Expensive Children in Poor Families: The Intersection of Childhood Disabilities and Welfare

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Foreword

President Clinton's promise to "end welfare as we know it" was fulfilled with the passage of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996. Most observers attribute the unprecedented decline in welfare dependency since then to a robust economy as well as to welfare reform, but the benefits of this economic activity have been spread unevenly. Previous PPIC studies have documented the formidable obstacles facing welfare recipients without basic skills as well as the mismatch between the experiences of low-income, never-married parents on the one hand and welfare regulations and the child support system on the other. In *Expensive Children in Poor Families: The Intersection of Childhood Disabilities and Welfare*, Marcia K. Meyers, Henry E. Brady, and Eva Y. Seto focus attention on another group of low-income families and the difficulties they face in moving off public assistance.

The report's main concern is to estimate the private costs and public effects of childhood disabilities, which the authors define as chronic physical, mental, and emotional conditions that limit activities, learning, and healthy development. After extensive interviews with household heads in four California counties, the authors conclude that 20 to 25 percent of welfare families have a disabled or chronically ill mother or child. Not surprisingly, they find that the direct and indirect costs of caring for these family members are a major factor in continued welfare dependency. Employable members of such families not only have greater demands on their time for home care of the disabled child, but a substantial share of the income they do secure is used to pay for specialized goods and services related to the child's disability or chronic illness. In short, a disabled child in the home presents a significant obstacle to economic self-sufficiency for these families.

The authors conclude that public assistance may be an essential part of an income packaging strategy for families with extraordinary private costs. To force these families to achieve full independence from means-tested programs would risk imposing other forms of hardship on already disadvantaged children. The public policy challenge facing California is to design an integrated system of multiple benefits, one that lets the family achieve a substantial level of financial independence yet supports the extra cost of a disability with the right mix of SSI, Food Stamps, health insurance, and general public assistance. Because these programs have different eligibility rules, funding sources, and service agencies, the hard policy work will be in the details of such a system. In this report, the authors show how (and how much) child disabilities hold families back from true income security. The challenge for policymakers is to use this evidence to design an integrated program that will serve vulnerable families today and into the future.

David W. Lyon
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Summary

All children require care, but children who have exceptional needs because of a physical disability, chronic health problem, or 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. However, poor children living in poor neighborhoods are far more likely than their more affluent peers to suffer from these conditions.

When poverty and disabilities intersect, the costs associated with children's care have particularly important implications for their families and for society. Poverty-related compromises in living conditions and health care elevate the risk that children will suffer from chronic and disabling conditions. At the same time, the care of a disabled or ill child can increase the risk that the family will be poor by imposing direct costs for medical and other care and indirect costs in the form of forgone earnings.

Childhood disabilities in poor families impose public costs as well. Some of these costs are associated with targeted services such as special education that are provided regardless of income. Others are associated with means-tested programs, particularly the Supplemental Security Income (SSI) program for low-income disabled children and adults. Still other costs are borne by the public sector when these families receive means-test assistance that is *not* targeted on disabled children, including Medicaid, welfare, and Food Stamps.

Although the private and public costs of caring for exceptional children may be high, we know relatively little about their magnitude or their distribution between families and government. Programs to aid low-income families have undergone change in recent years. Reforms have affected programs that are targeted specifically on disabled children, such as the SSI program, and others, such as welfare, that are not

specifically targeted but include large numbers of families caring for disabled children. As these policy reforms are evaluated and modified, it will be important to bring to bear the best and most extensive information possible to craft more effective policy approaches. Nowhere is this need for information greater than on issues of the costs of caring for disabled and ill children.

This study uses survey and administrative data collected in the mid-1990s in the State of California to examine the public and private costs associated with children in families at the intersection of two populations: those served by public welfare programs and those caring for disabled children. We consider direct private costs for families, in the form of out-of-pocket expenditures for disability-related goods or services, and the indirect private costs of forgone employment income. We consider public costs by examining rates and duration of participation in means-tested cash assistance programs. We conclude that poor parents with disabled children often face dismaying tradeoffs between meeting the special needs of their children or meeting the basic needs of their families, and between working or caring for their children. Assistance provided through public programs, particularly Medicaid or Supplemental Security Income (SSI), may reduce these tradeoffs and resulting compromises in families' well-being.

Data and Methods

Defining "costly" childhood disabilities poses a number of difficulties. For adults, the cost of a disability is equated with lost earning capacity and income. In the case of children, this approach seems too limited and even flawed. Many childhood disabilities and illnesses do reduce children's capacities in ways that have implications for their human capital and long-term earning prospects. In the short term, however, these conditions impose costs not through lost earnings, since children do not work, but through direct demands on families' financial and time resources and through the reduction in the quality of the child's everyday experiences. A more useful basis for defining childhood conditions, therefore, is one that captures the extent of the child's limitations and the corresponding burden on families' resources.

To estimate the costs of caring for children, we need data on children's disabilities and costs in a representative sample of poor families. Such data are hard to come by because very few surveys ask the in-depth questions needed to determine the scope and severity of disabilities; even fewer measure costs. For this study, we take advantage of data from in-depth interviews conducted with a representative sample of 1,764 English- and Spanish-speaking welfare households from four California counties: Alameda, and San Joaquin in the north and Los Angeles and San Bernardino in the south. An initial stratified random sample of about 15,000 single- and two-parent welfare (AFDC) recipient families was selected in October 1992 from administrative records of the California Department of Social Services; a subsample of English- and Spanish-speaking households was randomly selected from this sample and interviewed twice by phone. Wave I interviews were conducted in 1993–94. We base most of our analysis upon an 18- to 24-month follow-up (Wave II) interview that was conducted in 1995–96, to which we added detailed questions about children's disabilities and family costs.

Prevalence and Types of Children's Disabilities

Prevalence of Disabilities

Disabilities and chronic illnesses affected a significant share of the welfare recipient population in California. Between one-fifth and one-quarter of families who were in or had recently left welfare had a disabled or ill mother or child; about half of these families (10 to 12 percent of the welfare population) had a disabled child. Between 3 and 5 percent of families cared for children with severe limitations. Given falling welfare caseloads, it is likely that the prevalence of disability or illness among those who remain on welfare has grown since these interviews were conducted in the mid-1990s.

Types of Children's Disabilities

The children in these families suffered from a wide range of limiting conditions, and their special needs imposed both direct and indirect costs on their families. For about three-quarters of these children, the primary condition reported by the mother was physical; for the remaining one-quarter, it was a mental, developmental, or emotional problem. The correlation between condition and the severity of children's limitations is weak. There were few conditions that did not impose costs on some families. However, the frequency and magnitude of direct costs, and of indirect costs in the form of forgone earnings, were related to the number of disabled children in a family and to the severity of their disabilities.

Private Costs of Children's Disabilities

Special Expenses

About 45 percent of families reported that they incurred extra direct costs for specialized child care, special clothes, special foods, transportation, medicine, or health care for their special needs child or children in the prior month. Those costs averaged $134 for those families with any expenses (or $62 per month across all families, with and without expenses).

Work Reduction

Families also incurred indirect costs in the form of work reductions and forgone maternal earnings. Mothers with more than one moderately disabled child, or with any severely disabled children, were 20 to 30 percentage points less likely to have worked in the previous month than were mothers with healthier children. Using multivariate techniques to control for other individual and labor market factors, we estimate that care for a severely disabled child translates into $80 in forgone earnings per month, as a result of both lower probabilities of employment and reduced hours of work.

Material Hardships and Poverty

These financial burdens also translate into direct, material hardship for these families. Unless they received SSI, families with disabled children were more likely to be poor or extremely poor than other families, and direct out-of-pocket expenditures pushed between 4 and 12 percent of already poor families with disabled children into extreme poverty at 75 percent of the federal poverty line. The consequences for economic well-being were severe. Families with disabled children were not only more likely than other families to be extremely poor, they were also more likely to report experiencing concrete hardship. About 17 percent of families with only healthy, nondisabled children reported that children had gone hungry in the prior year because the family lacked money for food, but one-third or more of families with any disabled or chronically ill children reported hunger. In 22 percent of families with only healthy children, adults had gone hungry; between 33 and 73 percent of families caring for exceptional children experienced hunger among adults. Families with extra caregiving responsibility were also more likely to have had difficulty paying their housing costs, to have experienced eviction or periods of homelessness, and to have had phone or utility shutoffs because they could not pay their bills.

The Public Costs of Care

Receipt of Special Services

Families with special needs children sometimes received specialized services for these children, and the likelihood of participation in such programs increased with the severity of children's disabilities. The proportion of families with a child in a special education or early intervention program increases from over 43 percent of those with a single, moderately impaired child to 75 percent of families with more than one impaired child, at least one of whom was severely limited. Families were much less likely to be receiving case management from California Children's Services or Community Mental Health Services. Among families with a single, moderately disabled child, about 7 percent received services from California Children's Services, and 11 percent got help for their child through Community Mental Health Services. Among families with multiple and severely limited children, 25 percent were assisted through California Children's Services and 32 percent through Community Mental Health Services.

Receipt of Public Assistance

Families with disabled and ill children were also more likely than families with only healthy children to participate in nontargeted transfer programs for the poor, including welfare, Food Stamps, public housing, and Medicaid. For example, when contacted for the Wave II interview, just under three-quarters of families without disabled children were still receiving welfare, whereas between 81 and 99 percent of those caring for disabled children were still in the welfare system.

Remaining on Public Assistance

The presence of a disabled mother or child made it harder for a family to achieve full independence from the welfare system. Using a competing risks multivariate hazard analysis, we find that some families with very severely disabled members did leave welfare rather quickly, but their exit from welfare was actually a transition to the SSI program. Those families who did not exit to SSI appear to have very long stays on welfare. The magnitude of the effect of children's disabilities on welfare transitions is quite substantial. For example, after controlling for many other factors that affect welfare spells, the presence of a severely disabled child in the family created the same reduction in the likelihood of leaving welfare as a four-year reduction in the educational level of the household head and had twice the effect as that of of losing a partner (and potential wage-earner) from the family.

Public Programs and Private Well-Being

Ameliorating Extra Expenses with Programs

Medicaid and SSI appear to at least partially offset these costs and lower the risk of hardship. Among families with disabled children, those with SSI spent *more* on specialized goods and services for their children than similar families without SSI. This finding suggests that SSI is meeting its original purpose of helping families absorb the extra costs that result from chronic illnesses and disabilities. Among these same families, those with Medicaid spent *less* out of pocket on goods and services for their disabled children than families with either no insurance or only private insurance. Although we cannot observe whether these children in fact received the same level of goods and services, the lower level of direct spending by Medicaid recipients suggests that the program helps families meet the needs of their children without incurring burdensome private expenses.

Reducing Poverty and Hardship Through Public Programs

Even more compelling evidence of the role of government programs in offsetting costs is provided by our simulation of poverty and hardship. By using multivariate methods, we are able to control for other individual and family factors that may explain the higher levels of economic disadvantage observed among families with disabled children. After controlling for these factors, we find that the presence of a severely disabled child increased the likelihood that a family experienced material hardship by as much as 30 percentage points. For families that received SSI, however, the chances of going hungry, falling behind in their bills, being evicted, or having utilities shut off were about the same as those of families with only healthy children.

Conclusions

Our empirical analyses yield five broad conclusions. First, we find that a surprisingly high proportion of poor, welfare-reliant families absorb costs related to the care of disabled family members.

Our second conclusion is that childhood disabilities sometimes impose very high costs on very poor families. This may force some parents to make tradeoffs between meeting the needs of their children and meeting the basic needs of their families.

Our third conclusion is that parents with disabled children face tradeoffs not only in the purchase of basic goods and services but also in their allocation of time. Mothers with atypical children may find it more difficult than most to combine their caregiving work with employment, as evidenced by lower probabilities of employment and, among those employed, fewer hours of work.

Our fourth and related conclusion is that childhood disabilities and means-tested welfare use are closely intertwined. Families with seriously disabled children may be more likely to receive means-tested assistance than are families with only healthy children, and, once on aid, they are much less likely to leave. Some families with a disabled child leave welfare through a transition to the SSI program. If they do not, having a disabled child greatly reduces families’ chances of leaving welfare.

Our fifth and final conclusion is that the SSI and Medicaid programs appear to be working fairly well to help protect highly vulnerable families from the risk of economic insecurity and material hardship. Public programs may reduce these risks either by increasing the resources that families have available for specialized purchases or by offsetting the costs of specialized goods and services directly. To the extent that public programs have these effects, receipt of cash and in-kind assistance may serve an important role in promoting families' economic security and ability to care for special needs children at home. Recent policy reforms have focused heavily on reducing welfare reliance. For families who bear extraordinary private caregiving costs, however, concerns about welfare dependence may be misplaced. In fact, assistance from public programs may be an essential part of an income packaging strategy for families who assume extraordinary caregiving costs.

As a result of these findings, we make the following recommendations regarding policies affecting families with disabled children.

First, low-income families with severely disabled children should continue to receive unrestricted cash assistance through SSI. This policy appears to be well justified by the costs these families assume. Our findings indicate that these costs are intermittent and highly variable, even across families whose children have the same condition. Although these qualities might justify more precise targeting of benefits, such targeting is likely to be both expensive and intrusive. In particular, dispensing restricted cash assistance, vouchers, or in-kind benefits as needed would greatly increase the administrative costs for government and the application burden for families.

Second, the extension of Medicaid to families with disabled children is crucial. Disabled and chronically ill children are among those most medically at risk if they do not get appropriate preventive and ongoing health care. Their parents are among those who face the gravest financial risks if they lose health insurance for their children. For low-income families with disabled and chronically ill children, policies that guarantee continuous coverage and access are particularly crucial, both to increase medical security for these children and to provide an employment incentive for their parents.

Third, welfare eligibility rules should be adjusted to reflect the extra financial and caregiving demands on parents with disabled and chronically ill children. Even with full- or part-time work, these families may not be able to achieve full independence from the welfare system. Subjecting families with special needs children to benefit restrictions, time limits, and sanctions risks increasing hardship for already very disadvantaged families.

Fourth, welfare and Food Stamp work rules and employment supports should be modified to support families' movement to self-sufficiency while recognizing their special needs. For a small number of parents with very disabled or ill children, caring for these children may be the most important and perhaps only work that they can do. Many parents do combine their caregiving with employment, however. Going to work may be both difficult and expensive for such parents, particularly if their children need specialized child care. These parents may need extra employment services (such as enhanced child care benefits) to help them manage.

In short, we conclude that for families with expensive children, policies that support "partial independence" from public assistance make sense. Because these families need to spend more and can work fewer hours outside the home, many of them will not be able to achieve full independence from means-tested programs. To force them to do so prematurely would risk imposing additional medical and other forms of hardship on their oftentimes very vulnerable children. But neither should they be left to languish on the welfare rolls when and if they can achieve partial independence through employment. Government can support this independence both by providing extra employment-related support services, when needed, and by adopting welfare eligibility rules that permit families to package earnings with continued SSI, welfare, Food Stamp, and health insurance assistance.

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Acknowledgments

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We are also grateful for the feedback of several reviewers and discussants who read earlier versions of this research for presentation at the *Association for Public Policy Analysis and Management Eighteenth Annual Research Conference* (1996); the *Thirty-Sixth Annual National Association for Welfare Research and Statistics Annual Conference* (1996), and the *Association for Public Policy Analysis and Management Seventeenth Annual Research Conference* (1995). A portion of the findings have been reported in M. K. Meyers, A. Lukemeyer, and T. Smeeding, "The Cost of Caring: Public and Private Costs of Childhood Disabilities in Poor Families," *Social Service Review*, Vol. 72, No. 1, 1998, pp. 209–233; and A. Lukemeyer, M. Meyers, T. and T. Smeeding, "Expensive Children in Poor Families: Out-of-Pocket Expenditures for the Care of Disabled and Chronically Ill Children in Welfare Families," *Journal of Marriage and the Family*, Vol. 62, No. 2, 2000, pp. 399–415.

Finally, we would like to dedicate this work to the memory of Karen Garett, who helped us design the survey on which much of this analysis was based. In this study, as in many others, Karen helped formulate the research hypotheses, made sure that the questionnaire got the information needed to test those hypotheses, and carried out the field work involving a very hard-to-reach population.

Although this report reflects the contributions of many people, any errors of fact or interpretation are the responsibility of the authors alone.

1. Introduction

All children require care, but children who have exceptional needs because of a physical disability, chronic health problem, or 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 to children of any one class, race, or income group. Poor children, however, are far more likely than are their more affluent peers to suffer from these conditions.

When poverty and disabilities intersect, the costs associated with children's care have particularly important implications for their families and for society. Poverty-related compromises in living conditions and health care elevate the risk that children will suffer from chronic and disabling conditions. At the same time, the care of a disabled or ill child can increase the risk that the family will be poor by imposing direct costs for medical and other care and indirect costs in the form of forgone earnings.

Childhood disabilities in poor families impose higher public costs as well. Some of these costs are associated with targeted services for disabled children, such as special education, that are provided regardless of income. But others are associated with means-tested programs, particularly the Supplemental Security Income (SSI) program for low-income disabled children and adults. Still other costs are borne by the public sector when these families receive means-test assistance that is *not* targeted on disabled children, including Medicaid, public assistance, and Food Stamps.

The number of children receiving assistance through targeted disability programs grew dramatically in the 1980s. The growth in caseloads and costs was particularly dramatic in the SSI program, following administrative and legal actions that broadened eligibility criteria for children. The number of child SSI cases doubled between

1989 and 1991, for example, following the *Zelby v. Sullivan* Supreme Court decision that expanded the basis for determining child eligibility.

This growth in the child caseload fueled considerable debate about the purposes of cash assistance for families with disabled children and about the processes through which such families are identified. This debate intensified as it became clear that caseloads were also growing for two other, more controversial groups of recipients—adult drug addicts and aged immigrants. Studies of caseload growth also revealed, to the surprise and concern of some federal lawmakers, that many state welfare agencies were taking active steps to shift welfare recipients from state and state-federal welfare programs to the federally funded SSI program.

Fueled by concerns over caseloads and costs, and by speculation that state welfare agencies and families might be exaggerating children's conditions to qualify them for the more generous SSI benefits, Congress placed significant new restrictions on SSI eligibility as part of the 1996 Personal Responsibility and Work Opportunities Act. The 1996 legislative changes to the SSI program for children were implemented with considerable vigor by local offices. They were also implemented with substantial variation in different regions of the country, leading to wide variation in the proportion of cases that were denied or terminated under the new rules. This variation led to another round of administrative reforms, and the review and reinstatement of a portion of the child cases terminated under the 1996 rules.

The debate over the Supplemental Security Income program, and the reactive process of policy reform, reflected long-standing ambiguities about the purposes of children's SSI benefits. SSI was created in 1974 to support fully disabled or aged adults who were unable to work but did not have sufficient work history to qualify for Disability Insurance or Social Security benefits. Although children clearly did not qualify for benefits due to lost earning ability, Congress recognized that families who cared for disabled children were likely to incur special costs and restrictions on their labor force participation associated with the care of these children. However, there were few reliable data on the incidence or magnitude of these costs that could be used to resolve questions about the need for this assistance.

Information about the costs of caring for disabled and chronically ill children was hardly better when Congressional lawmakers turned their attention to the child SSI program in the 1990s. Data are readily available about total public expenditures for some targeted programs such as special education and Supplemental Security Income. Less is known about the public costs that result from families' participation in other, nontargeted programs such as Medicaid and welfare. *Private* costs—those born solely by the families of special needs children—have received even less attention. Yet the two aspects of the cost of caring are clearly related. The magnitude of the private costs for families has implications for their participation in a variety of public programs that partially offset these costs. And, as Jacobs and McDermott (1989) point out, "cost-cutting" with respect to public programs may be simply "cost-shifting" onto affected families.

The debate over the purpose of the SSI program for children, and over the level of benefits to be provided, has yet to be fully resolved. New questions have arisen in the wake of the 1996 welfare reforms about the interaction between SSI and welfare benefits, and about the needs of families in the welfare system who care for disabled children. This study begins to answer these questions using survey and administrative data from the State of California to examine the public and private costs associated with children in families at the intersection of two populations: those served by public welfare programs and those caring for disabled children (Figure 1.1). These are not the only families who incur costs or who have been affected by changes to the SSI program. However, they are a particularly important and interesting population because they are potentially subject to both welfare reforms and changes in SSI eligibility. They are also among the poorest families who care for special needs children and therefore the most vulnerable to exceptional caregiving costs.

