews began in October 1993; a follow-up (Wave II) interview was fielded beginning in May 1995. Wave II of the survey included a set of questions to identify and gather information about families with chronically ill or disabled children. Survey data are weighted to adjust for differences in sampling fractions by strata and for survey completion rates.

Sample Limitations and Generalizability

Several important characteristics of this sample should be noted. The sample for this study was designed to represent the AFDC population in four counties in California, representing over half of the welfare caseload for the state. The findings can be generalized to the welfare population in that state but may not fully represent the characteristics of families in the AFDC system elsewhere in the country. Because important groups were not included in this round of surveys, notably recent immigrants, caution must also be used even in drawing conclusions about California.

The sample has another important characteristic. As a cross-sectional sample, it “samples the stock” of all welfare cases and represents the experiences of families who were receiving welfare at a point in time. As substantial research in this field has demonstrated, this will not represent the experiences of all families who ever enter the welfare system. In particular, this

cross-sectional sample will overrepresent long-term, more highly disadvantaged welfare recipients relative to the larger number of short-term, relatively more advantaged families who cycle through the welfare system more quickly. The findings from this study are particularly useful for understanding the experiences of longer term welfare clients and the characteristics of welfare caseloads at any point in time.

Data from the second wave of a panel survey are used for this survey. These interviews were conducted up to three years after the sample was selected from AFDC records. Although all respondents were AFDC recipients when the sample was drawn, approximately one-quarter of families were no longer receiving AFDC at the time of the interview.

It is also important to note that this sample represents the experience of only a fraction all families with disabled children and of SSI recipient families. The sample of families represented here, those poor enough to qualify for AFDC, are an especially disadvantaged subset of all families who care for exceptional children. They are, however, the subset of families most likely to be affected by recent federal changes in welfare and the SSI program. Findings about the distribution and impact of private costs for this population of families have particular relevance for these policy changes.

Analysis

The first section of this paper presents a household-level analysis of families with special needs children and their direct, disability-related costs. To identify affected families, we asked respondents whether each child: 1) had a chronic health problem—physical, emotional, or mental—that limited the amount or kinds of things that he or she could do; 2) had a disability or handicapping condition that limited the amount or kind of things he or she could do; or 3)

received SSI benefits. We classified a family as including a special needs child if the respondent answered yes to any of these screening questions.

We used respondents' (mothers') reports to assess whether the child's disability imposed mild, moderate, or severe limitations on the child's activities and abilities. Factors coded as "severe" or "moderate" are summarized in Figure 1. Children who were identified as having special needs by our screening questions but who met none of the conditions for a moderate or severe disability were classified as "mildly" disabled.

For families with one or more special needs children, we describe in some detail the distribution, amount, type, and economic impact of direct, disability-related expenses. We measured disability-related expenses in two ways. First we asked whether the family had made any special purchases or incurred major costs, over \$100, since the wave 1 survey, because of the child(ren)'s disability. In addition, we also asked whether the family had experienced any disability-related expenses in the month before the interview and the amounts of those expenses. For the previous month's expenses, we asked families separately about six types of expenses: special clothes, special foods, transportation, medicine and health care, child care, and any other special expenses. Respondents with more than one special needs child reported aggregate expenses for all the children. To measure the economic impact of these expenses, we calculated each family's income and poverty status for the previous month before and after deducting special expenses.⁹

Finally, we analyzed the distribution of expenses at the level of the individual child to identify factors predicting more burdensome special expenses. Families with more than one disabled child (about 5.0 percent of our sample) presented two problems which may limit the applicability of our findings. First, we have only household-level data on special expenditures.

For families with more than one special needs child, we simply averaged the expenses across the number of disabled children. This is likely to introduce a conservative bias into our analysis, obscuring the impact of some variables. Second, for this paper we limited our analysis to the first child identified as disabled. This child is usually also the oldest of the disabled children. Thus, this tactic may limit the applicability of our findings to later-born and younger disabled children.