In Chapter 2, we present several scenarios that profile the circumstances and needs of families caring for disabled and chronically ill children. These scenarios describe families who were interviewed as a part of a larger study of welfare-reliant families in California. We use them to illustrate some of the issues and costs that arise when poor families care for expensive children. In Chapter 3, we review what is

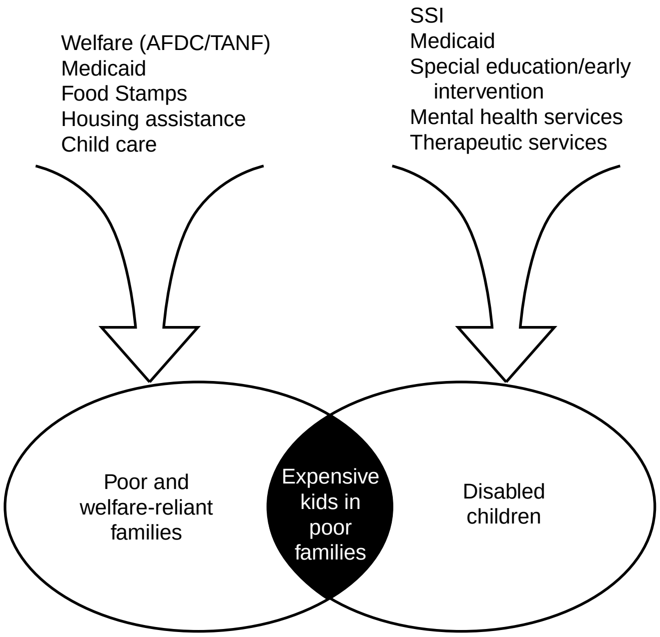

Figure 1.1—Expensive Children in Poor Families

known, and remains to be learned, about the prevalence and cost of childhood disabilities. In Chapter 4, we describe the data and analytic methods used in this study. We then turn to our findings. We address the private costs of caring for exceptional children in Chapter 5. We consider both direct economic costs, in the form of out-of-pocket expenditures, and indirect costs, in the form of employment reductions. To understand the *consequences* of these costs for very poor families, we consider changes in families' poverty status, once direct costs are considered, and the risk of concrete hardship associated with the care of an exceptional child. We consider the public costs of caring in Chapter 6. We examine rates of participation in two types of public programs: targeted disability services and means-tested income programs. To evaluate more fully the effect of disabilities on program use, we consider not only the probability that families receive benefits but also their chances of leaving welfare programs once enrolled. In Chapter 7, we consider the role of public programs in offsetting private costs. We estimate the effect of two forms of means-tested assistance—Medicaid and SSI—on families' ability to absorb the direct costs of care without financial hardship. In the final chapter we summarize our conclusions and consider policy recommendations, returning to the family scenarios (from Chapter 2) to illustrate our conclusions.

2. Poor Families with Expensive Children

Our understanding of the private costs of caring for disabled children is limited, in part because it so difficult to generalize the experiences of these families. The costs of caring for exceptional children are as diverse as children's special needs. The hardship that these costs impose on families is as varied as the families. Although our primary aim in this study is to draw general conclusions about these costs and hardships, it is useful to begin by considering individual cases. The following "scenarios" describe the characteristics of several families interviewed for this study. Although the study did not use the type of qualitative, in-depth interviews that would be appropriate for developing case studies, the detailed nature of the interview allows us to sketch "scenarios" for a few families using their responses to standardized survey questions about their income, expenses, living situation, and family health. These scenarios are not meant to be representative of the population in statistical terms. Rather, they are illustrative of the wide-ranging and diverse situations of families. Each family cared for at least one severely disabled child. All were on welfare in October 1992 and were interviewed twice over a period of three years until 1995. The sample of families, the data collection procedures, and the interview questions (including the definitions of moderate and severe disability) are described more fully throughout this report, but these profiles can be understood without a detailed grasp of these matters. They provide a sense of the difficulties and tradeoffs that poor families with severely disabled children may confront.

- Matilda [30812],[1] 33 years old, was born in Mexico and lived in Alameda County until a few years ago. She is now separated

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[1] This is the case number in the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II. All names are fictional.

from her husband and lives in Los Angeles. She has three children—two boys ages 12 and nine, and one girl five years old. The middle child is in poor health with heart problems that limit his ability to walk, run, go up stairs, and attend school regularly. His medical problems sent him to the emergency room twice in the last year and led to an overnight stay in the hospital. These medical problems also resulted in extra expenses for the family, including an ambulance bill and the cost of special medicines in the last month. Matilda is unaware of the SSI program and has never received child support. She relies on a combination of welfare and work, but with no partner in the household, it is difficult to get by with half-time employment. She has had her phone and gas and electricity turned off because she could not pay the bills and she is late with the rent every four or five months. For Matilda, making ends meet is a constant struggle, and her child's heart problems add additional challenges to her already difficult situation.

- Dorothy [20265], a 36 year old divorced mother of a 16 year old girl, lives with another unrelated adult in a small single-family house in San Joaquin County. Dorothy works as an animal caretaker, but her child's severe asthma sometimes limits her work hours. Her daughter has poor health generally, and her health problems make it hard for her to run, to go up stairs, and to participate in the usual activities for a girl her age. She also misses a lot of school because of her condition. Dorothy is not currently on public assistance; one consequence is that she does not receive Medi-Cal. She had to pay $110 in special expenses for her asthmatic daughter last month, including $95 for medications. In the last year, her strained finances caused her to go hungry on at least one occasion. She worries because there are special treatments that she would like to get for her daughter, but she cannot afford them.
- Gladys [30408] is 32 years old and divorced, was born in the United States, and lives in a three-bedroom public housing apartment in Los Angeles. She had her first child when she was 15, and she now has three children, ages 17, 15, and 11. All

have learning and behavioral problems and attend special classes at school; the eldest is also mentally retarded and receives SSI. Her 17 year old child needs a lot more help than other kids his age with eating, bathing, and dressing, and he cannot take part in many activities with his peers. He goes to school, but he misses classes a lot. He also has substantial medical problems. He was treated four times at an emergency room in the last year, and the family incurred substantial out-of-pocket costs in the last month for his special food, transportation, and medicines. Gladys herself has a significant physical condition that prevents her from working, although she has never applied for SSI. She has been on welfare for more than nine years, and describes herself as dissatisfied with her standard of living. Nevertheless, she does not think her job prospects are very good because she has only a 10th grade education and heavy caregiving responsibilities, so she has not been looking for work. She lives a precarious life—her children were sometimes hungry last year, for a two-month period she went to a free food program a few times each month, and she paid her rent late several times.

- Phyllis [21064], 27 years old, lives in San Joaquin County in a two-bedroom apartment with her three children, ages eight, seven, and four. She was on welfare in the past, moved off for a time, but returned after she separated and moved away from her husband 18 months ago. Her seven year old daughter has cerebral palsy and receives SSI. Her daughter cannot move very well and cannot participate in the usual activities for a child her age. She does go to school, but she needs a lot more help than other kids with eating, bathing, dressing, and getting around. Because of her child's cerebral palsy, Phyllis receives help from California Children's Services. She still incurred substantial out-of-pocket expenses in the last month for special clothes and transportation necessitated by her daughter's cerebral palsy. Phyllis graduated from high school and she has worked part-time as a secretary at an insurance company for the past 18 months, but her daughter's illness limits the amount and kind of work she can do. Through public assistance, Phyllis obtains

Medi-Cal, which is very important because in the last year her daughter received medical care at an emergency room five times. Because of her daughter's illness, Phyllis cannot work enough to get off welfare, and even if she could, the prospect of losing Medi-Cal is very frightening to her.

- Mary and Robert [20859] are married and live in a rented three-bedroom home in San Joaquin County with their five children—four boys ages 16, 14, 10, and six and one girl age three. Their 16 year old boy has developmental problems; their 10 year old son has cerebral palsy. Both boys receive SSI. Mary and Robert have been on public assistance continuously for the last nine years. Robert, 32 years old, has a 10th grade education and worked full-time last month and for 10 of the last 18 months. Although he works many hours, his earnings as a child care worker are low. Mary, age 35, has a GED, but caring for her disabled children limits her ability to work. With their earnings, welfare, Food Stamps, and SSI, Mary and Robert are able to pay their rent, phone, gas, and electricity on a regular basis and to provide sufficient food for the entire family. But they would like to get more services for the 16 year old son, and they must also cover special expenses for their disabled child, such as the van they rented last month to get him to the hospital when he was experiencing medical problems.
- Edith, 27 years old, and Ben, 30 years old [40045] are married and live in a rented two-bedroom mobile home in San Bernardino. They have only one child, Brandon, who is five years old and blind. He also suffers from developmental delays and chronic health problems such as asthma. In the last 18 months, he received medical care in an emergency rooms 15 times and stayed overnight in the hospital. Brandon cannot do the usual things of a child his age, and he is in a special school. Because of his medical problems he misses a lot of days at school, and Edith feels she is limited in her ability to work outside the home. In addition to the work limitations, the family incurred direct costs for special food and transportation in the last month because of Brandon's health and developmental

problems. Ben has a GED and works as a bus driver at a local school. Edith has a high school diploma and works at odd jobs. They are not currently on welfare, but they have been on and off in the last few years. Edith thinks that they are better off than a year ago when they were still on welfare, but their living situation has been precarious. In the past 18 months, they have moved four times (including once after they were evicted from their lodgings), and they have been in their current place for only one month. At one point they had to rely upon free food from food pantries for about a month.

- Beth and Joe [40550] live in a rented home in San Bernardino with their three boys ages 10, eight, and seven and their daughter age three. Because of blindness and developmental delays, their youngest boy needs a lot more help than other children and attends a specialized education program. Joe is 28 and works as a laborer in construction. He has been able to work 17 of the last 19 months. Beth, 27 years old with a 10th grade education, takes care of the four children and does not work, partly because she thinks she could make only about $4.25 an hour. After cycling on and off welfare for the last nine years, Joe and Beth were able to get off welfare four months ago. They now rely on Joe's earnings and on the SSI and Medi-Cal they receive for their disabled son.

These profiles demonstrate a number of recurrent themes. Children in poor families suffer from a diverse range of chronic, limiting, and disabling conditions.[2] Children in these families suffer from blindness, severe asthma, mental retardation, cerebral palsy, attention deficit disorder, heart problems, and mental and emotional difficulties. The extra burdens of caring for these children can be great. Some families

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[2] Although we use the terms disability, limitations, and special needs interchangeably in this document, some analysts distinguish among them. Researchers typically define chronic conditions as those that have lasted (or are expected to last) at least three months; chronic conditions are typically considered disabling only if they result in functional limitations or developmental abnormalities. The term special needs is used more globally to describe children who have conditions that require specialized care by parents, schools, medical providers, or other professionals.

report that their most disabled child requires a lot of help with basic activities such as eating, bathing, dressing, or getting around the house; others report that their children require special schools, special classes, or therapies.

Caring for these children can also be expensive. In our family profiles, most families had incurred some out-of-pocket expenses in the prior month related directly to the care of their special needs child; for a portion of these very poor families, such expenditures were high. Medical care can be a particularly common expense. Many of the families went to the emergency room with their child within the prior 18 months; several made multiple visits. Some parents reported that, in the last year and half, there was at least one time when they could not get the medical care that they thought their child needed.

Special needs also appear to interfere with parents' work options. Several of the mothers are themselves disabled and limited in their ability to work. Many report that their children's disability limits or even prevents their ability to work. Some mothers do work currently. Only one of the mothers profiled, however, works full-time, and even she reports that her work is limited by her daughter's disability.

These families cope with the costs and challenges of caring for special children in different ways. Most receive welfare. Some have been welfare recipients only intermittently in the past years; others are in the midst of a long spell of receipt. In addition, some families with severely disabled children receive extra income through the SSI program. However, other parents are not aware of the program, have never applied for help, or have been turned down for assistance.

What is most striking about these profiles, perhaps, is the level of hardship experienced by families and their children. Late payment of rent and utilities is common and leads to evictions, utility shutoffs, and homelessness for some. Reliance on food banks and other sources of free food is a necessity for most, but even with this form of help, some parents report that the family went hungry during the past year. Although most families have been able to retain Medicaid as part of their public assistance, a few lack even this form of security. These poor families are clearly living at the edge of economic survival. The extra needs of their disabled children may well have pushed them over that edge.

These profiles provide a first look at the characteristics of poor families with disabled children, the private costs they incur, and their use of public programs. They also suggest some of the policy conundrums that arise in the design of public programs to help offset families' private costs. How can we predict which childhood disabilities and illnesses are costly for families? How can we measure these costs and estimate the economic consequences for families? How can government programs reduce the burden of private costs without wasting public resources or creating undesirable incentives for families? These are the questions to which we now turn, first by reviewing prior research and then by presenting the findings from our study of California families.

3. Measuring Disabilities and Costs

Public programs can help offset the financial burden of caring for disabled and ill children by reducing families' costs or by increasing their resources. Programs that provide direct services, such as medical treatments or specialized education and child care, reduce families' costs for these services. Programs that transfer income directly to families, most notably the Supplemental Security Income program, increase families' financial resources for the purchase of these, and other, specialized goods and services. To develop sound policies for either type of program, we must begin by confronting a number of conundrums—from the difficulty of estimating need to the possibility that policies create perverse incentives.

Private Costs of Childhood Disabilities

Although estimates of the prevalence of disabling conditions vary considerably, most suggest that about 5 to 7 percent of children experience a condition that results in some impairment or limitation of their ability to engage in the usual activities of children their age (Aron, Loprest, and Steuerle, 1996). Although disabilities affect children of all income groups, children in low-income families have a 40 percent higher risk of being disabled than their affluent peers (Newacheck and McManus, 1988; McNeil, 1993). This elevated risk stems, in part, from exposure to living conditions and health care practices that increase the probability and the severity of illnesses and other potentially disabling conditions. Elevated blood lead levels and associated developmental problems among poor children, for example, have been linked to their higher probability of living in older, inner-city areas with high levels of lead in soil and housing. Other health problems that disproportionately afflict poor children, such as frequent and untreated ear infections leading to hearing loss, have been associated with inadequate access to medical care (Newacheck, Jameson, and Halfon, 1994).

The association between childhood disability and poverty appears to operate in the opposite direction as well, when the financial costs associated with the care of a disabled, fragile, or chronically ill child push a family into poverty. These costs are typically described 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, and rehabilitative services and devices) and the indirect or opportunity costs resulting from the loss of productive output by the caregiver (e.g., the loss of earnings resulting from increases in the extent and intensity of caregiving responsibilities) (Hodgson and Meiners, 1992; Jacobs and McDermott, 1989). Empirical studies suggest that these costs are frequent and often high.

The costs of caring for an expensive child can create a variety of dilemmas for poor families. These families are more likely than others to have a chronically ill, fragile, or atypical child, and they have fewer resources than others to absorb the costs of this care. For poor families with expensive children, the tradeoffs may be stark: whether to use the limited family income to meet the needs of the child for medical or other care, or to meet the family's needs for food, shelter, and other basics; whether to work more hours and pay for sometimes very expensive specialized child care, or to quit work altogether to qualify for welfare; whether to risk going without health insurance for a sometimes very ill child, or to make themselves poor enough to qualify for government insurance through Medicaid.

Public Costs of Childhood Disabilities

The private dilemmas of caring for a disabled child thus have public implications as well. Because these are very poor families, a portion of the resources devoted to their care come from public sources. A variety of targeted public programs provide special education, early intervention, and diagnostic, rehabilitative, and therapeutic care for exceptional children. By one recent estimate, total federal, state, and local expenditures in the United States for targeted special services for exceptional children reached $44.3 billion in 1993 (Aron, Loprest, and

Steuerle, 1996). 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, primarily for special education. At the federal level, the largest targeted program is the Supplemental Security Income program, which provided $5,364,000,000 in benefits to children in 1997 (Social Security Administration, 1998, Table IV. C1).

Childhood disabilities are also implicated in the costs of nontargeted transfer programs. 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 chronically ill children. The cost of Medicaid for an estimated 800,000 disabled children reached $3.4 billion in federal and $2.5 billion in state funds in 1993 (Aron, Loprest, and Steuerle, 1996). Children's disabilities may also have other largely unmeasured effects on participation in cash assistance programs and Food Stamps. The prevalence of disabilities is sharply higher among welfare recipients than among the general population (Blank, 1989; Spalter-Roth, Hartmann, and Andrews, 1992; Loprest and Acs, 1995), suggesting that these families may have both a higher probability of entering welfare and, once in the program, a lower probability of leaving. For families with disabled and ill members, uncertain access to private health insurance may increase the incentive to enroll in welfare programs that provide categorical access to public health insurance through the Medicaid program (U.S. General Accounting Office, 1995).

Public Policy Dilemmas: The Case of SSI

To the extent that they offset a portion of family costs, these programs represent a public response to the private dilemmas that arise when poor families care for expensive children. Because they involve the use of public mechanisms to effect a transfer and redistribution of private resources, they also raise a host of public policy dilemmas. On the one hand, there is pressure to maximize transfers to increase equality and produce socially desirable outcomes such as children's health. On the other, there is pressure to minimize transfers that involve redistribution of private resources and to maximize the efficiency with which resources are targeted. These dilemmas become particularly acute when the basis of eligibility is ambiguous, difficult to establish, or difficult to observe.

Programs that benefit disabled children in poor families raise all of these dilemmas, and many of these programs have become lightning rods for controversy in recent years. The federal Supplemental Security Income program has been one of the most controversial. The SSI program provides cash assistance to low-income individuals who are either elderly (and not covered by Social Security) or disabled. Before the mid-1980s, the number of SSI recipients was relatively stable; since then, the number of disabled recipients has increased by an average of over 8 percent annually (U.S. General Accounting Office, 1995). This change raised particular alarm in political circles when it became clear that children and two more controversial subpopulations—noncitizens and adults with mental impairments (including drug addicts and alcoholics)—accounted for the majority of the growth.

SSI caseload growth was particularly steep for child cases during the 1990s, following modifications to federal eligibility rules for SSI and other mental health services. Most notably, in 1990 in *Sullivan v. Zebley*, the Supreme Court required that the Social Security Administration (SSA) provide an individual, functional assessment for children whose disability did not qualify them for benefits under existing categorical criteria. At about the same time, SSA also revised its criteria for evaluating children claiming mental impairments (U.S. General Accounting Office, 1994). These policy changes were designed to correct perceived inequities in the eligibility criteria for the program. To apply the new rules fairly, the Social Security Administration directed regional field offices to conduct outreach to identify newly eligible children and those who were denied benefits under the earlier rules.

The combination of rule changes and outreach had predictable results for caseloads. In December 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 December 1993, SSI provided benefits to 770,501 children—13 percent of total beneficiaries. Between 1989 and 1994, the number of child cases, and total benefit payments, tripled (Kubrick, 1999).

Much of the growth in the child SSI caseload reflected a one-time addition of children who would not have qualified under the earlier rules, so these dramatic rates of growth are not expected to continue (U.S. General Accounting Office, 1995). Regardless of projections of future growth, the highly visible increase in the child SSI caseload in the 1990s and the pervasive antiwelfare sentiments of the period provoked strong criticism of the SSI program. Some of the program's critics questioned the basic premise of providing cash assistance to healthy parents of disabled children. The SSI program was created in 1974 to provide cash assistance to adults who were unable to work because they were totally and permanently disabled, or over the age of 65, and unable to qualify for benefits through Social Security. The legislative history of SSI suggests that Congress enacted the benefit structure for children because it accepted the argument that the needs of low-income families with disabled children were greater than the needs of other low-income families (Urban Systems Research and Engineering, 1979; Weishaupt and Rains, 1991; Burke, 1974; Woodward and Weiser, 1994). Other rationales included family support and preservation. To the extent that SSI benefits decrease the risk of economic insecurity among families with disabled children, it has been argued, the small cash grant to families may prevent more expensive and disruptive institutionalization of children (National Academy of Social Insurance, 1995).

Although the children's benefits in SSI were designed to offset some of the direct and indirect costs of providing family care to special needs children, the benefits were adopted with little information on the magnitude or distribution of those costs. The state of knowledge was hardly any better by the 1990s, when caseload growth provoked a reassessment of the program. Some critics argued that the cash grants provided to children through SSI are too broadly distributed, benefiting families who incur few if any additional costs for their disabled children. Others raised concerns, based mostly on anecdotal evidence, that the relatively generous SSI benefits created incentives for parents to coach their children to feign or exaggerate their limitations. Another source of controversy was the benefit differential between SSI and welfare (the former Aid to Families with Dependent Children or AFDC program, now the Temporary Assistance to Needy Families or TANF program). A single person has never been able to receive benefits from both SSI and welfare, but a family with a disabled child can combine benefits from both. If a child was eligible for either welfare or SSI benefits, the child's family was usually better off if the child received SSI benefits.[1] Garrett and Glied (2000) estimate that at least 32 percent of the post-*Zebley* caseload growth in SSI may be attributable to the SSI-AFDC benefit gap.

Alarmed by the growth in SSI and allegations that state welfare officials and families might be abusing the program, Congress moved to restrict SSI eligibility in the 1996 Personal Responsibility and Work Opportunities Act. The law narrowed the definition of disability to include only children who have "a medically determinable physical or mental impairment, which results in marked and severe functional limitations." The law eliminated the individual functional assessments mandated earlier in the settlement of the *Zebley* court case and restricted consideration of maladaptive behavior when evaluating mental impairments. As Loprest (1997) observes, "the clear Congressional intent of these changes was to eliminate benefits for less severely disabled children."

The Policy Conundrums

The controversy surrounding SSI underscores the dilemmas that arise when we seek to target public benefits on the basis of difficult-to-observe characteristics. The rationale for children's SSI benefits rests on the assumption that raising a special child imposes direct or indirect costs on families and that low-income families are particularly ill-equipped to absorb these costs without incurring hardship or jeopardizing the care of the child. As described by the Disability Policy Panel of the National Academy of Social Insurance (1995), children's SSI benefits are designed

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[1] For example, in 1993 a child eligible for the full federal SSI benefit would have received $434 per month (although actual payments are on average much lower). In most states, this amount was significantly greater than the marginal increase in welfare benefits that would have resulted from including an additional child in the case. In the median state, the maximum monthly welfare benefit in 1993 increased by $96 when family size increased from one to two and by $57 when family size increased from two to three. In California, a high-benefit state, the monthly increases in benefits were $197 and $120, respectively (U.S. House of Representatives, 1994).

to "level the playing field" for families who suffer the random shock of having a disabled or seriously ill child.

For this rationale to be justified, in general terms as well as in the case of an individual claimant, we must be able to resolve at least three difficulties that are associated with observing child and family characteristics. First, we must be able to define childhood disabilities and illnesses that impose costs on families. Second, we must be able to estimate the distribution and magnitude of these costs. Finally, we must be able to devise systems for identifying families in need without creating undesirable incentives. Each of these steps has proven difficult in the absence of reliable information about the private costs of childhood disabilities.

Defining Disabilities

The problem of defining "costly" childhood disabilities is fundamental. For adults, equating costs with lost earning capacity and income solves the problem of defining a costly disability. For the purposes of public and private insurance programs, disabilities are defined in human capital terms. Health is treated as capital stock that is affected by both exogenous factors (such as age and accidents) and an individual's own investments (such as preventive medical care) (Grossman, 1972a, 1972b). For the individual, compromises in health or functioning, whether caused by exogenous shocks or individual choices, are seen as losses of human capital and earning capacity. Disabilities impose "costs" by reducing income: They decrease the time an individual has available for productive activities or the range of possible activities.

This human capital framework is evident in the definition of eligibility for disability-related benefits (for adults) under the U.S. Social Security Act:

> For purposes of entitlement to disabled worker's benefits, disability is defined as: The inability to engage in any substantial gainful activity (see §603) by reason of any medically determinable physical or mental impairment (see §601) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.

In the case of children, the human capital framework provides much less guidance. Many childhood disabilities and illnesses do reduce children's capacities in ways that have implications for their human capital and long-term earning prospects. In the short term, however, these conditions impose costs not through lost earnings, since children do not work, but through direct demands on families' financial and time resources and through the reduction in the quality of the child's everyday experiences.

A more useful basis for defining childhood conditions would be one that captures the extent of the child's limitations and the corresponding burden on families' resources. Quantifying the extent of a child's limitation remains difficult, however, and linking variations in children's limitations to variations in family burden is even more problematic.

The difficulties begin with selecting the criteria for defining a disability. 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 all children are estimated to have a chronic health condition. Only a fraction of these conditions result in significant physical, mental, or psychosocial impairments, however. 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 resulting from 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 LaPlante, 1996; McNeil, 1993).[2]

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[2] 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 effect on children's health and functioning cannot be observed until children age. By one estimate (Wenger, Kaye, and LaPlante, 1996), 2.8 percent of children under age five compared with 7.5 percent of those aged five to 17 have a disabling condition.

Estimating Costs

The use of functional criteria improves the definition of childhood disabilities and provides some indication of the potential loss of earnings in the future. This still does not provide information about the *current* costs imposed on families who care for the child. Once the problems of defining relevant childhood conditions are surmounted, the problem of estimating the magnitude and the distribution of costs remains to be solved.

The costs associated with raising special needs children can be both economic and psychosocial (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 (McEwen, 1998; Reinhard and Horwitz, 1995; Baldwin, Brown, and Milan, 1995; Whyte 1992).

Although psychological costs may exact a considerable toll on families, public programs concern themselves more directly with economic costs. 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. 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, respite care, and numerous other items (National Academy of Social Insurance, 1995). Disabled and chronically ill children may also require special or more expert child care services while the parents are at work (Darling, 1987). In addition to being a direct cost, specialized child care can also increase the cost of employment for parents. The elevated needs of many exceptional children for direct care—from help with the activities of daily life to transportation to doctor and therapy appointments—may also exert downward pressure on parents' employment, imposing indirect costs on the family through reductions in earnings.

Research suggests that these costs are often substantial. Disabled children on average use more medical and health care services and incur health care expenditures nearly three times as great as nondisabled children (Newacheck and McManus, 1988). Other, nonmedical costs associated with the child's condition have also been found to be frequent and often very high (Jacobs and McDermott. 1989; Darling, 1987; Urban Systems Research and Engineering, 1979). Parents report both additional time spent in caregiving 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). Studies using large, nationally representative samples have found evidence of lower labor force participation among parents (overwhelmingly mothers) who care for disabled children (Salkever, 1982; Breslau, Salkever, and Staruch, 1982; Wolfe and Hill, 1995; Mauldon, 1991; Powers, 1999) and higher welfare reliance (Blank 1989).

These studies also find that the distribution of these costs is very uneven across families. Studies of the costs of childhood disabilities, even those restricted to a single or small number of disease categories, consistently report that costs are highly variable, with few or minimal costs observed in the majority of families and very high costs observed in a few (Leonard, Brust, and Sapienza, 1992; Newacheck and McManus, 1988; Jacobs and McDermott, 1989; Urban Systems Research and Engineering, 1979). Although researchers have tried to identify the specific disease categories or child characteristics that are associated with higher costs, the overarching conclusion is that variation remains greater *within* than *across* categories and few child characteristics predict either the probability or the magnitude of the costs that families incur.

Avoiding Waste, Abuse, and Undesirable Incentives

Problems arise in the definition of costly childhood disabilities, and in estimating those costs, because it is difficult to observe children's disabilities and even more difficult to observe the costs they impose on families. These problems also increase the risk that public programs will use eligibility criteria that waste resources or create perverse incentives for potential recipients.

Selective or targeted public programs must always strike a balance between two forms of error. Errors of *underinclusion* occur when eligibility criteria are too narrow or too rigidly enforced. In this case, potentially eligible claimants are incorrectly excluded from assistance. To the extent that this assistance achieves public purposes—such as improving developmental outcomes or reducing the chances that children will be institutionalized—society incurs the costs of having to provide more expensive remedial interventions at a later time. Errors of *overinclusion* occur when eligibility standards are too broad or inconsistently enforced. Under these conditions, ineligible claimants are incorrectly provided with assistance. The immediate costs to society are the direct costs of giving unnecessary assistance and the opportunity costs of forgone uses of limited resources. Long-term costs include the loss of program legitimacy if overinclusion is widespread.

A second concern is that of *overinclusion* as a result of program abuse. If benefits for disability programs are generous, and eligibility criteria are ambiguous, there is a risk that individuals with moderate limitations may exaggerate their symptoms or their economic losses to qualify for assistance. Debates about the SSI program in the 1990s were enlivened by stories of welfare-recipient parents who coached their children to feign or to exaggerate symptoms to obtain more generous SSI benefits. In the most extreme version of this argument, critics suggested that families had an incentive to increase their children's functional difficulties. In a 1994 article in the *Washington Post*, for example, a psychologist is quoted as observing "many of the problems these children manifest are largely traceable to parental neglect or abuse. . . . Behavioral and emotional problems or conduct disorder that are directly attributable to inadequate parenting are being called disabilities and the parents are receiving a cash award for having achieved them" (Woodward and Weiser, 1994). More careful scrutiny of charges such as these failed to find evidence of any widespread abuse of the program (National Academy of Social Insurance, 1995). Nevertheless, concerns persist that families may exaggerate children's symptoms in an effort to qualify for public benefits.

A third set of eligibility concerns revolves around behavioral incentives. When eligibility for public programs is limited by rules about income, earnings, or assets, there is a risk that this will create incentives for individuals to maximize their short-term interests in obtaining benefits while compromising their longer-term economic security. Two such incentives have been noted in means-tested disability programs. One is the incentive for families to divest themselves of assets to qualify for benefits. The U.S. General Accounting Office (1995) reported, for example, that between 1990 and 1994, as many as 3,500 SSI recipient households transferred ownership of resources (such as cash, houses, land, and other assets) to other family members to qualify for SSI benefits. Although such transfers of assets are legal, they raise questions about whether families are failing to make proper use of their own assets to meet the private costs of illness and disability.

Related concerns are created by the income limits in means-tested welfare programs such as SSI. Cash transfers have been shown to have a modest but consistent deterrence effect on employment (Moffitt, 1992). Because families whose earnings put them over the maximum for eligibility for SSI receive no cash assistance and may not qualify for medical assistance through Medicaid, the program may create incentives for families to leave or limit employment to meet the income limits. However, by doing so parents may also sacrifice income in the present and reduce their opportunity to accumulate work experience that will raise their earnings in the future.

4. Data and Methods

To address the policy conundrums that arise at the intersection of childhood disability and family policy, we need better and more extensive information about how many families are affected, the financial costs they incur, and the consequences of these costs for their economic well-being. This information is lacking, in part, because it is difficult to obtain. Very few surveys ask in-depth questions about the scope and severity of disabilities and their costs, and even fewer studies ask about disabilities among poor families. Once data are available, care must be used in interpreting them. The costs and burdens associated with disabled children are very real, but their causes, their extent, and their consequences can be easily misinterpreted. Care must be taken in defining disabilities. Estimates of private and public costs can vary depending upon the way questions are asked. Statistical methods for analyzing data must take into account sample characteristics and welfare program dynamics. We discuss some of these methodological issues in this chapter and return to them throughout this report. A detailed description of key measures (of disability and hardship) and prior research about their reliability is provided in Appendix D.

The Data

Most of our data come from Wave II of the California Work Pays Demonstration Project (CWPDP) AFDC Cross-Sectional Household Survey,[1] conducted 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.[2] An initial stratified random

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[1] California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II. Henry Brady Principal Investigator, and Marcia Meyers Project Director.

[2] We are indebted to Werner Schink of the California Department of Social Services who encouraged, promoted, and supported this and other research on welfare in the State of California.

sample of about 15,000 single- and two-parent welfare (AFDC) recipient families was selected in October 1992 from four California counties: Los Angeles, Alameda, San Joaquin, and San Bernardino. A subsample of English- and Spanish-speaking households was randomly selected from the initial sample and first interviewed on the telephone in Wave I in 1993–94. We base most of our analysis on an 18-month to 24-month follow-up (Wave II) telephone interview of these families, which was fielded in 1995–96. Interviews were completed with 2,214 families from the initial sample of 3,776 at Wave I (a 59 percent completion rate); Wave II interviews were completed with 1,764 of these families (an 80 percent recontact rate).

The four counties included in the sample represent almost 50 percent of the California welfare caseload, and they include two large urban populations, Los Angeles in the south and Oakland in the north. They also include the agricultural areas surrounding Stockton in the Central Valley county of San Joaquin, and the suburban, rural, and desert areas of San Bernardino County. Survey data are weighted to adjust for differences in sampling fractions by strata and for survey completion rates. Weights were constructed to adjust for differential sampling rates in each of eight strata (for county and AFDC-program type), and for differences in initial completion rates and attrition within strata and within language groups (English and Spanish). Weighted data closely represent the underlying population of AFDC cases in the four counties at the time the initial sample was drawn

In both waves, the adult caretaker (almost always a woman) for AFDC children was asked detailed questions about disability status, family and household composition, employment, household income, family well-being, and the use of social services. In Wave II of the survey, we included a set of questions to identify families with chronically ill or disabled children. We designed these questions to assess the type and severity of the child’s disabilities, expenses associated with the child’s condition, and the effect of the child’s disability on the parents’ employment and the family’s well-being.

For comparison purposes, we also use a complementary dataset of “new to welfare” families that initiated AFDC cases between 1993 and

1996 and were interviewed in the same time period.[3] Strictly speaking, these families might have been on welfare before, but they were "new" in the sense that they had not been on welfare since the sample was drawn or for the past year (whichever period was shorter). The interview protocol developed for the Wave II cross-sectional survey was administered to these families.[4] We call this the California Work Pays Demonstration Project (CWPDP) AFDC New to Aid Household Survey.

Additional data were obtained from county and state administrative records of the California Department of Social Services. In the original group of about 15,000 families from which the cross-sectional survey respondents were randomly chosen, all cases were on aid during the sampling month (October 1992), and two types of administrative data are available for these families: (1) monthly aid code, payment data, and information on family structure and membership from the county welfare office records from December 1992 to December 1995, and (2) statewide Medi-Cal MEDS data, which contain monthly aid codes from January 1987 to December 1995. The county data make it possible to identify the members of a household. The statewide MEDS data can be used to determine monthly AFDC and SSI receipt from January 1987 to December 1995 for individuals in a household.[5] This makes it possible

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[3] The cross-sectional sample was drawn to be representative of the four counties in October 1992. As new families entered the welfare roles, this sample would no longer be representative of those currently on welfare because it would lack any new to welfare cases. Hence, the new to welfare sample was drawn on a monthly basis to retain the representativeness of the county samples by adding a representative sample of those entering the AFDC program.

[4] For some of these cases ("Batch I" and "Batch II"), two waves of interviews were completed as with the cross-sectional survey, and we use the second or Wave II interview. For the remainder of the cases ("Batch III"), the Wave II interview was adapted to be used for one consolidated interview. For simplicity, we call the combination of the Wave II interviews for Batches I and II and the Batch III interview the Wave II interviews of the new to welfare cases. For details of the sampling method see the technical documentation for the CWPDP.

[5] The two administrative data sources complement one another. The MEDS file covers a much longer span of time than the county data, and it includes information on SSI participation as well as receipt of AFDC, but it has records only on individuals with no (reliable) linkages between persons in the same household. The county data provide

to determine with precision when cases began the AFDC spell that continued through December 1992,[6] when they left this spell, and when any members moved to SSI.

Sample Characteristics and Generalizability

Table 4.1 presents data on the characteristics of the cross-sectional sample. Although Alameda, San Bernardino, and San Joaquin are about one-fifth of the unweighted sample and Los Angeles is about two-fifths, almost three-quarters of the weighted sample is from Los Angeles, which reflects its large population. Nearly one-half of the parents in the sample were Latino, slightly less than half had not completed high school, and 27 percent were living with a partner (either married or cohabiting).[7]

A comparison of key demographic characteristics suggests that our sample is generally representative of the California welfare population, and somewhat less representative of the U.S. welfare population. In comparison to the welfare population of the state, the sample for this study contained somewhat more Latino families and fewer black families. The proportion of Latino families was much higher in the sample than in the U.S. welfare population as a whole, reflecting the large Latino population in California. The education level for the head of household in the study sample was also lower than that reported for the United States as a whole, although these differences may not be reliable because of large amounts of missing data for the United States. The average age of the head of household in the study sample also differed from the national profile. The lower education and older average age of

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much better information on the membership in a household, but they cover a much shorter period of time and they include only AFDC receipt.

[6] A small number of cases that were initially sampled in October 1992 but that left aid before December 1992 were excluded from the survey sample. In addition, for those cases that began their AFDC spell before January 1987, we use the survey data to establish the beginning of the spell.

[7] The sample was stratified by AFDC program type to correctly represent families who qualified for AFDC-FG (for one parent families) or AFDC-UP (for two parent families). We have elected to use the more inclusive coding of “partnered” in our analyses, which is consistent with recent research suggesting that income pooling is nearly as common among cohabiting couples as it among married couples.

Table 4.1

Household Characteristics in Cross-Sectional Sample Compared to the California and U.S. Welfare Populations
(in percent)

	Weighted	California	United States
County			
Alameda	8.2	4.1	0.7
Los Angeles	72.0	34.3	6.3
San Bernardino	15.6	7.0	1.3
San Joaquin	4.3	2.4	0.4
Race/ethnicity			
White	20.5	25.9	37.4
Black	28.4	17.4	36.5
Latino	47.8	41.5	19.9
Other	3.3	9.0	6.3
Education			
8th grade or less	19.3	n.a.	4.0[a]
Some high school	26.9	n.a.	17.6[a]
High School graduate or GED	29.8	n.a.	24.1[a]
Some college	21.2	n.a.	7.7[a]
College graduate or more	2.8	n.a.	7.7[a]
Living with partner	27.1	n.a.	n.a.
Age categories			
Under age 25	11.3	n.a.	30.9
25–40 years	64.4	n.a.	57.5
41 or greater	24.3	n.a.	11.5

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II; surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties; and U.S. House of Representatives (1996).

NOTE: Entries are weighted to be representative of the four counties. Numbers may not add because of rounding. Unweighted n = 1,764.

[a] Educational data for U.S. welfare population are available only for 54 percent of the caseload.

respondents in the study sample may reflect the cross-sectional sampling design, which is likely to be dominated by long-term welfare cases.

When the initial cross-sectional study sample was drawn, all families were welfare and Medicaid recipients and some were also receiving SSI for a disabled family member. By the time of the follow-up interview, approximately one-quarter of the families were no longer receiving welfare; some who had left welfare continued to receive Medicaid and others received no means-tested assistance. Data from the second interview thus represent both families in the welfare system and those beginning a transition to independence.

Several important characteristics of the cross-sectional sample should be noted. The sample was designed to represent the welfare population in four diverse counties in California, representing almost half of the welfare caseload for the state. Although we believe that the findings can be generalized to the welfare population in California, they may not fully represent the characteristics of families in the welfare system elsewhere in the country. Because important groups were not included in this round of surveys, notably recent immigrants who could not be interviewed in either English or Spanish, caution must also be used even in drawing conclusions about California. In addition, the data are from the 1992–1996 period, and welfare has changed dramatically since then.

The cross-sectional sample has another important characteristic. 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, a cross-sectional sample will not represent the experiences of *all* families who *ever* enter the welfare system. In particular, this cross-sectional sample more fully represents long-term, more highly disadvantaged welfare recipients than the larger number of short-term, relatively more advantaged families who cycle through the welfare system more quickly. The findings from this sample are particularly useful for understanding the experiences of longer-term welfare clients and the characteristics of welfare caseloads at any point in time. With the advent of time-limited welfare, these clients are increasingly becoming the focus of public policy in California and around the nation.

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

Analysis of Private Costs

In Chapter 5, we describe the distribution, amount, and type of direct, disability-related expenses. In deriving population estimates of direct costs, our data are limited in one important respect. As earlier research indicates, special medical and other expenses are not distributed evenly, either across families or across time for the same family. Although our sample is expected to represent the range of families (within the welfare population) who are likely to incur these costs, the time period is truncated in that we observe expenses only for the month before the interview. This limits information about intermittent adjustments that occur less often than monthly. Thus, our estimates of costs cannot be easily extrapolated to estimates of the annual costs to families. The proportion of families incurring costs over a longer period is likely to be greater than the proportion of families incurring costs within a given month. Similarly, among families with costs, the total cost over a year is probably greater than the amount reported for the preceding month but seems unlikely to be as great as 12 times the monthly amount.