We focus primarily on two independent variables for understanding expenses: the type of condition and its functional severity. For each child identified by our screening questions, we asked respondents to identify up to five conditions causing the child's impairment. Because the small numbers of children affected, we grouped children's conditions into eight broad categories. Four are classified as physical conditions: respiratory diseases (including asthma and chronic sinus infections); arthritis, deformities, and diseases causing muscle weakness; visual or hearing impairments; and all other physical conditions. Three additional conditions are classified as mental or psychological: behavioral and learning disorders (including attention deficit hyperactivity disorder), mental retardation and developmental disabilities (including autism), and mental and emotional illness. Speech impairments constituted an eighth and final category.¹⁰

Descriptive statistics are all weighted to correspond to the populations in each of the four counties. Differences across groups are evaluated with simple t-tests. Tests of statistical significance have been adjusted to account for design effects from the use of a stratified sample. (Eltinge and Sribney 1996). This adjustment effectively increases standard errors on all statistical tests and represents the most conservative test for significance. We report results that achieve a threshold of $p=.10$.

Results

Prevalence of Conditions

Chronic health problems and disabilities were frequent among this sample of AFDC recipient families: almost 40 percent of households had either a disabled mother and/or at least one child with special needs. As shown in Table 1, women in 20 percent of households reported the presence of at least one child with a chronic health problem or disability. Fifteen percent reported one special needs child in the household, and five percent reported more than one. Although disabilities and chronic illnesses were common among the children in our sample, the majority were mild to moderate by our definition of severity. Nevertheless, nearly 9 percent of all families cared for at least one child with a severe disability or illness. When adult disabilities and children's special needs are considered together, 38 percent of households were affected: 12 percent of households had at least one child with a special need, 18 percent were headed by a disabled mother (with no disabled children), and 8 percent had both a disabled caretaker and child.

As we expect, the prevalence of any limiting conditions for children and adults in our sample is much higher than most national population estimates. However, the general population is not the group most likely to be impacted by welfare reform. On the other hand, our estimate is similar to recent estimates of disabilities in the welfare population by Acs and Loprest (1994). Using several nationally representative data sources they estimate that 29 percent of AFDC recipient families have a mother or child with some functional limitation; in 18 to 21 percent, the mother has some limitation or the child has a serious disability.

Amount and Type of Special Expenses

Looking first at major expenses, about 12 percent of families report at least one major purchase or expenditure, over \$100, in the approximately 18 months between waves of the survey

(Table 2). Medical care (such as tests, hospital stays, or therapy) and special equipment (such as wheelchairs or braces) were the most common sources of major expenditures.

As shown in Table 3, nearly half (46.1 percent) of families with special needs children reported incurring some out-of-pocket expenses in the prior month. For those with expenses, the total amount ranged from \$5.00 to \$665, with a median cost of \$100 and a mean cost of \$135. For 12 percent, total expenses were relatively small (\$25 or less). However, almost 43 percent of those with costs (about 20 percent of all families with special needs children) experienced costs exceeding \$100 and for almost 12 percent of those with costs (6 percent of all families) costs were extremely high—exceeding \$300.

Unreimbursed medical expenses were the most common type of direct cost in the prior month (23 percent). Although common, medical expenses were quite moderate for most. Almost half paid less than \$25 in out-of-pocket medical expenses, and only 6 percent paid more than \$100. The next three most commonly incurred expenses, child care, special food, and special clothing, appeared more burdensome. Respondents incurring these costs reported average expenditures of \$119, \$83, and \$83 respectively.

Distribution of Expenses at the Household Level

We looked at two factors likely to increase a family's out-of-pocket expenses: the presence of a severely disabled child in the family and the presence of more than one special needs child (without regard to severity level) (Table 2). The presence of a severely disabled child in the family substantially increased both the likelihood and the amount of special expenses. More than half (53 percent) of families with a severely disabled child incurred disability-related expenses in the previous month compared to 41 percent of families with only mildly or moderately impaired children ($p=.09$). Among those families with costs, families with severely disabled children

experienced higher costs on average—\$167 in comparison to \$101 for families with less severely disabled children ($p=.02$). Families with a severely disabled child were more than twice as likely as those with a more moderately disabled child to have incurred a major expense (18 percent versus 9 percent) ($p=.09$).