We next consider the indirect costs for families in the form of forgone employment earnings. We begin by comparing employment rates for families with and without special needs children, and the self-reported employment reductions of mothers with more and less severely impaired children. To estimate more precisely the effect of the child's conditions on maternal employment, we used censored regression analysis to estimate the effect of children's disabilities (severity and type) on maternal employment, controlling for other individual, family, and program participation factors.

To interpret the effect of these private costs on families' well-being, we consider the effect of direct and indirect costs on poverty and on material hardship. We compare rates of poverty and extreme poverty for families with and without disabled children. Among families with special needs children, we compare poverty rates before and after adjusting family income for direct, out-of-pocket expenditures related to their child's disability.

Although having income below the poverty threshold is widely used as a proxy for economic well-being, it is not sensitive to differences in need across household. It has also been shown to be an imperfect predictor of actual hardship (see Mayer and Jencks, 1988, for example), in part because the resource measure (gross cash income) both underestimates family resources and ignores important nonelective expenses (see Edin and Lein, 1997, for example). These limitations are particularly relevant to the present analysis, insofar as we hope to capture the effect of variation in need—disability-related expenditures—on economic well-being. In an effort to estimate the net effect of these costs on families' economic security, we also compare experiences of material hardship across families that vary in the presence of disabled children and in the severity of their conditions. The contribution of children's disabilities to family hardship was measured more precisely using logistic regression. We regressed measures of child disability on the likelihood that the family experienced at least one of these problems ("any hardship"), controlling for other family characteristics. To interpret these results more directly, we used the regression coefficients to simulate the contribution of child disabilities to family hardship.

Analysis of Public Costs

Turning to the public costs of caring for disabled children (Chapter 6), we describe participation in both targeted and nontargeted public programs for families who differ by the presence and severity of child disabilities. Means-tested public assistance programs included cash aid (AFDC and SSI), in-kind programs (Food Stamps and subsidized housing), and public health insurance (Medicaid or Medicare). Specialized services included special education (for children over age 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.

To the extent that direct and indirect costs reduce families' economic resources, we expect that families who care for children with disabilities or chronic illnesses will be more likely to participate in means-tested assistance such as AFDC or TANF. Theory and research suggest that more, and more severe, disabilities and health problems will *reduce* human capital, earning potential, and the probability of leaving some form of assistance. But these same factors *increase* the probability that someone in the household will be eligible for cash assistance through SSI, either along with or instead of other forms of welfare. We show that earlier studies on the role of disabilities in welfare transitions have failed to find consistent effects because they estimated an "average" of these two offsetting effects.

5. The Private Costs of Care

The identification of disabilities or illness, especially in children, is often difficult. Even doctors sometimes disagree on a diagnosis. In a survey, we must rely on self-reports from parents about their children. One of the best ways to ensure high-quality and accurate responses to survey questions about health is to ask very specific and pointed questions. We did this by asking a battery of questions about each child in the respondent's family. Respondents were first asked two screening questions: whether any of their children (1) had a chronic health problem—physical, emotional, or mental—that limited the amount or kinds of things that he or she could do, or (2) had a disability or handicapping condition that limited the amount or kind of things he or she could do. If the parent answered yes to either of these questions, we asked them to identify up to five specific diseases or conditions that were responsible for the limitation. We then asked a series of questions about the functional limitations that these conditions imposed. We classified a family as including a special needs child if the respondent answered yes to either of the screening questions; we classified the severity of the condition using the questions about functional limitations (summarized in Table 5.1). We determined whether the mother had any limiting conditions by asking standard survey questions about whether she had a physical, emotional, or mental condition that limited the amount or kind of work she could do and by asking her to rate her own health. We classified a parent as having a disability or health limitation if she reported a work-limiting disability or rated her health as “poor” (see Appendix D for additional detail about measures).

Prevalence of Disabilities

Chronic health problems and disabilities were frequent in our samples of welfare recipient families. As shown at the top of Table 5.2, when we use the cross-sectional sample, only 60.3 percent of the

Table 5.1

Coding of Severity: Disabilities and Chronic Illnesses

Children's Conditions
Moderate: *Mother reports specific condition or diagnosis and one or more of the following functional limitations due to condition:*
Needs "a little" more help with daily activities than other children his/her age (e.g., eating, bathing, dressing, or getting around the house).
Unable to take part in usual activities for child of his/her age.
Attends special classes or receives special education services.
Misses "some" days of school.
Limited in ability to crawl, walk, run, or use stairs.
Severe: *Mother reports specific condition or diagnosis and one or more of the following functional limitations due to condition:*
Child needs "a lot" more help with daily activities than other children his/her age (e.g., eating, bathing, dressing, or getting around the house).
Misses "a lot" of days of school.
Prevented from going to school.
Mothers' Conditions
Moderate: *Mother reports that she has a physical, mental, or emotional condition that limits the type of work she can do or the hours she can work.*
Severe: *Mother reports that she has a physical, mental, or emotional condition prevents her from working at all.*

families escaped having some illness or disability of the mother or the children. About 28.9 percent of the households had an ill or disabled mother and 19.5 percent of households reported the presence of at least one child with a chronic health problem or disability. When adult disabilities and children's special needs are considered together, 39.7 percent of the households were affected: About one-quarter of these households (10.8 percent of the total sample) had children with special needs, half were headed by a mother who was disabled or in poor health,

Table 5.2

Summary of Prevalence of Mother and Child Disabilities
(in percent)

	Mother's Health and Disability Status		
Children's Health and Disability	No Disabilities or Health Limits	Some Disabilities or Poor Health	Total
In cross-sectional sample			
No disabled/ill children	60.3	20.2	80.5
One or more disabled/ill child	10.8	8.7	19.5
Total	71.1	28.9	100
In new to welfare sample			
No disabled/ill children	76.9	14.4	91.3
One or more disabled/ill child	5.5	3.2	8.7
Total	82.4	17.6	100.0

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II; Survey: English/Spanish Interviews March 1993–May 1994 Sample (Wave 2); Survey: English/Spanish Interviews January 1995–August 1996 Sample (Combined Wave); and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Entries are weighted to be representative of the four counties. Numbers may not add because of rounding. Unweighted n = 1,711.

and one-quarter included *both* a disabled or ill mother and one or more disabled or ill children.

Because a cross-sectional sample represents the "stock" rather than "flow" of cases in the welfare caseload, it will be dominated by those cases that remain in the system longest. If disabilities are associated with longer stays on welfare, we would expect a prevalence estimate based on a cross-sectional sample to be higher than one based on cases that are new to welfare. The flow of new cases onto the rolls, which are dominated by cases that cycle off aid more quickly, may be more representative of the prevalence of disabilities in the low-income population that includes many who are not on welfare. When we consider a sample of "new to welfare cases," we find a distribution that is similar to what we found for the cross-sectional sample but with lower prevalence of disabilities among both mothers and children. In the bottom panel of Table 5.2, we see that nearly one-quarter of families had special needs. Slightly more than one-fifth of these (5.5 percent of the total sample) had special needs because of a disabled child, about three-fifths because of a disabled or ill mother, and somewhat less than one-fifth because both mother and child had limitations.

Caregiving costs for families vary not only with the presence of disabled and ill children but also with the severity of their needs and the number of such children within the family. We classified the severity of children's conditions according to the degree of functional limitation: from moderate to severe. If a child was identified as having a chronic condition but met none of these criteria, he or she was classified as only mildly disabled. For mothers, we classified the condition as severe only if she reported that it limited her from working altogether.

Table 5.3 breaks down the cross-sectional sample by severity of disabilities and number of disabled children, and Table 5.4 does the same

Table 5.3

Prevalence of Mother and Child Disabilities in Cross-Sectional Sample

	Mother's Health and Disability Status			
Children's Health and Disability Status	No Disabilities or Health Limits	Moderate Disabilities or Poor Health	Severe Disability	Total
No disabled/ill children	60.3	14.1	6.1	80.6
One disabled/ill child:				
Mild disabilities	1.3	0.3	0.3	1.8
Moderate disabilities	5.1	2.2	1.2	8.5
Severe disability	2.9	0.9	0.5	4.3
More than one disabled/ill child:				
All Mild disabilities	0.3	0.0	0.0	0.3
Any moderate, no severe disabilities	1.0	1.3	0.7	3.0
Any severe disability	0.4	0.8	0.4	1.6
Total	71.1	19.7	9.2	100.0

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Entries are weighted to be representative of the four counties. Numbers may not add because of rounding. Unweighted n = 1,711.

Table 5.4

Prevalence of Mother and Child Disabilities in New to Welfare Sample

	Mother's Health and Disability Status			
Children's Health and Disability Status	No Disabilities or Health Limits	Moderate Disabilities or Poor Health	Severe Disability	Total
No disabled/ill children	76.9	11.5	2.9	91.3
One disabled/ill child:				
Mild disabilities	0.4	0.1	0.0	0.5
Moderate disabilities	2.8	1.4	0.6	4.8
Severe disability	1.2	0.7	0.1	2.0
More than one disabled/ill child:				
All Mild disabilities	0.0	0.0	0.0	0.0
Any moderate, no severe disabilities	0.7	0.0	0.0	0.7
Any severe disability	0.3	0.4	0.0	0.7
Total	82.4	14.1	3.5	100.0

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews March 1993–May 1994 Sample (Wave 2); Survey: English/Spanish Interviews January 1995–August 1996 Sample (Combined Wave); and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Entries are weighted to be representative of the four counties. Numbers may not add because of rounding. Unweighted n = 1,291.

for the new to welfare sample. According to our criteria, 11.5 percent of the families in the cross-sectional sample had children with moderate limitations and 5.9 percent had children with severe limitations. Almost 5 percent of the sample has more than one disabled or ill child. These figures are smaller for the new to welfare sample; almost 3 percent of these families cared for a child with a severe limitation. Over 9 percent of mothers in the cross-sectional sample reported that their conditions preclude work, as did more than 3 percent of those in the new to welfare sample.

Considering either the estimate based on the cross-sectional or new to welfare sample, the prevalence of limiting conditions in this population is much higher than estimates for the general population. However, our estimates are similar to recent estimates of disabilities in the welfare population by Loprest and Acs (1995). In Table 5.5 we compare our estimates to those of Loprest and Acs, who used several nationally representative data sources to estimate the prevalence of disabilities and poor health among AFDC recipient families. Although samples and definitions vary slightly across the studies, some comparisons are possible.

Given the structure of the cross-sectional and new to welfare samples on which our estimates are based, we would expect our estimates to bracket those developed using other surveys, particularly panel surveys

Table 5.5

Comparison of Prevalence of Disabilities to Other Data Sources

	AFDC Household Survey		AFDC Recipients in Nationally Representative Surveys[a]		
	Cross-Sectional Sample	New to Welfare Sample	SIPP	NHIS[b]	NLSY[c]
Mothers					
Work-limiting disability[d]	26.1	13.6	16.6	17.8	19.2
Poor health	2.8	4.0	n.a	4.5	n.a.
Disability *or* poor health	28.9	17.6	n.a.	n.a.	n.a.
Children					
Children with limitation[e]	n.a.	n.a.	11.1	15.9	15.1
Families with limited child	19.4	8.7			
Families					
Mother or child limited	29.7	23.1	27.4	29.5	28.9

SOURCES: AFDC Household Survey; authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II; Survey: English/Spanish Interviews March 1993–May 1994 Sample (Wave 2); Survey: English/Spanish Interviews January 1995–August 1996 Sample (Combined Wave); and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Entries are weighted to be representative of the four counties. Numbers may not add because of rounding. Unweighted n = 1,711.

[a] National samples: Loprest and Acs (1995).

[b] National Health Interview Survey.

[c] National Longitudinal Survey of Youth.

[d] Work-limiting disabilities were measured in all surveys as a problem that limits the amount of kind of work the respondent could do.

[e] Limitations were defined as limitations in major activity (NHIS), as a functional limitation (SIPP), or as a work, school, or physical limitation (NLSY).

such as the Survey of Income and Program Participation (SIPP). If disabilities and poor health are associated with longer stays on welfare, we would expect families in our cross-sectional sample, which has a high proportion of long-term welfare recipient families, to have higher rates of disability; likewise we would expect families in our new to welfare sample to have lower rates of disability and health problems.

This is essentially what we find. Among mothers, work-limiting disabilities were reported by 26.1 percent of women in our cross-sectional and 13.6 percent of women in our new to welfare samples. In nationally representative samples, 16.6 to 19.2 percent of women on AFDC reported affirmatively to the nearly identical question. Mothers reported poor health at a rate of 4.0 percent in our cross-sectional and 2.8 percent in our new to welfare sample; in a nationally representative sample the rate is 4.5 percent. (We combine these two indicators (work limiting disabilities *or* poor health) into our composite indicator of adult disability.)

For children, both samples and questions are less comparable across datasets, rendering comparisons difficult. Nationally representative samples, using parent reports of child disabilities and limitations, estimate that between 11.1 and 15.9 percent of children in AFDC households have a limiting condition. Because our data are weighted to households rather than children, we report disabilities at the family level. We estimate that between 19.4 (cross-sectional sample) and 8.7 (new to welfare sample) percent of families on AFDC cared for at least one disabled child—once again, bracketing estimates from other surveys.

Estimates across the surveys are even closer when we use a common level of analysis: AFDC families in which either the mother or a child has some limiting condition. For this measure, national surveys estimate 27.4 to 29.5 percent of families are affected, whereas the AFDC household survey for the two samples yields an estimate of 29.7 percent for those already on welfare and 23.1 percent for those new to welfare. This comparison gives us considerable confidence about the reliability of our estimates.

These data suggest that between 20 and 25 percent of poor families in the welfare system include families with disabled or ill mothers or children and that those families most at risk for long-term welfare stays have an even higher prevalence of disabilities and chronic illness among mothers and children. As those most able to leave welfare continue to do so, it seems likely that families with disabilities and chronic illnesses will make up an increasing share of the welfare caseload.

Types of Disabilities

For each child identified by our screening questions, respondents were also asked to identify up to five conditions causing the child's impairment. For purposes of this analysis, we use only the first listed impairment for the eldest child with a disability in the family. Because many impairments affect only a small number of children, we grouped children's conditions into eight broad categories. Four are classified as physical impairments: (1) respiratory diseases (including asthma); (2) arthritis, deformities, and diseases causing muscle weakness; (3) visual or hearing impairments; (4) all other physical conditions. Another three are classified as mental impairments: (5) behavioral and learning disorders (including attention deficit hyperactivity disorder); (6) mental retardation and developmental disabilities (including autism); and (7) mental and emotional illness. Speech impairments constitute a final category.

Almost three-quarters (71.7 percent) of children's disabilities were physical impairments and one-quarter (25.5 percent) were mental impairments. As shown in Table 5.6, both types of conditions imposed limitations that range from mild to severe for individual children.

Almost two-thirds of the physical impairments (about 45 percent of all disabilities) were respiratory diseases, in particular, asthma. The very high prevalence of asthma in this population is consistent with other studies, which find that poor children, living in poor-quality housing and neighborhoods, have the highest rates of morbidity and mortality from asthma in the country (Rosenstreich et al., 1997; Call et al., 1994; Sarpong et al., 1996). In this sample, children with respiratory disabilities were more likely to be moderately (not severely) disabled than were children with other conditions. However, because so many children had respiratory illnesses, those who were coded as having a

Table 5.6

Distribution of Child Disabilities by Diagnosis of First Child with Disability for Households with Disabled Children

(in percent)

	Severity of Child's Disability			
Disability	Mild Disability	Moderate Disability	Severe Disability	Total
Physical impairment				
Respiratory	3.1	29.1	12.8	45.0
Arthritis, deformity, muscle weakness	0.1	1.9	1.2	3.2
Visual/hearing impairment	1.0	3.8	0.2	5.0
Other physical	5.0	6.7	6.7	18.4
All physical	9.3	41.4	21.0	71.7
Mental Impairment				
Behavioral/learning disorder	0.4	9.9	3.6	13.9
Mental retardation/developmental delays	0.2	2.9	3.2	6.2
All/emotional illness	0.5	2.7	2.1	5.3
All mental	1.1	15.5	8.9	25.5
Speech impairment	0.5	1.7	0.0	2.3
Condition not known	0.0	0.2	0.4	0.5
Total	10.9	58.8	30.2	100.0

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Entries are weighted to be representative of the four counties. Numbers may not add because of rounding. Unweighted n = 372.

severe limitation because of these respiratory illnesses constitute the largest single category of children with severe conditions.

After respiratory impairments, the second largest category of impairments was a broad group of other physical diseases and disabilities, from cancer to epilepsy and cystic fibrosis. Conditions such as these affected nearly one-fifth of disabled or ill children and over one-third imposed severe limitations. The remainder of the physical impairments includes visual and hearing impairments and arthritis, deformity, and muscle weakness.

Another one-quarter of all conditions are classified as mental impairments. Of these, behavior and learning disorders were the most common, closely followed by developmental problems or mental retardation and mental illness. Over 50 percent of children with mental retardation or developmental disabilities were severely limited; 40 percent of those with mental and emotional illness were also classified as severe. Behavioral and learning disorders, in contrast, were predominantly coded as moderately limiting.

The Frequency and Magnitude of Direct Costs

We measured the *direct* disability-related expenses incurred by families in two ways. First we asked whether the family had made any special purchases or incurred major costs, over $100, since the prior survey, because of any child's disability. Second, we asked whether the family had experienced any disability-related expenses in the prior month, and the amount of those expenses, in six categories: special clothes, special foods, transportation, medicine and health care, child care, and any other special expenses.[1] For the purposes of analysis, we separate child care expenses from all other expenses. Respondents with more than one special needs child reported aggregate expenses for all the children in each category. Table 5.7 shows how expenses varied with the number of disabled children and the severity of their condition.

Looking first at *major* expenses, 12.5 percent of families reported at least one major purchase or expenditure, (over $100), in the 18 months between waves of the survey. 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.

A much greater proportion of families with special needs children incurred some out-of-pocket expenses in the prior month. Thirty-eight percent of such families reported incurring some expenses other than child care in the prior month, averaging $105. Nearly 20 percent reported special expenses associated with child care for a disabled child, averaging $120. Since some families with disabled children reported no special expenses in the previous month, the average expenses over all

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[1] These questions were designed to elicit only extra or special expenses related specifically to the child's disability. However, in the case of child care, it is possible that respondents were unable to separate the extra marginal cost of care due to the child's special needs and reported the full cost of care. For our analysis, we assume that the reported cost of child care does represent only extra or special expenses, but conclusions with respect to this variable should be interpreted cautiously.

Table 5.7

Out-of-Pocket Disability-Related Expenses of Families with Disabled Children

Expenses	All Families	One Disabled Child: Moderately Disabled	One Disabled Child: Severely Disabled	More Than One Disabled Child: All Moderately Disabled	More Than One Disabled Child: Any Severely Disabled
Expenses in the last year					
Percent with expenses > $100	12.5	13.0	18.5	2.1	29.3
Expenses other than child care last month					
Percent with any	38.0	30.6	51.3	41.0	65.3
Average amount, $	104.53	68.57	123.33	74.25	143.37
Standard deviation, $	102.03	80.72	137.92	61.98	136.07
Child care expenses last month					
Percent with any	18.8	25.5	8.9	8.2	33.4
Average amount, $	119.98	135.22	55.16	116.21	122.89
Standard deviation, $	83.62	86.60	33.42	73.93	109.12

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Entries are weighted to be representative of the four counties. Average amounts and standard deviations are among those families with any expenses. Unweighted n = 372.

families with disabled children, whether or not they reported expenses, was about $62.

As has been found in other studies, direct expenses associated with the care of a disabled child were highly variable across families. Both the severity of the condition and the number of children affected help explain variation in non–child care costs. Families with more than one disabled child were substantially more likely to have paid for special clothing, food, transportation, or medical costs, and they paid nearly $20 more on average. Families who cared for any child with a severe limitation were nearly twice as likely to incur such expenses than those with less severely affected children and, among those who did, incurred expenses that were more than twice as great. Families with a single severely disabled child were less likely to have paid for specialized child care than were those with a single, moderately impaired child, either because they provided full-time parental care or because they had access to care through public programs. Given this, it is surprising to note that among families with more than one special needs child, families with at least one severely disabled child were more likely to be using specialized care. Since we cannot assign child care costs at the child level, we cannot determine whether this reflects more use of paid care for severely impaired children among these families or use of care for a less-compromised child in the family. The lack of significant variation in out-of-pocket costs for specialized child care across these families supports the latter explanation.

In terms of specific expenses (see Table 5.8), unreimbursed medical expenses are the most common, reported by nearly one-quarter of families. Although common, medical expenses were moderate for most. Specialized child care was the next most common form of expense, and it was the most expensive category of expense.

The type of condition did little to predict families' financial burden (see Table 5.9). Families were slightly more likely to incur costs if their child had a physical condition, but they paid more, on average, if the child's condition was a mental impairment.

Table 5.8

Distribution of Out-of-Pocket Disability Expenses for Families with Disabled Children

Type of Expense	% of Families with Expense in Last Month	Average Amount of Expense, $	Standard Deviation of Expense, $
Clothing	8.6	82.14	48.23
Food	14.5	84.84	51.81
Transportation	6.2	48.86	26.48
Medical	23.5	49.49	55.43
Child care	18.8	119.98	83.62
Other	6.5	87.43	98.67
Total (all types)	46.2	134.89	123.82

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Entries are weighted to be representative of the four counties. Average amounts and standard deviations are among those families with any expenses. Unweighted n = 372.

Table 5.9

Distribution of Out-of-Pocket Expenses by Diagnosis for Households with One Disabled Child

Diagnosis	Expenses in Last Month: % of Families with Expenses	Expenses in Last Month: Average Expenses, $	Expenses in Last Month: Standard Deviation, $	% of Families with Expenses > $100 Since Wave 1
Physical impairment				
Respiratory	43.8	101.67	75.16	10.1
Arthritis, deformity, muscle weakness	30.1	92.18	24.80	7.6
Visual/hearing impairment	33.5	249.51	96.89	46.5
Other physical	52.4	135.12	119.68	15.2
All physical	44.9	120.87	94.65	14.2
Mental Impairment				
Behavioral/learning disorder	38.6	173.15	93.74	6.2
Mental retardation/developmental delays	41.2	70.66	65.43	0.0
Mental/emotional illness	43.8	154.34	142.06	15.8
All mental	40.7	137.72	101.90	6.9
Speech impairment	63.6	202.91	141.94	52.4
Condition not known	100.0	83.44	31.67	0.0

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Entries are weighted to be representative of the four counties. Average amounts and standard deviations are among those families with any expenses. Unweighted n = 283.

Perhaps the more striking finding from these data is the *lack* of variation across categories. Excluding the small number of children whose first diagnosis was speech impairments, the probability of incurring costs in the prior month ranges between 30 and 52 percent. Only one category other than speech impairments was associated with average monthly costs of more than $200; the balance had average costs that ranged narrowly between $70 and $170. No diagnostic category, including the large category of children with respiratory diseases, or the oftentimes controversial "soft" diagnoses of mental and behavioral disorders, can be identified as creating little or no financial burden for families.

The Frequency and Magnitude of Indirect Costs

Out-of-pocket expenditures are not the only way in which care for special children is costly. Special needs children are also expensive in terms of time. Many parents with exceptional children combine their caregiving work with work outside the home. If the caregiving demands become too high, however, parents may be forced to reduce or forgo employment to provide full-time care for their child.

We measured these indirect costs by considering the effect of child disabilities on mothers' employment. Respondents were asked whether they were currently employed in a "regular" job. Because the employment of low-income parents and those with young children is often volatile, the survey also included questions about any work (at "odd jobs") in the prior month. Women who reported either regular or odd jobs in the prior month were asked for their hours of employment. Mothers who cared for any children with chronic mental, physical, or emotional conditions were asked additional questions about whether care for those children caused them to reduce their employment at present and whether they expected this care to reduce employment 12 months in the future.

The data (Table 5.10) suggest that these low-income families are paying opportunity costs in terms of their employment. Overall, just over one-third of all survey respondents (36.6 percent) indicated that they had worked for pay in the prior month. This rate of employment is considerably higher than estimates based on welfare records but still somewhat below estimates based on in-depth ethnographic studies. Edin and Lein (1997), for example, report that 46 percent of welfare recipients obtain some of their income through employment. These discrepancies may be due to high levels of work in underground or illegal activities (reported by 8 percent of Edin and Lein's respondents.)

Although these estimates may not capture the full extent of employment among current and recent welfare recipients, they do permit comparisons across families. In comparison to mothers with healthy children, those with disabled or ill children were less likely to be employed in the prior month. About two-thirds of mothers with only healthy children were not working when contacted. About the same

Table 5.10

Employment Rates by Child Disability for All Families
(in percent)

			One Disabled Child		More Than One Disabled Child	
Mother's Employment Status and Impact of Child(ren)'s Condition	All	No Disabled Child	Moderately Disabled	Severely Disabled	All Moderately Disabled	Any Severely Disabled
Employed last month	33.0	35.3	34.0	17.5	16.2	5.2
Limits mother's work now		n.a.	34.5	63.1	49.0	95.2
Limits ability to work at all		n.a.	10.6	26.5	11.5	52.7
Limits hours available for work		n.a.	24.0	36.6	37.6	42.6
Limits work in 12 months		n.a.	22.4	38.5	33.0	78.0
Limits ability to work at all		n.a.	7.1	15.9	4.0	40.9
Limits hours available for work		n.a.	15.3	22.7	28.9	37.1

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Entries are weighted to be representative of the four counties. Unweighted n = 1,711.

proportion of mothers with a single, moderately disabled child were not employed. In contrast, less than 20 percent of mothers with more than one or any severely disabled children report hours of employment.

Mothers' self-reports also indicated that care for special needs children depressed employment. One-third of those with only one moderately disabled child indicated that care for the child made it difficult to work. The percentage of mothers reporting barriers to work increased dramatically with the number and severity of children's special needs. Of those with a single severely disabled child, 63 percent reported barriers, and nearly all of those with multiple and at least one severely disabled children did so. Mothers were more sanguine about their employment prospects in one year into the future, perhaps because they expected their children's need for care to decline or supportive public or family services to increase. Nevertheless, from 22 to 78 percent expected that caring for special children will cause them to limit their work in the next year.

Although mothers with disabled children are observed to work less than other mothers in our sample, it is possible that this difference reflects other, unobserved characteristics of these mothers. Mothers who were out of the labor force for other reasons may also have attributed their lack of employment to the need to care for their children, biasing the estimate upward. To isolate the effect of caring for a special needs child from other factors that affect employment, we use regression techniques to estimate the reduction in employment probabilities and hours associated with children's special needs while controlling for other factors that influence the employment decision. Details of the estimation and full results are provided in Appendix A. Table 5.11 provides a summary of the effect of children's disabilities.

As would be predicted from prior research, mothers were less likely to be employed, and worked fewer hours, if they were younger, had fewer years of education, had never been married, had health problems, had

Table 5.11

Selected Results, Impact of Childhood Disabilities on Mothers' Employment in the Prior Month (Tobit Estimates)
(in percent)

	Any Child with Moderate Limitation	Any Child with Severe Limitation
Change in the probability of employment (among all mothers)	–0.03	–0.15***
Change in hours of employment (among mothers who were employed)	–3.18	–15.32***

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Model also controls for individual, family, local labor market, and design effects. Full results are provided in Appendix A. Unweighted n = 1,732. Statistical significance level indicated as ***p < .01.

more children, or had any children under the age of six (see Appendix A). Employment was also lower in families who were eligible for higher welfare benefits (based on the number of AFDC-eligible children). Receipt of SSI for any family member other than the mother herself was not significant, although the coefficient was moderately large. Mothers' probability of employment also decreased two percentage points, and hours decreased by about 2.3 per month among those employed, with each one point increase in the local unemployment rate.

After controlling for these individual and structural factors, children's disabilities explained a significant share of the remaining variation in employment outcomes. As shown in Table 5.11, the presence of a child with only moderate limitations was not significantly related to mothers' employment although the effect is negative (suggesting a reduction in employment). In those families caring for a child with a severe limitation, however, mothers' probability of employment was 15 percent lower, and mothers who were employed worked an average of 15 fewer hours per month. This suggests that care for more severely impaired children imposed a greater employment barrier for mothers. At the prevailing minimum wage of $5.15 per hour, 15 hours of forgone employment translates into $77 in forgone income each month among those who were employed. Assuming a minimum wage rate of pay and accounting for both reductions in the probability of employment and reductions in hours worked among those employed, mothers forgo an average of approximately $80 per month in employment income if they care for a severely disabled child.

The Economic Consequences for Families: Poverty and Hardship

These data suggest that the care of a disabled child had considerable financial implications for families, particularly for those caring for any severely impaired child. In absolute terms, their direct costs averaging just under $150, and forgone earnings of $80 or more, may seem small. However, even relatively small out-of-pocket expenses may create a significant burden on a low-income family with few resources to spare. To measure the effect of special expenses on the economic well-being of the family, we calculate each family's income and poverty status for the previous month before and after subtracting the total special expenses relating to the care of a special needs child (all "extra" or special costs relating to child care and other costs). Because SSI makes a significant contribution to cash income, we consider outcomes separately for families who did and did not receive SSI for a disabled child. And because so many of the families in this sample are poor, we report families' economic status relative to extreme poverty—defined here as 75 percent of the federal poverty threshold.

Before adjusting incomes for special expenses, we find that 68 percent of families with a disabled child and no SSI had incomes at or below 75 percent of the poverty line. Families with a disabled child who received SSI were doing somewhat better, on average. Only 20 percent of these families were extremely poor.

The federal poverty threshold measures economic hardship in terms of resources (cash income) relative to need (basic food expenses multiplied by three), adjusting for family size. Although this formula may capture the loss of earned income associated with the care of a disabled child, it does not capture the higher level of need in these families. When we adjust families' income by subtracting the direct, out-of-pocket expenditures for the care of disabled children, a much higher proportion of these families are observed to be living in extreme poverty. Nearly three-quarters (72 percent) of families without SSI and one-third (32 percent) of those with SSI have incomes below 75 percent of the poverty line once the extra expenses associated with their disabled child are considered. The direct out-of-pocket expense of caring for a disabled child pushed somewhere between 4 percent and 12 percent of already poor families into extreme poverty.

Income poverty may still not capture the full effect of these private costs, however. When very poor families face extraordinary costs, they are unlikely to have a cushion of income or savings on which to draw. Meeting the needs of a special child may force families to make choices—between purchasing specialized goods and services for this child or meeting the basic needs of the family.

We can get some idea of whether families make such tradeoffs by comparing their experience of income-related hardship in the prior year.

Respondents were asked about five specific forms of hardship: whether adults or children ever went hungry because there was not enough money for food, whether the family had faced eviction or had any episodes of homelessness, whether rent or mortgage payments had been missed on more than three occasions, or whether they had their utilities or phone shut off. If the extra costs associated with caring for disabled children caused families to make tradeoffs between expenditures for the "extra" care of children and other basic necessities, we might expect families with special needs child to report higher levels of material hardship.

As predicted, on nearly all of these indicators (see Table 5.12), families with greater caregiving responsibilities reported greater levels of hardship. 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, but one-third or more of families with any disabled or chronically ill children reported hunger. In 22 percent of families with healthy children, adults had gone hungry; but between 33 and 73 percent of families caring for exceptional children experienced hunger among adults. Families with a greater level of extra caregiving

Table 5.12

Percentage of Households with Hardship Since Last Interview by Child Disability for All Families

			One Disabled Child		More Than One Disabled Child	
	All	No Disabled Child	Moderately Disabled	Severely Disabled	All Moderately Disabled	Any Severely Disabled
Children ever hungry	20.5	17.3	33.4	32.3	31.6	43.4
Adults ever hungry	25.0	22.0	32.6	36.6	37.5	72.6
Late with rent or mortgage three or more times	18.1	17.5	19.0	15.7	23.5	38.7
Evicted or homeless	6.5	5.8	12.3	2.7	9.3	19.1
Utility or phone shutoff	30.5	29.9	24.9	34.0	43.6	55.7

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Entries are weighted to be representative of the four counties. Unweighted n = 1,711.

responsibility were also more likely to have had difficulty paying their housing costs, to have experienced eviction or periods of homelessness, and to have had phone or utility shut-offs because they could not pay their bills.

6. The Public Costs of Care

Families absorb substantial direct and indirect costs caring for children with disabilities and chronic illnesses. Not all of the costs associated with the care of these children are private, however. Public programs shoulder a portion of the burden as well. Most public expenditures on behalf of disabled children are used to provide direct services, principally through school-based special education and early intervention programs. If families are poor enough, government programs may also offset a portion of private caregiving costs through targeted and means-tested transfer programs.

Disabilities and Public Program Participation

Aggregate spending figures provide one measure of the extent to which public programs share the burden of care for exceptional children. However, spending figures do not tell us much about the likelihood that individual families use these programs. Families with disabled and ill children are by definition more likely than others to participate in specialized educational and therapeutic programs for children. These same families are also overrepresented in nontargeted programs providing income, food, housing, and medical assistance.

We measured families' participation in targeted programs by asking parents who cared for any disabled or ill children whether those children received services from a variety of local, state, and national programs. Participation in these programs was relatively common among these families, and the likelihood of receiving services was closely associated with the severity of their children's limitations. About 43 percent of families with a single, moderately disabled child had that child in special education services, in comparison to 75 percent of families with more than one impaired child, at least one of whom was severely limited[1] (see Table 6.1). Fewer families were receiving case management from California Children's Services or Community Mental Health Services. Although lower overall, participation rates in these programs also increased substantially with the number and severity of special needs in the family.

Some families with severely disabled adults or children were also eligible to receive cash assistance through SSI, either alone or in combination with AFDC. Nearly 5 percent of families *without* special needs children were receiving SSI for another household member. In those families with moderately to severely disabled children, between 23 and 46 percent were receiving SSI for one or more family members.

It is more surprising to find a similar pattern in nontargeted, means-tested welfare programs. Although just under three-quarters of families without disabled children were still receiving welfare when contacted (from 30 to 42 months after the sample was drawn), between 81 and 99 percent of those caring for disabled children remained in the welfare system. Rates of participation in the Food Stamp program were similar, ranging from 71 percent of those with no special caregiving responsibilities to as high as 88 percent of those with the highest level of extra caregiving burden. The percentage of families in subsidized housing (or receiving housing subsidies) varied from a low of 18 percent among those with no special needs children to between 25 and 38 percent of those with special needs children.

Rates of Medicaid participation also increased along with the presence and severity of children's disabilities. To standardize estimates at the family level, Medicaid participation figures are reported for one randomly selected child in each family. (This may or may not have been the disabled child.) About three-quarters of families with only healthy children were still receiving Medicaid for at least one child when families were interviewed. In contrast, from 83 to 100 percent of families with any disabled children were still in the program. Not surprisingly, rates of

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[1] 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 6.1

Program Participation by Number and Severity of Disabled Children for All Families (in percent)

		One Disabled Child		More than One Disabled Child	
Type of Participation	No Disabled Child	Moderately Disabled	Severely Disabled	All Moderately Disabled	Any Severely Disabled
Special services, any child in					
Special education or early intervention	n.a.	43.9	39.6	65.1	74.7
California Children's Services	n.a.	6.9	21.5	22.8	25.3
Community mental health services	n.a.	10.7	10.9	13.7	32.3
Means-tested income[a]					
Currently receiving AFDC	72.9	81.2	85.6	86.9	99.0
Currently receiving SSI	4.9	22.7	33.8	30.7	45.8
Currently receiving either AFDC or SSI	74.4	82.9	89.1	88.0	99.8
Means-tested in-kind					
Currently receiving Food Stamps	71.6	73.6	79.4	82.3	88.2
Currently in subsidized housing	17.7	25.1	28.6	27.4	37.9
Public health insurance					
Medicaid or Medicare (child)[b]	77.0	83.3	82.5	89.7	100.0
Medicaid or Medicare (mother)	67.4	72.8	86.9	72.3	81.2

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Entries are weighted to be representative of the four counties.

[a] AFDC or SSI for anyone in household.

[b] Public health insurance (child measure) = randomly selected child. Unweighted n = 1,711.

Medicaid coverage were lower for parents than for children, across all of the groups. Although mothers in families with special needs children were less likely to be insured than their children, they were still more likely to be Medicaid recipients than were mothers who had only healthy children. This may reflect higher rates of welfare participation among families with special needs children.

The disproportionate representation of families with disabled children in means-tested welfare programs may be directly related to lower rates of employment and higher rates of poverty among these families. For families at the margin of poverty, absorbing direct out-of-pocket expenses may consume any financial assets providing a cushion against a slide into poverty. The indirect costs may be even more devastating. 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."

Disabilities and Welfare Exits

The Hobbs et al. observation is consistent with a great deal of theory and evidence suggesting that children's disabilities increase the likelihood that their families will be poor. It seems reasonable to expect that families with disabled children will also be more likely to use means-tested, categorical welfare programs and, once enrolled, less likely to leave them. However, this expectation is not confirmed by a substantial empirical literature on the dynamics of participation in welfare programs, most particularly on entries and exits from the AFDC program. A number of analysts have included measures of disability in their estimations of the probability and the duration of welfare use. To date, empirical results have been mixed.

The most commonly used measures of adult disabilities are self-reports of activity limiting disabilities and poor health. A number of analysts have found evidence that these indicators of disability and health problems are associated with higher probabilities of welfare receipt (e.g., Blank, 1989; Hutchens, 1981) and lower probabilities of welfare exits (e.g., O'Neill, Bassi, and Wolf, 1987; Sandefur and Cook, 1997). Results have been inconsistent, however, and vary with the population studied and measure of disability used. Other analysts (e.g., Plotnick, 1983) have found no association.

Only a few researchers have included measures of the added caregiving responsibilities associated with disabled children. In her study of the role of medical need and Medicaid receipt on AFDC participation, Blank (1989) finds that reported poor health of other household members—who may be dependent children—increases the probability of AFDC participation. In one of the few analyses of welfare durations that include measures of both child and adult disability, Acs and Loprest (1999) find that the presence, number, type, and severity of functional limitations reported by an adult woman all significantly reduce her probability of leaving AFDC for employment; however, these same measures are not significantly associated with other types of welfare exits (for example, those resulting from changes in household composition, marriage, or increases in transfer income). They find almost no evidence that measures of children's functional limitations reduce the probability of welfare exits.

Given the consistent finding that child disabilities reduce the parent's labor supply, the inconsistency of the empirical findings on disability and welfare are puzzling. Our resolution of this paradox is quite simple. Most studies of transitions from AFDC have grouped all exits from the program together. This means that transitions entirely off assistance are treated the same as transitions to SSI. This failure to distinguish between transitions "from welfare" and transitions "between welfare programs" has potentially serious implications for estimating the effect of disability on welfare exits. Theory and research suggest that more, and more severe, disabilities and health problems will *reduce* human capital, earning potential, and the probability of leaving some form of assistance. But these same factors *increase* the probability that someone in the household will be eligible for cash assistance through SSI, either along with or instead of other forms of welfare. It is possible that earlier studies on the role of disabilities in welfare transitions have failed to find consistent effects because they estimated an average of two offsetting effects.[2]

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[2] Although a single individual could not receive benefits from both SSI and AFDC programs, a family with a disabled child or a disabled mother could combine benefits from both. For example, a disabled child could receive SSI benefits while the rest of the

Our approach to solving these problems is to conduct multivariate hazard analysis using a combination of data from the household survey with administrative data obtained from welfare payment records.[3] Administrative payment data from state and county welfare systems make it possible to determine with precision when families began their spell of AFDC receipt, when that spell ended, and when any members moved to SSI.[4] Our general strategy was the following. Each case in the sample was receiving AFDC or AFDC and SSI as of December 1992 (by sample design). Each case was followed until December 1995 using administrative data until (a) it left AFDC entirely by moving completely off aid, or (b) it left AFDC entirely by moving to SSI alone; remaining cases (those receiving AFDC or AFDC and SSI continuously until December 1992) were treated as censored.[5]

In Appendix B we describe a multivariate hazard analysis that estimates the effect of disabilities on exits from AFDC, controlling for other individual and family factors. We use a method that accounts for "competing risks." This technique was developed in biomedical research for situations where mortality is the result of competing risks such as heart disease and cancer. In these circumstances, the duration of one's life depends on which disease strikes first. Similarly, with welfare spells, the duration of one's spell depends on which change in status comes first—getting SSI for one's child or finding some way to get off welfare such as working or getting married.