In contrast to severity, the presence of more than one special-needs child showed no significant impact on either likelihood or amount of expense for the family. Families with more than one special needs child appeared somewhat more likely to have incurred costs in the preceding month (52 versus 44 percent), but the difference was not statistically significant. Those with more than one special needs child also reported spending more in the prior month (\$159) than did families with just one special needs child (\$125); again, the difference was not statistically significant. The small marginal difference in spending by families with more than one disabled child might reflect economies of scale on some expenses, unmeasured differences between the children in the family, and/or a lack of precision in our measurement of costs. It is also possible that, for these very low income families, there is an absolute limit on resources for special expenses such as these. Particularly for families relying on AFDC and Food Stamps, the incremental increase in benefits for each additional household member may be too small to allow proportionate spending as the number of special needs children in the family increases.

Economic Impact of Special Expenses

Even relatively small expenses can present a significant burden on low-income families with few resources to spare. For more than one-third of the families experiencing costs in the preceding month, expenses exceeded 10 percent of total monthly income for the family; for 17 percent, expenses exceeded one-quarter of total income (Table 4). For the median family with costs, special expenses consumed 7 percent of the month's income. As would be expected, the

impact was greater among those with a severely disabled child. Forty-four percent of these families who had costs paid more than 10 percent of their income in special expenses, and the median family with expenses experienced costs equal to 9 percent of total family income.

Table 5 shows the impact of those expenses on family poverty, by comparing poverty rates for families with special needs children, before and after adjusting for the out-of-pocket expenses associated with their children's conditions. Several conclusions are notable.

First, before adjusting for the cost of special expenses, families with special needs children tended to be somewhat better off than families without special needs children. Fewer families with special needs children lived below poverty (58 versus 69 percent), and a smaller percentage were very poor—with incomes at or below 75 percent of poverty (26 versus 36 percent). When incomes were adjusted to reflect out-pocket-costs associated with the care of disabled children, however, the poverty of families with special needs children became more severe. The fraction of families with special needs children living below the poverty line increased from 58 to 62 percent when out-of-pocket costs were considered, and the number in deep poverty increased to more than one-third (36 percent).

Second, and most troublesome, the primary impact of out-of-pocket expenses was to increase substantially the percentage of extremely poor families: those at or below 75 percent of poverty-level income. In the case of families with more than one special needs child, this impact was particularly dramatic, increasing the percentage in deep poverty from 35 to more than half (53 percent). Duncan and colleagues (forthcoming) find that similarly defined deep poverty results in a significantly higher risk of poor educational performance and diminished abilities and achievements for nondisabled children more generally. Hence, deep poverty is something to be avoided in general and particularly for families with one or more disabled children.

Finally, Table 5 demonstrates that most of the relatively “better off” status of families with disabled children was due to participation in the SSI program. When families with severely disabled children are separated according to whether their disabled child or children receive SSI benefits, the results suggest families with SSI benefits were substantially better off, with only 11 percent living in deep poverty and 32 percent at or below poverty. On the other hand, those with a severely disabled child and no SSI benefits were the most disadvantaged of the lot. Even without considering special expenses, 41 percent lived in deep poverty. After accounting for special expenses, this percentage increases to 57 percent. With or without consideration of special expenses, fully three quarters of these families lived at or below poverty.

Distribution of Expenses: Individual Factors

Understanding what differentiates families with and without burdensome expenses is necessary if we are to develop effective and efficient policies for low-income families with special needs children. Table 6 summarizes differences in the probability and level of special expenses by the characteristics of respondents and of the first (usually oldest) disabled child in the family. Monthly expenses are reported per disabled child; in families with more than one special needs child, the expenses are a simple average per disabled child.

Child Characteristics. The severity of the disabled child’s condition was the single best predictor of the probability that families would incur expenses and the magnitude of those costs. Families were more likely to have any expenses in the prior month ($p=.12$) and high expenses in the interval since Wave 1 interviews ($p=.07$) if their child had a severely limiting condition. Among families with expenses, those with severely disabled children spent, on average, \$135 in the prior month for the special needs of their child, in comparison to an average of \$87 spent by parents with only moderately limited children ($p=.03$). Likewise, families in

which the disabled child had been hospitalized during the period between Wave I and II interviews were significantly more likely to have had high expenses in that interval, and their average expenditures in the prior month were over \$50 higher per child ($p=.09$).

The impact of the type of condition was less consistent. The probability of incurring any expenses in the prior month, and high expenses in the interval since Wave 1, was not significantly different for families with physically and mentally disabled children. The average level of expenditures per child for those with expenses did differ significantly, however, with higher expenditures reported by families in which the child's primary diagnosis was a mental condition ($p<.08$). When the type and severity of the child's condition were interacted, families with children who had severe mental disabilities had a consistent pattern of greater expenditures: although their probability of incurring costs did not differ from other families, their probability of incurring costs over \$100 in period since Wave 1 was higher (although the difference was not statistically significant) and, for those with costs, actual expenditures per child were over \$70 higher in the prior month than those of other families ($p<.05$). A similar pattern was not evident for families caring for children with severe physical disabilities.

Specific Condition. Within the broad categories of physical and mental impairments, some specific conditions appeared to impose higher costs than others (Table 7). Across physical conditions, the probability of incurring costs in the prior month ranged from 32 to 52 percent, a nonsignificant difference. When the magnitude of monthly costs was regressed on dummy variables for specific conditions (with respiratory conditions as the excluded category), however, overall results indicate that differences in expenditures by condition were significant ($p<.01$). (The significance of estimations for each of the conditions was variable.) The data suggest several different patterns that may characterize spending on the special needs of children. Respiratory

problems, including asthma, were the most common conditions reported in this population, and the families of these children were quite likely to incur some expenses associated with their children's conditions (49 percent). Expenses for these children were generally low, however: families with costs averaged \$79 per children and 31 percent had total costs of \$25 or less. In contrast, cost were less frequent but sharply higher for families whose children had sensory impairments (hearing impairments, deafness, vision impairments and blindness). The average monthly costs for these children were \$169 and over half of families had expenses of \$100 or more.

Similar patterns can be observed for families whose children had mental disabilities. Families whose children had developmental delays (including mental retardation and autism) were the most likely to incur any expenses (49 percent) but their costs were lower on average than those of other families (\$101 per child). Those caring for children with learning and behavioral disorders were less likely to incur costs (32 percent), but among those who did, costs were substantially higher at \$174 per child.¹¹

Conclusions and Discussion

The disability status of children in low-income families is receiving more scrutiny in the wake of recent federal changes to the AFDC and SSI programs. This study finds evidence that disabilities and chronic illness affect substantial number of adults and children in the welfare population. We find that as many as one fifth of families in a sample of current and recent welfare recipients in California care for a child with a moderate to severe condition; in 8 percent of families, the mother is also disabled. These figures are higher than estimates for the general population but similar to estimates using nationally representative samples of welfare recipients.

In some respects the findings reported here on the out-of-pocket expenditures by low-income and welfare-recipient families are also quite similar to those of researchers who have examined other populations with disabled children. In any given month, close to one-half of these low-income families who had special needs children incurred extra, out-of-pocket expenses associated with the care of those children. For some, these costs were quite modest. But for about 20 percent of all families with disabled and chronically ill children, the costs in a single month exceeded \$100.

These findings extend those of other studies by demonstrating the impact of these costs on the economic well-being of very poor families and the role of SSI in partially offsetting these costs. When family incomes were adjusted to reflect out-of-pocket expenditures for disabled and ill children, the percent of families with special needs children living below the poverty line increased from 58 to 62 percent, and the proportion in deep poverty increased from 26 percent to more than one-third. In the case of families with more than one special needs child, the impact of special expenses was particularly dramatic, increasing the proportion in deep poverty from 35 percent to more than half.