Full results of the hazard analysis are provided in Appendix Table B.1. As would be expected, families with more children under age six are less likely to leave welfare for complete independence, whereas those in which the mother has higher education and lives with a partner or spouse

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household received AFDC. If a child were eligible for either AFDC or SSI benefits, the child's family was usually better off if the child received SSI benefits.

[3] For these analyses, 159 cases were excluded because of missing data.

[4] A small number of cases that were initially sampled in October 1992 but that left aid before December 1992 were excluded from the survey sample. For those cases that began their AFDC spell before January 1987, we use the survey data to establish the beginning of the spell.

[5] Note that this coding combines cases that remained on AFDC alone with those that changed to AFDC plus SSI, because both states involve no movement *off* AFDC.

are more likely to experience a transition to independence. In the fully specified model for transitions from welfare to SSI, few covariates (other than disability) reach statistical significance, suggesting that this transition is less dependent on other individual or family characteristics.

Table 6.2 presents the results for the disability variables, once other factors are controlled for. The first column, "Transitions off Aid," reports estimates of the effects of disability on the transition from AFDC to being completely off aid. The second column, "Transitions to SSI," reports results for a transition to SSI (alone). The disability variables have very substantial consequences for the movement to SSI. Severe disabilities have a greater effect than moderate ones, and children's disabilities emerge as more influential than those of mothers. In addition, moderately disabled children seem likely to move their family to SSI whereas moderately disabled mothers do not. This greater importance of children's disabilities might be a real effect, but it also might be the result of our greater ability to measure children's disabilities and their transitions to SSI. Whatever the explanation for these

Table 6.2

Competing Risks Model of Transitions off AFDC
(standard errors in parenthesis) (in percent)

Disabilities	Transitions off Aid	Transitions to SSI
Moderately disabled children	–0.8	1.65*
	(.17)	(.64)
Severely disabled children	–1.39**	2.26**
	(.44)	(.83)
Moderately disabled mother	–.34*	–0.41
	(.16)	(.55)
Severely disabled mother	–.59	.94
	(–0.3)	(–0.5)

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Statistical significance indicated by * $p < .05$, ** $p < .01$. Complete results are reported in Appendix B.

differences, it is hardly surprising to find that disabilities move families to SSI.

It is much more surprising given the previous literature to find that disabilities substantially reduce the ability of families to move to complete independence off AFDC and SSI. The effect is very substantial for severely disabled children and it is still quite substantial for severely disabled and even moderately disabled mothers. For example, the effect of a severely disabled child is about double that of not having a partner in the household. Or it is about equal to a four-year reduction in the mother's educational level. The effect of a severely disabled mother is about one-half this magnitude.

This analysis suggests that disabilities and health problems are a significant factor in transitions out of the AFDC program in several ways. They significantly decrease the chances that households leave welfare entirely (that is, make transitions to no aid) through changes in behavior or other circumstances, and they increase the probability that households leave welfare through administrative mechanisms by making transitions to the SSI program. In policy terms, these exits might be thought of as transitions to "independence" and to "partial independence," respectively. It is especially interesting that children's disabilities have larger effects for these transitions than do mothers' disabilities.

7. Public Programs and Private Well-Being

The analysis in Chapter 5 reveals that somewhere between one-fifth to one-quarter of the families in the public welfare system care for children with disabilities and that these families assume substantial direct and indirect costs associated with this care. Chapter 6 suggests that these families are overrepresented not only in targeted disability programs but also in means-tested cash, food, housing and medical assistance programs. Not only are they more likely to participate in these programs, they are likely to stay for a longer time. Recent welfare reforms have emphasized the reduction of welfare "dependence." For families who bear extraordinary private caregiving costs, however, concerns about dependence may be misplaced. In fact, assistance from public programs may be an essential part of an income packaging strategy for families who assume extraordinary caregiving costs.

We have argued that families who care for a disabled or ill child may face an increased risk of economic hardship for two reasons. They are likely to have fewer economic resources, insofar as care for that child limits parents' availability for paid employment. They are also likely to have greater demands on those resources, because of the purchase of specialized goods and services related to the child's disability or illness. Either constraint will have similar results—limiting families' consumption and possibly forcing them to make tradeoffs between the purchase of specialized goods for the disabled child and basic goods for other family members. Although families with special children may not appear worse off in terms of income, they are likely to be worse off in terms of income available for other needs and in their experience of material hardship.

Public programs could reduce this risk by addressing either problem: by increasing the resources that families have available for these specialized purchases or by offsetting the costs of specialized goods and services directly. To the extent that they do so, cash transfers and in-kind assistance promote economic security and families' ability to care for special needs children at home. Two programs warrant special consideration in this regard: Supplemental Security Income and Medicaid.

Public Programs and Private Spending

One standard by which we might judge the value of these programs is by asking whether they *increase* the availability of specialized goods and services for disabled and ill children. If cash transfers through SSI and in-kind health benefits through Medicaid have the intended effect of helping economically vulnerable families care for these children, we would hope to see *more* expenditures on behalf of children with less direct tradeoff on consumption choices.

To examine the effect of Medicaid and SSI on families' out-of-pocket expenditures, we examine in Table 7.1 these direct costs separately for families who did and did not receive benefits.

Program participation is generally associated with out-of-pocket expenditures in the expected directions. Families who receive SSI for their disabled children were slightly more likely than those who do not to incur out-of-pocket expenses. More important, their spending was a substantial 67 percent higher. If families had Medicaid, in contrast, they were much *less* likely to incur direct expenses than those families who had either no health insurance or private coverage. Families with Medicaid also spent less than half the amount, on average, out of pocket.

These results are consistent with program design. Although both programs may help offset costs, SSI and Medicaid would be expected to have different effects on families' expenditures. Since SSI provides an unrestricted cash benefit to families, if families use this cash to purchase goods and services for special needs children we would expect to observe SSI-recipient children receiving more specialized goods and services than other children, and their parents spending *more* on such goods and services than other parents. This is in fact what we observe in the data. Medicaid, in contrast, provides only in-kind assistance in the form of medical services and goods. If Medicaid helps provide some of the same

Table 7.1

Out-of-Pocket Disability-Related Expenses of Families with Disabled Children

	All Families with Disabled Children
Families without SSI	
Special expenses last month	
Percent with any	45.5
Average amount	$51.87
Standard deviation	$92.08
Families with SSI	
Special expenses last month	
Percent with any	47.7
Average amount	$87.20
Standard deviation	$145.52
Families without Medicaid	
Special Expenses last month	
Percent with any	75.9
Average amount	$122.08
Standard deviation	$116.43
Families with Medicaid	
Special expenses last month	
Percent with any	42.3
Average amount	$54.58
Standard deviation	$108.62

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Entries are weighted to be representative of the four counties. Unweighted n = 372.

specialized goods and services that parents would otherwise purchase directly, we would expect to observe Medicaid-recipient children receiving the same or higher level of goods and services as other children, but their parents spending *less* than parents of children without Medicaid. This is again what we observe in the data. As we would expect, having SSI appears to increase families' purchase of goods and services for their disabled children, and Medicaid reduces the out-of-pocket costs that they incur.

Public Programs and Economic Well-Being

A second standard against which we might judge these programs is the extent to which they *decrease* the hardship experienced by poor families who care for expensive children. If the “extra” resources from public programs were effective in offsetting the direct and indirect costs associated with the care of a disabled child, we would expect to see them decrease the heightened risk of poverty and material hardship experienced by these families.

As described above, before adjusting for out-of-pocket expenses, families with disabled children were only slightly poorer than families with only healthy children. Indeed, those who received SSI for their children appear to have been somewhat better off than other poor families in terms of both income and poverty status. Yet families with disabled and ill children were more likely to experience income-related hardship, in the form of hunger, housing instability, and utility shutoffs. Higher rates of hardship may reflect increased demands on family resources relating to the special care needs of their children. Families with disabled and ill children may make tradeoffs between the medical and other needs of their exceptional children and routine family expenses such as food, rent, and utilities.

To examine the effect of children’s disabilities more directly, and to explore the effect of SSI on reducing these tradeoffs, we use regression techniques to isolate the effect of disabilities and SSI receipt on the risk that the family was poor or extremely poor and the risk that they experienced one or more forms of hardship: going hungry, missing rent payments, or experiencing eviction or a utility shutoff. This technique allows us to control for other factors that might increase the risk of poverty and hardship—including education, race, marital status, employment status, and number of children in the home. (Full details of the model and estimation are provided in Appendix C.)

To interpret these results, we use the regression coefficients to simulate the contribution of child disabilities and of SSI receipt to the probability that the family was poor or experienced one or more forms of concrete hardship. The probabilities were first calculated for an “average” family in the sample by setting independent variable values at the average for the sample.[1] A severely disabled child was then "added" to the family and the probability of hardship was reestimated. A similar process was used to determine hardship probabilities for families with more than one disabled child and for families with more than one disabled child and at least one severely impaired child. To estimate the effect of SSI on these outcomes, families with severely disabled children were also "given" SSI in the same fashion.

The results reported in Table 7.2 are dramatic. The families in this sample were very likely to be poor. Among families who did not receive SSI, caring for a disabled child raised the likelihood of poverty slightly, by one to two percentage points. The presence of a special needs child had a slightly larger effect on the likelihood of extreme poverty, raising it from 84 to as high as 90 percent. If the family received SSI for a disabled child, however, their risk of poverty was greatly reduced. Between 45 and 52 percent of SSI recipient families were predicted to be living in poverty, and only 13 to 18 percent to be living in extreme poverty.

The role of SSI in the economic well-being of these families is captured even more vividly in our predictions of concrete hardship. Hardship was common in this sample of very poor families. Even families that reported no disabled or chronically ill children had about a 50 percent probability of having experienced one or more forms of hardship in the prior year. If they cared for at least one disabled child and did *not* have SSI, their chances of material hardship were much greater. Among families with more than one but no severely disabled children, 59 percent were predicted to have experienced hardship; if the family cared for any severely disabled children, the likelihood increased to between 71 and 79 percent. If they received SSI, however, families with disabled children had similar or even slightly lower chances of experiencing hardship than did their counterparts with only healthy children. SSI did not move these families far from economic insecurity: Even with the extra income from SSI, between 38 and 61 percent of these families were predicted to have experienced hardship. But the *extra*

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[1] The resulting "base" or comparison case had the following characteristics: It was a family headed by a white, Anglo, single female respondent living in Los Angeles, with the average level of education for the sample (10.43 years), who was caring for the average number of children (2.2), and who was not currently employed.

risk of hardship associated with the care of a special needs child was largely offset by receipt of SSI.

Table 7.2

Predicted Impact of Child Disability and SSI Receipt on Family Economic Well-Being (in percent)

			More Than One Disabled Child	
	No Disabled Child	One Severely Disabled	None Severely Disabled	Any Severely Disabled
Probability of being poor (at or below 100% poverty)				
No SSI	89.6	90.2	91.7	92.1
With SSI	89.6	45.0	49.7	51.2
Probability of being extremely poor (at or below 75% poverty)				
No SSI	84.0	86.0	88.0	89.5
With SSI	84.0	13.8	15.9	18.2
Probability of hardship (hunger, housing instability, utility shutoffs)				
No SSI	49.3	71.1	59.4	78.8
With SSI	49.3	51.0	38.2	61.1

SOURCES: Authors’ calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTES: Simulation based on logistic regression, controlling for individual, family, and design factors. Full results are provided in Appendix C. Unweighted n = 1,682.

8. Conclusions and Policy Implications

Our empirical analyses yield five broad conclusions. In presenting our thoughts, we return to the family profiles from Chapter 2 to give a human face to our summary observations.

Conclusions

First, we find that a surprisingly high proportion of poor, welfare-reliant families absorb costs related to the care of disabled family members. By our broadest definition, 40 percent of families on welfare at a point in time and 33 percent of recent entrants have either a mother or one or more children with a chronic condition. Nearly 12 percent care for children with moderate limitations and another 6 percent care for children with severe problems. These conditions varied from asthma, the most prevalent condition, to heart problems, cancer, cerebral palsy, mental retardation, mental illness, and learning disorders. Parents' reports about the direct costs of caring for children with these conditions suggest that the severity of the child's problem is directly related to the financial burden for families. The child's condition, on the other hand, is not predictive of the frequency or magnitude of family costs. Every disease or disability category is seen to impose direct costs on at least some families. Finding no relationship between condition and burdens may reflect our relatively small sample or a lack of precision in our measures of conditions or costs. It is consistent, however, with other studies that have found more variation in costs within than across disease categories.

Our second conclusion is that childhood disabilities sometimes impose very high costs on very poor families. This may force some parents to make tradeoffs between meeting the needs of their children and meeting the basic needs of their families. Material hardship was common in this sample of welfare-reliant families, and we estimate that the probability that a family experiences some form of income related hardship is 22 percentage points higher when it cares for a severely disabled child (without SSI). Our family profiles help us understand why this would be so. Consider the case of Matilda, the mother of three who had separated from her husband and returned to welfare when we spoke to her. The care of her nine year old son, who has a heart condition, imposed out-of-pocket expenses in the prior month for uncovered health care services. Given that her son's condition causes him to miss school frequently and sent him to the hospital three times in the prior year, these costs may arise frequently. But given Matilda's welfare income, they are likely to be unmanageable. On months such as these, she is likely to face a choice between paying for the critical and emergency health care needs of her son and paying the rest of the family bills. Such a forced choice may help explain why she had utility shutoffs, lost telephone service, and fell behind in her rent several times over the year.

Even families who manage to pull ahead by going to work may not move far from these risks. In the case of Edith and Ben, the family was off welfare and both were working when we contacted them—Ben as a bus driver and Edith doing odd jobs when she could. Even with their earnings and with the SSI they received for their blind and developmentally disabled five year old son, the couple had trouble making ends meet. Their son's chronic health problems, which sent him to the emergency room 15 times in about 18 months, undoubtedly added to the family's economic and emotional stress. In the year before our interview, economic stress took the form of multiple residential moves, at least one eviction, and trips to the food pantry when there was not enough money for food.

One of the most worrisome forms of disadvantage reported by these families is the potential loss of health insurance. For many families hovering around the poverty line, the loss of welfare or a few dollars more in earnings can lead to the loss of Medicaid. For parents with developmentally or medically fragile children, this loss may be disastrous. Consider the case of Dorothy, the divorced mother of a 16 year old girl with severe asthma. Dorothy was managing to work full-time when we talked with her, despite the fact that her daughter often missed school because of her medical problems. Without welfare, however, Dorothy and her daughter had no source of health insurance. Her job as an animal caretaker did not provide any coverage and Dorothy could not afford to purchase private insurance. In the month before our interview, she had to pay out-of-pocket medical expenses related to her daughter's asthma. Without insurance, even such routine medical expenses are burdensome for a family as poor as this. If they are too great, the parent and child may forgo them entirely. Indeed, Dorothy reported to us that there were times the prior year when her daughter went without needed medical or therapeutic care. If her daughter has a medical emergency, it is not clear where Dorothy will turn for help.

Our third conclusion is that parents with disabled children face tradeoffs not only in the purchase of basic good and services but in their allocation of time. Mothers with atypical children may find it more difficult than most to combine their caregiving work with employment. In our sample, mothers who had a severely disabled child were about half as likely to be employed as those with only healthy children. Two-thirds or more of mothers with severely disabled children also indicated that care for those children limited their ability to work. When we control for the other human capital and institutional factors that might explain their lack or reduction in employment, we estimate that these mothers forgo $80 in earnings every month.

The family situations profiled in Chapter 2 suggest something of the dilemmas that these families face. Some mothers have very great caregiving burdens. Beth, for example, had four children, including a seven year old son who was blind and developmentally delayed. When we spoke with her, the family was getting by on her husband's earnings. SSI offset some of the financial burden of caring for their special needs child. But it did nothing to offset the direct caregiving needs of a child who could not do usual childhood activities and needed a lot more help with daily activities than other children. Beth still had a preschool child to care for as well. Even when all her children are school age, a time when many mothers return to work, caring for her disabled son and other children may be a full-time job.

The challenges of combining specialized caregiving work and employment are even greater for single mothers. Phyllis worked in the month prior to our interview and also cared for three children, one of whom has cerebral palsy. But her earnings were low and she still relied on Medicaid for health insurance. Dorothy was managing to work full-time when we spoke, perhaps because, at 16, her severely asthmatic daughter was old enough to care for herself most of the time. But Dorothy reported that her daughter was out of school a lot because of the asthma and that it interfered with her own ability to work. Even when she was able to work full time, both she and her daughter went without health insurance.

Our fourth and related conclusion is that childhood disabilities and means-tested welfare use are closely intertwined. Families with seriously disabled children appear more likely to receive means-tested assistance than are families with only healthy children, and, once on aid, they are much less likely to leave. In fact, having a disabled child reduced a family's chances of leaving welfare (other than for SSI) at about the same rate as losing a spouse or partner in the family. Some families with disabled children fit the profile of long-term "welfare dependent" or reliant families. Gladys, a divorced mother of three, had her first child at 15. All three of her children had learning and behavior problems; one was mentally retarded and receives SSI. Despite the fact that all three of her children were nearly grown, Gladys had not worked at all in the 19 months before we talked with her. This may be due to her own physical and health problems. It may also be a by-product of her limited education and the nine years she had spent on welfare. Gladys gets by on welfare, her son's SSI, and housing assistance. Her life is not easy—she had trouble paying bills and feeding her family in the last year. And her prospects for a better, more independent life appear limited.

Although some families fit this stereotypical profile of the welfare-reliant, others use welfare as a way to balance the demands of caregiving and economic support. For these families, means-tested cash assistance is a critical part of an income package. Phyllis, who separated from her husband 18 months before our interview, was supporting herself and her three children by combining earnings from a part-time secretarial job, welfare, and SSI received for her seven year old daughter with severe cerebral palsy. She incurred costs in the prior month for special clothing, transportation, and specialized child care for her daughter. She was also paying for 20 hours of day care per week for her four year old so that she could go to her part-time job. Compared to other families in our sample, Phyllis was doing fairly well and SSI had a lot to do with it. Even with the extra help, however, caring for a severely disabled child meant that Phyllis could not work enough hours to get completely off welfare. For her, packaging earnings from a part-time job with welfare and SSI may be necessary to achieve reasonable economic security.

Consider another case, that of Mary and Robert and their five children. Two of their children were disabled enough to receive SSI; one had very disabling cerebral palsy. The family had received welfare for many years but Robert had also found work as a child care worker when we spoke with them. When they packaged the SSI with welfare and Robert's earnings, they may have been doing fairly well. They may have been able to absorb the extra costs of caring for their disabled children, such as the special transportation to the hospital needed in the prior month. Income packaging provides them a measure of security which, given their circumstances, they are likely to need for some time to come. Mary and Robert seem to be working hard to meet their responsibilities, including the care of two special needs children. Without the added cushion of SSI and welfare, they might not be able to make it at all.

This leads to our fifth and final conclusion, which is that the SSI and Medicaid programs appeared to be working fairly well to help protect highly vulnerable families from the risk of economic insecurity and material hardship. Our ability to draw conclusions about the contribution of Medicaid is quite limited because most of the families in this low-income sample were still on Medicaid. But we do observe that families with Medicaid paid *less* out of their own pockets to meet the medical and other needs of their disabled children than did those with either no health insurance or private insurance. This observation suggests that, if they are providing their children with the same level of specialized goods and services, Medicaid-eligible families are able to manage their children's care with fewer economic compromises for the family.

Our conclusions about the role of SSI are less tentative. The fact that families with disabled children who received SSI were less income poor than those who did not comes as no surprise. The fact that families with SSI were also much less likely to have suffered material hardship than otherwise similar families is both notable and encouraging. It suggests that for many poor families, such as those profiled above, the extra income from SSI provides a cushion against the uncontrollable and sometimes high costs that arise with the care of children who have disabling health, developmental, mental, and physical conditions.

Implications for Policy

Programs affecting disabled children and their families have generated a surprising amount of controversy in recent years. Debates about SSI eligibility, welfare work requirements for parents with disabled children, and the extension of Medicaid to these families have been highly charged. Policies have been changed repeatedly and, given prevailing sentiments about welfare, they are likely to change again in the future.

Setting policy for programs such as these is difficult. Transfer programs must always balance the goals of providing optimal support and assistance and minimizing public costs. When programs involve unearned income transfers, there are additional concerns about the duration of support and the possibility that the support itself discourages work and encourages dependency. When the basis of eligibility and need for this assistance is ambiguous or difficult to observe, as in the case of costly childhood disabilities, these conflicts become even more acute.

In the case of aid for families with disabled children, a lack of good data about the prevalence and financial consequences of childhood disabilities has helped fan controversy. Observers have argued about whether children on SSI are in fact disabled, and whether their families need and use the extra SSI income for child-related expenses. The most benign criticisms suggest that because SSI payments are both higher for the family and less expensive for state and local governments, the incentive to enroll children overinflated program rolls in the 1990s. The most severe critics charge that parents are exaggerating their children's limitations or even worsening their conditions to increase their welfare income and avoid work requirements. Without family-level data on the types and magnitude of costs absorbed by parents with disabled children, these policy-related arguments have been very difficult to resolve.

This study does not provide all the data we would need to understand the financial and psychosocial circumstances of poor families who care for expensive children. We cannot draw final conclusions or make detailed recommendations about the direction of public policy. However, these data do provide important new estimates of the private financial burdens that these families bear.

These data strongly suggest that families with disabled children, but without SSI income, are much worse off than otherwise similar families. Our cross-sectional observation of child disabilities and economic well-being cannot establish the reasons for economic hardship with certainty. It seems likely that the higher direct and indirect costs associated with the care of special needs children contribute to families' poverty and material hardship, but we cannot rule out the possibility that lower work participation, higher poverty, and greater material hardship among families with disabled children are caused by other factors. These families may differ from other poor families in other, unobserved ways that cause them to be less able to achieve economic security.

Although we cannot rule out other explanations for the heightened economic disadvantage of families with disabled children, these analyses indicate that the high cost of caring for these children is a major factor. Families report substantial direct and indirect costs associated with their children's disabilities, and their heightened risk for hardship persists even after we control for other adult and family characteristics. Mothers with disabled children report that they have difficulty working, and this effect also persists even after controlling for family, human capital, and labor market conditions. To the extent that these employment withdrawals reduce mothers' accumulation of work experience and reduce their earning power, care for expensive children may exact costs far into the future.

Given these findings, along with those about the positive role of SSI and even welfare as a part of an income package, we offer the following recommendations for the inevitable next rounds of reform in the welfare, SSI, and Medicaid programs.

First, the provision of unrestricted cash assistance (SSI) for families with severely disabled children appears to be well justified by the costs that poor families assume. Costs are highly variable, even across families whose children have the same conditions. In our one-month snapshot, many families reported no costs but a minority reported very high costs. On the one hand, this variability might justify more and more precise targeting of benefits, to be sure that they go only to families who actually incur costs. Some analysts have proposed replacing cash assistance entirely with in-kind benefits. On the other hand, given the variable and intermittent nature of these costs, greater targeting is likely to be both expensive and intrusive. We could identify no category or set of conditions that did not impose costs on some families. These costs were as varied as medical devices (for example, asthma inhalers), nonprescription medications, transportation (for example, van service to take physically challenged children to the doctor), treatments (for example, speech and mental health therapies), clothing (for example, diapers for incontinent children), and specialized child care for children who could not easily go to regular child care settings. Dispensing restricted cash assistance, vouchers, or in-kind benefits as needed would greatly increase the administrative costs for government and the application burden for families.

Proposals to limit SSI to certain categories of children, or certain types of costs, or to replace unrestricted cash benefits with in-kind goods and services could also increase the burden and financial insecurity of already very burdened parents. Rather than restricting SSI, we believe that the program should be expanded in several ways. Vigorous outreach efforts should be continued to make sure that those families potentially eligible for the program are made aware and encouraged to apply. Families should continue to receive help in working their way through the often complicated application process that may deter some deserving families. Finally, our data suggest that recent efforts to narrow the eligibility criteria for children’s SSI may be misplaced. Parents of children who have the so-called “soft” disabilities such as learning and attention deficit disorders may face direct and indirect caregiving costs that are similar to those of parents with children who have other conditions.

Second, protecting Medicaid coverage for families with disabled children is crucial. Disabled and chronically ill children are among those most medically at risk if they do not get appropriate preventive and ongoing health care. Their parents are among those who face the gravest financial risks if they lose health insurance for their children. Both anecdotal reports and empirical studies suggest that the fear of losing Medicaid deters employment and welfare exits (Yelowitz, 1995), with the strongest effects observed among those likely to incur high medical costs (Moffitt and Wolfe, 1992). Recent changes in Medicaid policy, including the expansion of the Child Health Insurance Program and the decoupling of Medicaid eligibility from welfare eligibility under the 1996 Personal Responsibility and Work Opportunity Act (PRWORA), have been designed to increase access to coverage for children in low-income, working families. However, declining Medicaid caseloads suggest that many families are not able to access these benefits (Ku and Bruen, 1999). For low-income families with disabled and chronically ill children, policies that guarantee continuous coverage and access are particularly crucial, both to increase medical security for these children and to provide an employment incentive for their parents.

Third, welfare eligibility rules should be adjusted to reflect the extra financial and caregiving demands on parents with disabled and chronically ill children. For many of these families, welfare is an important component of an income package and should be made available for as long as the family needs it. Even with full- or part-time work, these families may not be able to achieve full independence from the welfare system. The 1996 PRWORA decisively changed welfare from an entitlement, under AFDC, to time-limited assistance under TANF. Caseloads have declined by about 50 percent nationwide and by 80 percent or more in some states. These caseload reductions have been interpreted as evidence of successful reform by many observers. They have also increased the proportion of families in the welfare system who are very disadvantaged, as those most able to survive outside the welfare system exit or are denied entry. Although the effects of these changes for relatively healthy families are still debated, there is reason for concern about their implications for families with heavy caregiving burdens. Subjecting families with special needs children to benefit restrictions, aggressive deterrence policies, time limits, and sanctions risks increasing hardship for already very disadvantaged families.

Fourth, TANF and Food Stamp work rules and employment supports should be modified to support families' movement to self-sufficiency while recognizing their special needs. For parents with disabled and ill children, child caregiving may consume greater than average time, energy, and other resources. These parents also face special challenges and extra expenses when they go to work outside the home. This suggests that states will need to modify welfare-related work requirements for these families. For a small number of parents with very disabled or ill children, caring for these children may be the most important and perhaps only work that they can do. Many parents do combine their caregiving with employment, however, and even those who care for very severely impaired children could benefit in the long run by spending some time in the work force and accumulating human capital. Work outside the home also provides important respite. But going to work may be both difficult and expensive for such parents, particularly if their children need specialized child care. In part to avoid these costs, many states are now completely exempting families with SSI-recipient children from work requirements and, consequently, from the receipt of work-support services. A better policy approach might be to provide *extra* employment services (such as enhanced child care benefits) to help parents manage.

In short, we recommend that poor families with expensive children are among those for whom policies that support "partial independence" on public assistance make sense. Because they need to spend more and can work fewer hours outside the home, many of these families will not be able to achieve full independence from means-tested programs. To force them to do so prematurely would risk imposing additional medical and other forms of hardship on their oftentimes very vulnerable children. But neither should they be left to languish on the welfare rolls when and if they can achieve partial independence through employment. Government can support this independence both by providing extra employment-related support services, when needed, and by adopting welfare eligibility rules that permit families to package earnings with continued SSI, welfare, Food Stamp, and health insurance assistance.

These recommendations do not address the very real concern that, for some percentage of the caseload, SSI functions like other welfare programs to support and encourage long-term dependence on government programs. Our data do not shed much light on whether malingering, misrepresentation, or dependence are more prevalent among families who receive SSI than among those who do not. They do confirm the expectation that some of these families are very troubled and heavily reliant on welfare programs. We find that families with more than one disabled child, in particular, and those in which both the child and the mother have limiting conditions, are exceptionally disadvantaged and almost exclusively reliant on welfare. For these families, disabilities may be better understood not as an “exogenous shock” to the families’ economic well-being but as one of several indicators of serious functional difficulties. They are likely to be among the families characterized as “multiproblem” or “hard to serve” who are coming to dominate welfare rolls as those more able to leave do so. For these families, enhanced employment supports and opportunities for income packaging are unlikely to either increase self-sufficiency or reduce economic hardship. There is little reason to believe, on the other hand, that simply terminating welfare and SSI or imposing more stringent work requirements will bring about enduring changes for multiproblem families. These families and their disabled and ill children are likely to be those most in need of intensive, long-term rehabilitative services.

Finally, as welfare rolls decline, we can expect that families with disabled children will become an increasing fraction of the remaining caseload. Very little is currently known about these families, and we have taken only some first steps toward characterizing and understanding their circumstances, resources, and needs. Ongoing studies are necessary to see how they are faring in the new world of welfare. We strongly recommend that updated surveys be conducted on a regular basis to determine how well these families are coping. Regular studies can provide the knowledge needed to design the innovative public policies that will be needed to avoid the human tragedies that will occur if these families are allowed to fall between the cracks of the overlapping programs and eligibility restrictions that only imperfectly fit their needs.

Appendix A

Maternal Employment Estimation

Our estimate of mothers' employment is based on a standard static labor supply model. In this model, individuals choose the combination of market and nonmarket activities that allows them maximum utility with respect to consumption of goods and leisure (Killingsworth, 1983). Mothers' decisions about whether and how much to work outside the home are a function of factors such as available work and wages, availability of income from other sources (husband's earnings, property, or other unearned income), productivity of time spent in other work, and household tastes. Because women assume the primary caregiving burden for children, we expect their employment decisions to be particularly sensitive to the level of caregiving responsibilities, including the ages and number of their children and the availability of alternative care arrangements (Berndt, 1991; Heckman, 1993; Killingsworth, 1983; Killingsworth and Heckman, 1986; Blau and Ferber, 1992).

We estimate a reduced form specification of this model in which a mother's employment is a function of structural, demographic, and human capital variables. The model presented here adds variables designed to capture the extra demands of caring for disabled children. Employment is hypothesized to decrease with the presence of a disabled or ill child and as the severity of children's functional impairments increases from moderate to severe.

We control for *demographic and human capital factors* using measures that follow from the standard labor supply model and prior empirical research. As a proxy for expected wage, we include variables for a respondent's human capital (race, education, health, age, and age squared). Because women's labor supply choices are sensitive to the presence and earnings of partners/spouses, we include a variable for current cohabitation status. Because empirical research suggests that work and welfare behaviors differ for women who were ever married, we also control for respondents' marital status (as ever or never married).

We include other variables measuring characteristics that facilitate or inhibit women's employment: the presence of any children under age six (assumed to reduce employment) and the presence of adults in the household other than respondent and her spouse or partner (hypothesized to increase labor supply by increasing the number of adults available for child care).

Our model also includes measures of income and *structural factors* that are hypothesized to affect a woman's employment choices. We include variables for the level of AFDC and SSI benefits available to the woman and other non-means-tested family income (spouse's earnings, child support, and income from family and friends). All are expected to have an income effect that depresses a mother's labor supply. Because both AFDC and SSI are means-tested programs in which benefits are likely to be reduced as earnings rise, we measure them with proxies (i.e., the number of AFDC-eligible children and whether any family member other than the respondent receives SSI) to reduce endogeneity problems.[1] As a measure of local employment opportunities, we include county unemployment rates for the month before the interview.

The limited observation period (employment in prior month) creates difficulties when estimating the effects of family and individual factors on employment. We use a censored regression or Tobit model for this estimation (Greene, 1997). This estimation method adjusts linear estimates when a portion of the observations are censored at zero (i.e., no employment is observed in the month before the interview). Because they reflect the effect of the independent variables on both (1) the probability of working, and (2) the change in hours of work among those employed, Tobit regression coefficients can be difficult to interpret. Therefore, following McDonald and Moffitt (1980), we also calculated the proportion of the mean total response to a change in an independent variable that is due to the response of those with a nonzero probability

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[1] We tested the employment model both with and without the SSI variable and the results were approximately the same. The inclusion of the SSI indicator reduces the size but not the statistical significance of the indicator for a severely disabled child in the family. This suggests that the income effect of SSI may explain part of the reduction in maternal labor supply in these families and the inclusion of the SSI indicator improves the precision of the estimate of the "caregiving" effect.

(i.e., any employment) and decomposed the coefficients into two separately reported measures: (1) the marginal effect of the independent variables on the hours of work and (2) the effect of the independent variables on the probability of having any employment.

Variable means and standard deviations are provided in Table A.1. Full regression results are reported in Table A.2.

Table A.1

Independent Variables in Employment Estimation: Means and Standard Deviations

Variable	Description	Mean (SD)
Child disability		
Severity of impairment	Moderate functional impairment	.10 (.30)
	Severe functional impairment	.09 (.28)
Control variables		
Respondent's education	Years of education	10.84 (2.94)
Respondent's race	African American	.26 (.44)
	Latino	.40 (.49)
	Other, nonwhite	.05 (.23)
Partner status	Respondent is married or cohabiting	.41 (.49)
Number of children	Biological, adopted, or step-children	2.31 (1.33)
Respondent health	Respondent is in poor health	.11 (.31)
Respondent age	Age in years	34.36 (9.19)
Age squared	Age in years squared	1265 (730)
Marital status	Respondent never married	.34 (.47)
Any child < 6	At least one child younger than six	.53 (.50)
Other adults	No. of adults other than spouse or partner	.43 (.86)
Non-means-tested income	Prior-month income ($100s) divided by the square root of family size	3.60 (7.48)
Any SSI recipient	Spouse, partner, or child receives SSI income	.08 (.27)
Design controls		
County	Alameda County	.22 (.41)
	San Bernardino County	.18 (.39)
	San Joaquin	.24 (.43)
Experimental status	AFDC case in the experimental group	.63 (.48)
Aid group	AFDC-UP (unemployed parent)	.32 (.46)

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

Table A.2

Effect of Childhood Disabilities on Mothers' Employment in the Prior Month (Tobit estimates)

	Coefficient	Standard Error	Conditional Response[a] (given Y > 0)	Change in Probability[b] (Y > 0)
Adult characteristics ("expected wage")				
Respondent's education (years)	8.66***	1.49	2.57	0.02
Respondent is African American	–9.71	10.42	–2.88	–0.03
Respondent is Latino	3.82	9.68	1.13	0.01
Respondent is other non-white	10.26	15.78	3.04	0.03
Respondent reports poor health	–51.37***	12.59	–15.24	–0.15
Respondent's age (years)	9.12***	2.75	2.71	0.03
Respondent's age squared	–0.14***	.04	–.04	–0.00
Respondent has never married	–16.85*	8.84	–5.00	–0.05
Family characteristics				
Any child < 6	–35.98***	8.80	–10.68	–0.11
Respondent has partner/spouse	15.77	9.87	4.68	0.05
No. other adults	.12	4.16	0.04	0.00
Income variables				
Other non-means-tested income ($100s)	1.76***	.51	0.52	0.01
No. of AFDC children	–11.64***	3.31	–3.46	–0.04
SSI recipient (not respondent)	–22.09	18.64	–6.56	–0.07
County unemployment rate (previous month)	–7.67***	2.94	–2.28	–0.02
Child disability variables				
Moderate disability	–10.70	11.77	–3.18	–0.03
Severe disability	–51.63***	17.28	–15.32	–0.15
Design controls				
Alameda County	–27.52**	11.63	–8.17	–0.08
San Bernardino County	–18.77*	10.59	–5.57	–0.06
San Joaquin County	12.57	13.58	3.73	0.04
Experimental group	7.32	7.24	2.17	0.02
Aid group	–12.62	9.51	–3.74	–0.04
S.E.			120.218	
Log likelihood			–4606.75	
Fraction working			.38	
Fraction of mean total response due to response of those working			.30	

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Unweighted n = 1,732. Statistical significance levels indicated as * p<.10; **p<.05; ***p<.01.

[a] Marginal response measured at the mean for all variables

[b] Marginal change for continuous variables. Discrete change for dummy variables.

Appendix B

Event History Analysis of Welfare Transitions

Technical Issues

Our concern with transitions from AFDC is best approached through event history modeling (Tuma and Hannan, 1984; Heckman and Singer, 1985; Blossfeld and Rohwer, 1995) in which the duration of spells on welfare is explicitly modeled. To estimate an event history model for our data, we must deal with three technical problems.

Sampling the Flow Versus Sampling the Stock

The survey data we use is a sample of the “stock” of welfare recipients and not the “flow” of welfare recipients into welfare. It is well known that a cross-sectional sample of welfare recipients includes a much larger number of those with long spells than those who are new to welfare. The intuition for this is simple. A cohort of those who are new to welfare includes people with both short and long spells. Those with short spells will come and go whereas those with longer spells will remain on welfare. Therefore, a cross-sectional survey has a much higher chance of sampling a person with a long spell than a person with a short spell. Consequently, a cross-sectional survey does not provide a random sample of spells. This means that standard event history methods, which are designed to analyze a random sample of spells, will produce biased results.

A number of authors (Hamerle, 1991; Guo, 1993) have discussed the ways that using cross-sectional samples produces biased results. Consider, for example, the construction of a hazard function from a cross-sectional sample of welfare durations. A hazard rate is calculated as the ratio of those leaving welfare in a given period of time divided by those at risk for leaving because they were still on welfare at the beginning of the period. In a cross-sectional sample of cases, there will be very few who leave welfare in a short period of time (because short spells are undersampled) and many who are at risk (most of whom have long spells). Hence the hazard rate for short durations will be very low. But as time goes on, the hazard rate will appear to increase. This increasing hazard contradicts all of the research on welfare of which we are aware. Every other study has found that the rate of leaving welfare declines over time.

Lancaster (1979) showed that consistent estimates of the hazard function can be obtained by using a conditional maximum likelihood procedure that is described in greater detail in Hamerle (1991) and Guo (1993). This procedure requires knowing the starting times for each spell and the duration of the spell as of the time of sampling. We have this information for our sample, and we can implement this method in any program allowing for time-varying covariates.

Functional Form

With the relatively small amount of data available to us, it seems sensible to simplify the estimation problem by assuming some parametric form for the hazard function. There are many possible choices, but we have chosen the Weibull because it allows for both monotonic increasing and monotonic decreasing hazards, because it includes the exponential or constant hazard rate model as a special case, and because several piece-wise exponential models provided no better fit than the Weibull. The Weibull hazard h(t) is the following function of time (t) on aid:

$$h(t) = ba^{b}t^{b-1} \qquad (1)$$

where a and b are unknown parameters that must be greater than 0. If b = 1, then this reduces to the exponential model with a constant hazard rate, h(t) = a. The parameter a can be interpreted as the baseline level of the hazard function and the parameter b indicates how much it increases with time (for b > 1) or decreases with time (for b < 1).

The parameters a and b can be expressed in terms of covariates. The usual practice is to express only a, the baseline level of the hazard function, in terms of covariates, and we have followed this approach. For a vector of covariates X (which include a column of 1s for a constant term), we use a standard exponential linkage function so that:

$$a = \exp(XA^*), \qquad (2)$$

where A* is a vector of parameters including a constant A. With this linkage function, the values of A* can be positive or negative and a will still be greater than 0, as it must be. Although we do not use covariates for the b parameter, we express it in the same way:

$$b = \exp(B). \qquad (3)$$

This reparameterization means that a value of 0 for B indicates that a constant hazard rate is appropriate for the data. A negative value indicates a decreasing hazard, and a positive value indicates an increasing hazard. It also means that a positive coefficient for a covariate implies that an increase in the covariate will increase the hazard rate, that is, the rate of leaving welfare.

Most research on AFDC exits has used models of this type with a single outcome or a single transition. When this kind of model is estimated for the cross-sectional sample, the disability effects are almost all statistically insignificant; they are substantively small compared to the effect of education or even having a partner in the household; and somewhat perversely, cases with a severely disabled mother are more likely to exit AFDC than cases with a moderately disabled mother. If disabilities matter, then this model does not seem to capture their effects—perhaps because the model conflates competing effects.

Multiple Transitions and Competing Risks

The possibility of competing effects leads to competing risks models. In these models, it is assumed that people can end their current status, such as being on AFDC, in more than one way and that these ways compete with one another. In our present situation, a competing risk model assumes that each individual can be characterized by two durations on AFDC (or on AFDC plus SSI). One duration, let us denote its length by T_1, ends with a transition off aid entirely (i.e., not receiving AFDC or SSI). The other duration, let us denote its length by T_2, ends with a transition off AFDC to SSI alone. Only one of these transitions is observed, and it is the one for which the duration T_1 or T_2 is smallest because it occurs first. If T_1 and T_2 are correlated, then there are severe limitations on what can be estimated (Lawless, 1982, Chapter 10), but if they are assumed independent, then it is straightforward to generalize standard models to estimate competing risks models. We assume that T_1 and T_2 are independent to make progress in understanding the effect of disabilities.