By definition, all of the families in this sample were current or recent AFDC recipients. A smaller number, 11 percent, were also receiving SSI for one or more disabled family members. The impact of the extra income provided by the higher SSI benefits on family poverty was clear, even after adjusting for these expenses. Among families receiving SSI for a severely disabled child, 32 percent were living at or below poverty and only 11 percent were living in deep poverty, even after special expenses were considered. These families were, on average, slightly better off than other AFDC reliant families with no disabled children. Among families with severely

disabled children who did not receive SSI benefits, in contrast, fully three quarters were poor and 57 percent were living in deep poverty.

These findings suggest that SSI has an important anti-poverty impact and that the special expenses imposed by some disabled children may warrant the additional income SSI benefits provide to those families. There was great variability in the probability of incurring costs and in their magnitude, however, and few characteristics other than the severity of the child's condition were consistent predictors of costs or high costs. Families with children who had mental disabilities had somewhat higher expenses than those whose children had physical conditions, but differences were neither consistent nor large.

The current debate about SSI for children has been fueled by disagreements about the justification for, and the impact of, the higher benefits available to low-income families through SSI (in comparison to the marginal increase in AFDC benefits). This study suggests that for some families, this extra income may provide an important cushion against a slide into deep poverty. If extra expenses are incurred only by some families, however, it is possible that SSI or other disability benefits could be targeted more narrowly. Identifying the factors associated with higher expenses is an important area for further research. Further, direct, out-of-pocket expenses represent only a portion of the potential economic impact of special needs children. An assessment of the total economic impact requires consideration of the extent to which these children's need for special care limits their parents' ability to earn employment income. Additional research is also needed into indirect economic costs such as these.

The burden that out-of-pocket expenses impose on a family will depend on both the magnitude of the extra costs and the frequency of their occurrence. Some types of disabilities, such as asthma and allergies, may impose modest but regular expenses for medication, special

diets, and other adjustments. Others, such as sensory impairments, may require less constant but more extensive accommodations—such as special equipment and modifications to the home. Over time, both patterns of expenditure may be quite burdensome for low income families. Because this study collected data only for a single month, however, it is not possible to differentiate between recurring and intermittent expenses.

The costs of caring for children with different types and severity of condition may be uneven over time, but the probability of incurring any special costs was surprisingly even across conditions. This suggests that, at least at this level of aggregation, few conditions could be excluded as imposing few or no costs on families. In fact, the disease categories that have come under the closest scrutiny in the SSI debate—the so called “soft” categories of behavioral disorders, learning disorders, and speech impairments—were associated with some of the highest out-of-pocket costs for families.

The results of this study suggest caution for revisions to cash assistance program for families caring for disabled children. As states develop new programs of Temporary Assistance for Needy Families to replace AFDC, the special expenses and constraints of the nearly one-fifth of families with disabled children must be recognized. Early plans in some states have identified families with severely disabled children, particularly those receiving SSI, as needing special exemptions from work requirements and time limits. Alternately, these parents may benefit from extra support during a transition to work. Even more than other disadvantaged adults, these parents of disabled and chronically ill children may need direct services (such as specialized child care) and extra resources to purchase special goods and services (such as equipment or transportation) that would ease the financial and caretaking burden associated with the care of an exceptional child.

Even more caution is urged with regard to SSI, the program that has provided extra resources for some low-income families with special children. The original justification for children's benefits—the potential hardship that care for a disabled child imposed on a low income family— appears justified for many poor and welfare-recipient families. Although better targeting of this assistance may be possible, these data do not suggest any broad categories or types of children's conditions that do not impose financial burdens on at least some families. SSI benefits appeared to have the greatest impact in reducing severe poverty among families with seriously disabled children. A significant curtailment of the program, as mandated by the federal PRWO, may significantly increase hardship for economically vulnerable families and developmentally fragile children. It may also increase the difficulty for states attempting to transform AFDC into a program of temporary assistance. Rather than reducing public costs and family hardship, this may simply represent a new form of “cost shifting”—from public programs to economically marginal families, and from federal to state and local governments.