A competing risks formulation assumes that there are two hazard rates, $h_1(t)$ for the transition from AFDC to being off aid entirely and $h_2(t)$ for the transition from AFDC to being on SSI alone. Each hazard rate is assumed to have separate parameters: a_1 and b_1 for $h_1(t)$ and a_2 and b_2 for $h_2(t)$. As we did above, we allow a_1 and a_2 to vary only with the covariates and we use a standard exponential linkage function:

$$a_1 = \exp(XA_1^*) \text{ and } a_2 = \exp(XA_2^*). \tag{4}$$

Although we do not use covariates for the b parameter, we express it in the same way:

$$b_1 = \exp(B_1) \text{ and } b_2 = \exp(B_2). \tag{5}$$

Thus, with two competing risks we will obtain two columns of estimates of coefficients for each model instead of just one as in a typical regression.

Results

Table B.1 presents estimates of three versions of the competing risks models. The first set of columns, “Transitions off Aid,” are for the transition from AFDC to being completely off aid. The second set of columns is for “Transitions to SSI.” Each model yields one set of estimates for transitions off aid and another for transitions to SSI. The three models are estimated with different sets of covariates—“Demographics and County Dummies Only,” “Disability Only,” and a “Full Model” including everything in the other two models.

Table B.1

Competing Risks Weibull Model of Transitions off AFDC

	Transitions off Aid			Transitions to Aid		
	Demographic & County Dummies Only	Disability Only	Full Model	Demographic & County Dummies Only	Disability Only	Full Model
Demographic characteristics						
Education	0.38***		0.36***	0.02		0.07
	(0.07)		(0.07)	(0.18)		(0.22)
Age (25–40)	–0.19		–0.11	0.43		0.04
	(0.17)		(0.17)	(0.67)		(0.73)
Age (> 40)	–0.62*		–0.42	1.29		0.92
	(0.24)		(0.24)	(0.82)		(0.87)
Black	–0.81***		–0.78***	0.18		0.07
	(0.19)		(0.19)	(0.41)		(0.42)
Latino	–0.06		–0.09	–2.33*		–2.30*
	(0.15)		(0.14)	(0.36)		(1.06)
Partner in household	0.78***		0.72***	0.23		0.49
	(0.13)		(0.13)	(0.36)		(0.40)
No. of children < 6	–0.29***		–0.27***	0.06		0.06
	(0.08)		(0.08)	(0.22)		(0.24)
No. of children ≥ 6	–0.04		–0.03	0.13		0.08
	(0.06)		(0.06)	(0.18)		(0.20)
County effects						
Alameda County	0.18		0.21	–0.31		–0.49
	(0.17)		(0.16)	(0.56)		(0.61)
San Bernardino County	–0.05		–0.03	0.65		0.56
	(0.18)		(0.17)	(0.52)		(0.56)
San Joaquin County	–0.05		–0.02	0.51		0.42
	(0.18)		(0.16)	(0.49)		(0.52)
Disabilities						
Moderately disabled children		–0.23	–0.08		1.63**	1.65*
		(0.19)	(0.17)		(0.59)	(0.64)
Severely disabled children		–1.64***	–1.39***		2.15**	2.26**
		(0.49)	(0.44)		(0.76)	(0.83)
Moderately disabled mother		–0.40*	–0.34*		–0.23	–0.41
		(0.18)	(0.16)		(0.52)	(0.55)
Severely disabled mother		–0.68*	–0.59*		1.32*	0.94
		(0.30)	(0.28)		(0.57)	(0.52)
Weibull hazard parameters						
A coefficient	–4.87	–4.31	–4.78	–7.88	–8.20	–8.66
	(0.26)	(0.09)	(0.25)	(1.19)	(0.91)	(1.46)
B coefficient	–0.21	–0.28	–0.17	0.04	–0.01	–0.04
	(0.09)	(0.09)	(0.08)	(0.25)	(0.24)	(0.28)
Log likelihood	–2644.41	–2683.88	–2614.32			

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Weighted n = 1,605. Statistical significance levels indicated as * p < .05, ** p < .01, and *** p < .001. Cell entries are exponential of Weibull coefficients, standard errors in parentheses.

Appendix C

Hardship Estimation

To describe the consequences of direct and indirect caregiving costs for families' economic well-being, we use regression techniques to estimate the effect of these costs on the probability that families experienced direct, material hardship in the prior year. Our model assumes that the probability of experiencing hardship is a function of families' income relative to needs (see, for example, Federman et al., 1996; Mayer and Jencks, 1988). We hypothesize that families who care for disabled children will have a higher probability of hardship because they have both less income (because of reductions in maternal employment) and greater needs (because of direct expenditures for disability-related medical, child care, and other goods and services).

Hardship was measured using responses to six survey questions. Respondents were asked whether they had every experienced each of four forms of hardship in the prior year: (1) adults or children had gone hungry, (2) the family had experienced an eviction or period of homelessness, (3) they had been late paying their rent or mortgage, or (4) they had experienced utility or phone shutoffs. A single indicator of "any hardship" was created by coding "yes" if any of these forms of hardship were reported.

Independent variables controlled for family characteristics assumed to affect the likelihood of hardship through either income or needs: the respondent's education, marital (cohabitation) status, number of children under age 18, current work status, and race or ethnicity. Because public housing assistance significantly affects income available for other needs, we also controlled for whether the respondent was in public housing or receiving Section 8 housing vouchers. Additional control variables were included to adjust for the sample design (county, program type, and experimental status in the state welfare reform waiver project).

The contribution of child disabilities to economic well-being was 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, we included an indicator for whether any child received SSI.

We use a logistic regression to estimate the dichotomous outcome (any or no hardship) (Maddala, 1983). The logistic regression coefficients represent the increase or decrease in the log of the odds of the outcome given a change in the predictor variable. It is difficult to transform logistic regression coefficients into more readily understood marginal probabilities because the model is nonlinear; independent variables would be expected to make a different marginal contribution at different points in the distribution. To improve the precision and clarity of the findings, we interpret the coefficients by constructing a simulation.

The probability of any hardship was first calculated for an "average" family in the sample by setting independent variable values at their means: the "base case" was a family headed by a white, Anglo, single female respondent with the average level of education for the sample (10.43 years), who was caring for the average number of children (2.2), and who was not currently employed. (The values for the sample control variables were set to Los Angeles County, "family group" or single parent AFDC case, and experimental group.) The probability of experiencing hardship in the prior year was calculated for this "base case" or average family. A severely disabled child was then "added" to the family and the probability of hardship was reestimated; the family was then "given" SSI and the probability of hardships estimated once again. A similar process was used to determine hardship probabilities for families with more than one disabled child and for families with more than one disabled child, at least one of whom was severely impaired.

Means and standard deviations for all variables in the model are provided in Table C.1. Full regression results are provided in Tables C.2 and C.3.

Table C.1

Independent Variables in Poverty and Hardship Estimations
(Means; Standard Deviations in Parentheses)

Variable	Description	Mean (SD) n = 1,732 Unweighted
Child disability		
Severity of impairment	At least one child has severe functional impairment	.04 (.21)
Control variables		
Respondent's education	Years of education	10.43 (3.04)
Respondent's race	African American	.28 (.45)
	Latino	.48 (.49)
Partner status	Respondent is married or cohabiting	.27 (.44)
Number of children	Biological, adopted, or step-children	2.22 (1.30)
Employment	Respondent had any paid work in prior month	.37 (.48)
Policy Variables		
Any SSI recipient	Disabled child receives SSI income	.05 (.21)
Design controls		
County	Alameda County	.22 (.41)
	San Bernardino County	.18 (.39)
	San Joaquin County	.24 (.43)
Experimental status	AFDC case in the experimental group	1.37 (.48)
Aid group	AFDC-UP (unemployed parent)	1.09 (.29)

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

Table C.2

Logistic Regression Results of Probability the Family Experienced Poverty in the Prior Month

	Poor (100% Poverty Line)		Extremely Poor (75% Poverty Line)	
	Coef.	S.E.	Coef.	S.E.
Adult and family characteristics				
Respondent's education (years)	–.1283***	.0293	–.0867***	.0247
Respondent has partner/spouse	–1.5378***	.1621	–1.6721***	.1606
No. of children in household	.3214***	.0598	.2160***	.0529
Respondent is employed	–1.7306***	.1324	–1.9515***	.1249
Respondent is African American	.4614***	.1757	.0006	.1693
Respondent is Latino	.4222**	.1665	.2070	.1597
Policy variables				
Child receives SSI	–2.4140***	.2963	–3.6511***	.3820
Child disability variables				
Any severely disabled children	.0590	.2866	.1587	.2932
More than one child disabled	.2464	.3063	.3317	.3079
Design controls				
Alameda County	.0381	.1958	.4141*	.1874
Los Angeles County	.0105	.1765	.0853	.1664
San Bernardino County	–.1698	.1931	–.1317	.1867
Program type = AFDC-FG (single parent)	.7097***	.1729	.7482***	.1661
Experimental status = yes	–.0249	.1326	–.0369	.1243
Constant	2.0846	.4846	1.2848	.4329

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Unweighted n = 1,682 households. Statistical significance levels indicated as * p < .10, ** p < .05, and *** p < .01.

Table C.3

Logistic Regression Results of Probability the Family Experienced Hardship in the Prior Year

	Coef.	S.E.
Adult and family characteristics		
Respondent's education (years)	–.002	.019
Respondent has partner/spouse	–.476 ***	.126
No. of children in household	.115 ***	.043
Respondent is employed	.031	.105
Respondent is African American	.416 ***	.145
Respondent is Latino	.176	.135
Policy variables		
Any housing subsidy	–.230 *	.128
Child receives SSI	–.860 ***	.259
Child disability variables		
Any severely disabled children	.930 ***	.248
More than one child disabled	.410 *	.247
Design controls		
Alameda County	.032	.157
Los Angeles County	–.014	.138
San Bernardino County	–.005	.155
Program type = AFDC-FG (single parent)	.208	.133
Experimental status = yes	–.038	.103
Constant	–.417	.352

SOURCES: Authors' calculations from the California Work Pays Demonstration Project Survey: English/Spanish Interviews Wave II and surveys of Alameda, Los Angeles, San Joaquin, and San Bernardino Counties.

NOTE: Unweighted n = 1,682 households. Statistical significance levels indicated as * p < .10 and *** p < .01.

Appendix D

Disability Measures

Mothers' Disability and Health Status

Our measures of the disability status of survey respondents (mothers) rely on two standard questions used in a variety of surveys (including the CPS, Panel Survey on Income Dynamics (PSID), Retirement History Survey, and Health Interview Survey (HIS)): whether the respondent had a "physical, mental or emotional condition that limited the amount or type of work she could do" and whether she rated her health in comparison to other people her own age as "excellent, good, fair or poor." (Questions are provided in Table D.1.)

A large literature on adult disabilities has grappled with the question of the accuracy of self-reported disability and health status. These issues raise particular concerns when adults are asked to report about work-limiting disabilities. Estimates of adult disabilities based on the standard question used in this and many other surveys tend to produce population estimates that are higher than administrative data on participation in disability-related cash assistance programs (Social Security Disability Insurance (SSDI) and Supplemental Security Income). Among adults, administrative records indicate that in the early 1990s, over 4 percent of the working-age population were receiving disability insurance. Estimates for approximately this same time period from the self-reported data in the CPS are that over 6 percent of working-age adults were unable to work because of health reasons (Haveman et al., 1995).

Differences between self-reported disability and participation in disability programs are usually understood to reflect the fact that adults may be disabled without meeting the eligibility requirements for cash assistance programs through SSDI (substantial work history) or SSI (limited income). Adults who self-report disabilities may also have conditions that are not severe enough to qualify them for these programs.

Table D.1

Survey Questions

For determining respondent disability and health status (asked of ALL respondents):

Do you have a health condition—physical, emotional, or mental—that limits the amount or kind of work at a job you can do?

> If yes: Does this condition prevent you from working at a job at all or does it only limit the kind or amount of work you could do at a job?

Now for a few questions about your health. In general, how would you rate your health these days—Excellent, Good, Fair or Poor?

For determining children's disability status: (asked for ALL resident child under age 19):

Do any of your children had a health condition—physical, emotional, or mental—that limits the amount or kind of activities he or she can do?

Do any of your children have a disability or handicapping condition?

Do any of your children receive Supplemental Security Income (SSI) due to a disability or handicapping condition?

(asked for EACH child identified as meeting any one of the three conditions above):

What is the health condition or disability? (Up to three verbatim answers recorded)

Because of his/her (physical/health/emotional/mental) (problem/condition), does (NAME OF DISABLED CHILD) need more help than other children his/her age doing things like eating, bathing, dressing, or getting around the house?

> If yes: Does he/she need . . .
> only a little more help, or
> a lot more help than other children his/her age?

Does any (problem/condition) NOW keep (NAME OF DISABLED CHILD) from going to school?

[If school age] How much impact does (NAME OF DISABLED CHILD)'s (problem/condition) have on his/her school attendance?

> Is he/she able to attend school regularly,
> does he/she miss a lot of days because of his/her (problem/condition),
> or does he/she miss only some days because of his/her (problem/condition)?

[If school age] Does (NAME OF DISABLED CHILD) attend special school or special classes or receive special education services because of his/her (problem/condition)?

Is (NAME OF DISABLED CHILD) able to take part in the usual kinds of activities done by most children his/her age?

[If older than 1 year] Does (NAME OF DISABLED CHILD)'s condition limit his/her ability to walk, run, or use stairs?

[If younger than 1 year] Does (NAME OF DISABLED CHILD)'s condition limit his/her ability to crawl, walk, run, or use stairs?

Self-reports of disability and health problems may be biased upwards because of factors such as respondents' misunderstanding of questions, their consideration of transitory illnesses, or the social desirability of invoking a health problem to explain nonwork, receipt of disability benefits, or other contingent behaviors (see Burkhauser et al., 1993; Stern, 1989). An employment-related definition of disability may also be endogenous with the individual's expectations regarding employment (for example, because women are less likely to be employed than men overall they are also likely to describe themselves as having employment-limiting disabilities) and with the type of work that the individual expects to perform (Loprest, Rupp, and Sandell, 1995).

The possible endogeneity of self-reported disabilities based on work limitations is of particular concern when measures of disability based on work limitations are used to model employment and other economic outcomes. Although the problem of bias cannot be ruled out, there is substantial evidence that self-reported measures of disability are both robust and minimally biased predictors. Self-reported measures are widely used in employment models and have proven themselves to be robust predictors of, among other outcomes, labor force participation and welfare use (see Haveman et al., 1995; Wolfe and Hill, 1995).

With regard to whether these estimates are biased by the use of a potentially endogenous measure, the crucial issue is whether individuals who have misreported disability status are, in fact, healthy enough to work. The literature suggests that although self-reports of disability may produce estimates that are higher than other sources of information (for example, clinical assessments), individuals who report themselves to be disabled or in poor health are generally not in good health but, rather, have problems that may not be severe enough to meet an alternative standard such as eligibility standards for disability insurance.

In their study of the increase over time in both self-reported disabilities and participation in disability programs, for example, Bound and Waidmann (1992) decompose the increase in self-reported disabilities, the decline in labor force participation, and the increase in participation in disability insurance programs among men in the 1970s. They conclude that liberalization of disability benefits during the 1970s appears to have led to an "earlier accommodation" of health limitations by providing alternatives to employment for individuals with less severe health and disability problems. Their analysis suggests that individuals with “relatively poor health” may have been particularly sensitive to the combination of declining demand for low-skilled workers and increasingly liberal disability benefits during this period. They do not conclude that healthy but unemployed adults became more likely to report themselves as disabled during this period, but, rather, that as the threshold for receipt of disability insurance was lowered, individuals with less severe conditions were both more likely to self-report and more likely to obtain disability benefits. As they conclude, the data provide little evidence that the increase in labor force withdrawals associated with self-reported disabilities represents malingering on the part of these individuals. Rather, that “the evidence suggests that most of those did so [left the labor force] and began receiving disability transfers did suffer from potentially disabling conditions” (p. 1417).

Similar conclusions are reached by Kubick (1999), who examined changes in the prevalence of childhood disabilities reported by parents before and after changes that liberalized eligibility for the SSI program. Using data from the National Health Interview Survey and the March Current Population Survey, he finds that the rule changes were followed by a substantial increase in the percentage of low-income children identified as having health impairments, relative to high-income children. Parents in states with higher benefit differential between SSI and AFDC were more likely to identify their children as having a health impairment, and more likely to seek medical treatment and special education services for their children. He concludes that the SSI expansion was effective in encouraging poor families to identify and treat health problems in their children.

Further evidence that the gap between alternative measures of disability reflects differences in the severity, rather than the existence, of a disability is provided by studies of individuals whose claims for disability are rejected (reviewed in Bound, 1991). Clinical studies of these individuals reveal that although they were not deemed sufficiently disabled to work, the majority (as many as two-thirds) were *not* “capable of work under normal conditions” (p. 1432).

Stern (1989) makes use of detailed information about medical conditions available in the NHIS to addresses the issue of endogeneity directly. To address the question of the accuracy of self-reported, work-limiting disabilities, he uses the NHIS data to compare self-reports of work-limiting disabilities (the question used in our survey) to self-reports of specific, usually physician-diagnosed, conditions. In general, the correlation between the two types of measures is very strong, and more severe conditions are associated with a higher probability of reporting work-limiting disabilities. (Loprest, Rupp, and Sandel (1985) report similar results using the NHIS and restricting their sample to women.) However, the correlation is not perfect, suggesting that some respondents either misunderstand the questions or misreport their status. Interestingly, this includes both individuals who report a work-limiting disability but no specific conditions, and those who report conditions that would generally be considered to impose limitations (for example, blindness), but do not report a work limitation.

Stern (1989) goes on to address the question of whether the more general measures of "work-limiting disabilities" is an endogenous and therefore biased measure by estimating two-stage employment probability models that use instruments constructed from either reported conditions or self-reports of work-limiting disabilities or poor health. He concludes that the summary measures (of work limitations and poor health) are robust and exogenous to the employment measure and therefore "provide good proxies for estimating the effect of disability on participation" (p. 391).

The general consensus among researchers who have examined these issues is, not surprisingly, that more and more detailed measures (for example, measures of functional limitations) are preferable to single measures. However, our reading of the literature suggests that the standard questions regarding work-limiting disabilities and health status, which we used in this study, have shown themselves to be robust and minimally biased measures. Although all individuals who report themselves as having disabilities and poor health may not meet other criteria, such as eligibility for disability insurance, we believe that they are quite likely to have some level of health compromise.

Children's Disability Status

As noted above, concerns about overreporting and endogeneity have been raised most often with regard to adults' self-reports of disability status. Although it is possible that parents are also likely to misreport children's disabilities, which are the central concern of this study, there is little evidence to suggest that these measures are biased or endogenous to self-reports of parental employment. In fact, in the case of adult disabilities, proxies are believed to be *less* likely to report disabilities (about a family member) than are respondents themselves (about their own health), probably because of incomplete information (Bound and Waidmann, 1992). Because parents are the caretakers of their children, there is less reason to believe that they do not have information about their health and disability status.

Because children's disabilities are the primary focus of this study, we spent considerably more of the interview collecting detailed information about the existence, type, and severity of their conditions. Children with chronic health problems and disabilities were identified by asking mothers two separate questions concerning whether any of their children: (1) had a chronic health problem—physical, emotional, or mental—that limited the amount or kinds of things that he or she could do; and (2) had a disability or handicapping condition that limited the amount or kind of things he or she could do. We identified a household as including a child or 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 moderate to severe 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 a series of 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.

We believe that these questions provide as reliable a measure of children's disabilities as is possible using telephone surveys. However, given the considerable difficulties of caring for children with physical, mental, and emotional conditions, parents may be inclined to overestimate the severity of children's disabilities. Parents who are receiving welfare and not employed may also be inclined to identify problems among their children to justify their status. Given these concerns, we were conservative in our coding of children's conditions. When mothers reported that their child had a condition, but did not provide a specific condition or diagnosis, or did not describe the child as having functional limitations, we did not code that child as having a disability. Among those children for whom the mother identified a condition and at least one functional limitation, we used reported functional limitations to distinguish between children with "moderate" and "severe" problems. (See Table 5.2 in text.)

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