Endnotes

1. In this paper, unless otherwise indicated, we use “disability” and “disabled” to mean a long-lasting mental or physical condition which limits the child’s ability to take part in the usual activities (such as school, play, or self-care) of a child that age. A “special needs” child is a child with such a condition.
2. Benefits for children were added to the SSI program in a political compromise. The House Ways and Means Committee initially added these benefits, explaining that disabled children living in low-income households were among the most disadvantaged of Americans, that they had greater needs than other children, and that they were therefore deserving of special help (H.R. Rep. No. 231, 92nd Cong., 2d Sess., reprinted in 1972 U.S. Code Cong. and Admin. News 4989, 5015). The Senate at first rejected this view, but benefits for children were ultimately accepted in a House-Senate conference. Urban Systems Research and Engineering (1979) outlines the Congressional debate in *Survey of Blind and Disabled Children Receiving Supplemental Security Income (SSI) Benefits*, as do Weishaupt and Rains (1991). Because SSI legislation was enacted within the context of sweeping welfare reforms proposed by the Nixon administration, Congress paid comparatively little attention to the issue of SSI benefits for children (Burke 1974; Woodward and Weiser 1994). Woodward and Weiser (1994) and Burke (1974) describe the political context.
3. On an aggregate level, all medical costs are direct costs (Hodgson and Meiners 1982). We focus on the impact of a special needs child on the family’s available income. Arguably, some portion of private insurance premiums paid by the family should be included in our measure of direct costs resulting from the child’s illness. The studies that we reviewed have not attempted to address the complex issue of determining the portion of insurance premiums, if any, attributable to the illness. We do not have data on private insurance premiums, and so we do not address this issue.
4. Children with activity limitations reported average total expenditures of \$760 in 1980. Children without limitations reported \$263.
5. Disabled children reported average out-of-pocket expenses of \$135 compared to \$76 for nondisabled children.
6. Newacheck and McManus’s (1988) figures suggest that more than half experienced out-of-pocket costs of approximately \$50 or less in 1980. Approximately 10 percent incurred costs exceeding \$200 in 1980.
7. Not all studies included all of these cost categories.
8. The sample includes a small number of male respondents, but respondents were overwhelmingly women.

9. Specifically, we added together all income received by the family for the preceding month, including food stamps. To determine poverty status, we annualized this figure and divided it by 1995 Census bureau poverty level income for families of comparable size.
10. We omitted three children as having unclassifiable conditions
11. Since children were coded on the basis of their first disability, it is possible that some children had multiple conditions that are not reflected in this analysis.

Figure 1. Coding of Severity: Children’s Health Conditions and Disabilities

Moderate

Child meets one or more of the following conditions

Needs “a little” more help than other children his/her age with daily activities
(e.g., eating, bathing, dressing, or getting around the house).

Unable to take part in usual activities for a child of his/her age.

Attends special classes or receives special education services due to condition.

Misses “some” days of school due to condition.

Limited in ability to crawl, walk, run, or use stairs.

Severe

Child meets one or more of the following conditions

Needs “a lot” more help than other children his/her age with daily activities
(e.g., eating, bathing, dressing, or getting around the house.)

Misses “a lot” of days of school due to condition.

Prevented from going to school at all by condition.

Receives Supplemental Security Income (SSI) benefits.

**Table 1. Prevalence of Disability among Mothers and Children
California Families Receiving AFDC in November 1992
(weighted: n=1,704)**

	Number of Families						
	All Families n (column percent)	By Number of Disabled Children			By Severity of Child's Disability		
		None n (row percent)	One n (row percent)	More than One n (row percent)	None n (row percent)	Mild to Moderate n (row percent)	Severe n (row percent)
No disability, mother or child	1,052 (61.7)	1,052 (100.0)	0 (0.00)	0 (0.00)	1,052 (100.00)	0 (0.00)	0 (0.00)
Mother only disabled	311 (18.3)	311 (100.0)	0 (0.00)	0 (0.00)	311 (100.0)	0 (0.00)	0 (0.00)
Child(ren) only disabled	200 (11.7)	0 (0.00)	167 (83.5)	33 (16.5)	0 (0.00)	118 (59.3)	81 (40.7)
Both mother and child disabled	141 (8.3)	0 (0.00)	89 (63.1)	52 (36.9)	0 (0.00)	75 (52.8)	67 (47.2)
Total, all families	1,704 (100.0)	1,363 (80.0)	256 (15.0)	85 (5.0)	1,363 (80.0)	193 (11.3)	148 (8.7)

Source: Authors' calculations from California AFDC Household Survey, Wave II.

Table 2. Out-of-Pocket Disability-Related Expenditures
California Families with Special Needs Children Receiving AFDC in November 1992
(weighted: n = 341)

Family Characteristics	Out-of-Pocket Expenses			
	Expenditure Greater than \$100 Since Wave 1 (percent of families)	Any Expenses Last month (percent of families)	Amount of Expense Last Month (among families with expenses) (in dollars)	
			Mean	Median
All families with one or more disabled children	12.5	46.1	134.53	100.00
Number of disabled children				
One	12.9 (n.s.)	44.2 (n.s.)	124.79 (n.s.)	100.00
More than one	11.4	51.8	159.42	68.25
Severity				
No severely disabled children	8.7 (t = 1.69) ^a	40.7 (t = 1.68) ^a	101.50 (t = 2.37) ^b	67.63
One or more severely disabled	17.5	53.1	167.48	122.00

^aDifference of means (or proportions) significant at the .10 level.

^bDifference of means (or proportions) significant at the .05 level.

Source: Authors' calculations from California AFDC Household Survey, Wave II.

**Table 3. Out-of-Pocket Disability Related Expenses Last Month
California Families with Special Needs Children Receiving AFDC in November 1992
(weighted: n=341)**

Type of Expenses	Families with Expenses		Of Families with Expenses				
	Number	Percent	Mean	Median	Maximum	Percent Less than \$26	Percent Greater than 100
Clothing	29	8.6	83.20	70.00	301.00	6.8	17.6
Food	49	14.5	83.25	70.00	301.00	5.8	24.2
Transportation	22	6.4	49.20	50.00	250.00	29.3	1.3
Medical	80	23.4	48.58	30.00	301.00	46.2	6.0
Child care	64	18.9	118.60	100.00	301.00	11.7	34.4
Other	23	6.6	89.90	40.00	301.00	6.1	29.6
Total (all types)	157	46.1	134.53	100.00	665.00	12.2	42.7

Source: Authors' calculations from California AFDC Household Survey, Wave II.

**Table 4. Out-of-Pocket Disability Related Expenses
as a Percent of Income
California Families with Special Needs Children Receiving AFDC in November 1992
(weighted: n=335)**

Percent of Family Income Consumed by Expenses	Percent of Families with This Level of Expense	
	Percent of Those with Expenses (n=155)	Percent of All Families
0 percent	na	53.9
0.01 to 5.00 percent	33.7	15.6
5.01 to 10.00 percent	30.8	14.2
10.01 to 25.00 percent	18.5	8.5
Greater than 25.00 percent	17.0	7.9

Source: Authors' calculations from California AFDC Household Survey, Wave II.

**Table 5. Poverty Status with Adjustments for Out-of-Pocket Expenditures
California Families Receiving AFDC in November 1992
(weighted: n=1322)**

Poverty Category	Percent of Families							
	No Special Needs Children	All with Special Needs Child(ren)	By Severity				By Number of Disabled Children	
			Mild to Moderate	Severe		One Child	More than One Child	
				All Families	No SSI ^a			With SSI ^b
75 percent or less of poverty level								
Income	36.0	26.1	32.3	18.0	40.8	0.7	22.8	35.5
Income less expenses	na	36.2	40.5	30.6	56.8	10.8	30.4	53.2
75 to 100 percent of poverty level								
Income	32.8	31.7	37.1	24.6	35.0	16.9	34.5	23.8
Income less expenses	na	25.8	30.0	20.2	19.0	21.2	29.7	14.1
100 to 125 percent of poverty level								
Income	9.3	18.3	11.6	27.1	10.1	39.9	18.4	18.1
Income less expenses	na	15.7	11.8	20.8	10.1	28.9	17.6	10.3
125 to 150 percent of poverty level								
Income	7.2	7.6	5.7	10.2	8.2	11.6	7.5	7.9
Income less expenses	na	7.7	6.4	9.4	8.2	10.2	7.1	9.2
Greater than 150 percent								
Income	14.7	16.3	13.3	20.1	5.9	30.9	16.8	14.7
Income less expenses	na	14.6	11.3	19.0	5.9	28.9	15.2	13.2

^aNo child in the family receives SSI benefits.

^bAt least one child receives SSI benefits.

Source: Authors' calculations from California AFDC Household Survey, Wave II.

Table 6. Expenses by Child's Characteristics
California Families with Special Needs Children Receiving AFDC in November 1992
 (weighted: n=341)

Characteristic of Oldest Disabled Child	Expenses		
	Expenses Greater than \$100 Since Wave 1 (percent of families)	Any Expenses Last Month (percent of families)	Amount of Expense Last Month among Families with Costs (per child) ^a
Girl	9.33 (ns)	45.66 (ns)	\$113.18 (ns)
Boy	14.65	46.73	\$107.02
Mother's (respondent's) race			
African American	14.65 (ns)	49.78 (ns)	\$101.86 (ns)
Latina	8.70	45.12	\$108.17
White	11.76	38.90	\$75.82
Hospitalized in prior 18 months	23.85 (t=-1.87)*	49.14 (ns)	\$148.95 (t=-1.69)*
No hospitalizations	9.49	45.69	\$97.83
Disability severe	18.34 (t=-1.83)*	52.93 (ns)	\$135.29 (t=-2.18)**
Disability mild or moderate	8.54	41.44	\$87.18
Physical disability ^b	12.14 (ns)	48.43 (ns)	\$96.92 (t=-1.76)*
Mental disability ^b	11.86	38.88	\$146.01
Severe physical disability ^b	15.38 (ns)	54.94 (ns)	\$114.25 (ns)
All others ^b	10.89	42.69	\$105.14
Severe mental disability ^b	19.69 (ns)	45.49 (ns)	\$171.57 (t=2.21)**
All others ^b	10.79	45.96	\$97.51

^aIn families with more than one disabled child, expenses per child were calculated as an average of total expenses.

^bExcludes children with speech impairments and two with unclassifiable disabilities.

*Significant at the .10 level.

**Significant at the .05 level.

Source: Authors' calculations from California AFDC Household Survey, Wave II.

**Table 7. Out-of-Pocket Disability Related Expenses, Average Per Child
California Families with Special Needs Children Receiving AFDC in November 1992
(weighted: n=339)^a**

Type of Condition	Expenses		
	Expenditure Greater than \$100 Since Wave 1 (percent of families)	Any Expenses Last Month (percent of families)	Mean Expense Last Month among Families with Expenses
Respiratory (n=155)	9.73	49.21	\$78.65
Arthritis, deformity, muscle weakness (n=11)	6.31	31.51	\$78.46
Visual/Hearing impairment (n=16)	34.83	40.42	\$169.46
Other physical (n=62)	13.38	51.53	\$128.03
All physical (n=244)	12.14	48.43	\$96.92 ^b
Behavioral/learning disorder (n=48)	10.29	32.35	\$174.13
MR/DD (n=22)	11.67	49.20	\$100.65
Mental/emotional illness (n=18)	16.23	43.90	\$152.00
All mental (n=88)	11.86	38.88	\$146.10 ^b
Speech impairment (n=7)	34.84	42.34	\$197.87

^aAll values for n rounded to nearest whole number. Excludes two cases that could not be classified as mental, physical, or speech impairment.

^bDifference of means significant at the .10 level (t=1.76).

Source: Authors' calculations from California AFDC Household Survey, Wave II.

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