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A Profile of Children with Disabilities Receiving SSI: Highlights from the National Survey of SSI Children and Families

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Summary

This article provides a nationally representative profile of noninstitutionalized children 0 to 17 years of age who were receiving support from the Supplemental Security Income (SSI) program because of a disability. To assess the role of the SSI program in providing assistance to low-income children with disabilities and their families, it is important to obtain detailed information on demographic characteristics, income and assets, health and disabilities, and health care utilization. Yet administrative records of the Social Security Administration do not contain many of the relevant data items, and the records provide only an incomplete picture of the family relationships affecting the lives of children with disabilities. The National Survey of SSI Children and Families fills this gap. This summary article is based on survey interviews conducted between July 2001 and June 2002 and provides some highlights characterizing children with disabilities who were receiving SSI and their families.

Most children receiving SSI (hereafter referred to as "SSI children") lived in a family headed by a single mother, and less than one in three lived with both parents. A very high proportion, about half, were living in a household with at least one other individual reported to have had a disability. About 70 percent of children received some kind of special education.

SSI support was the most important source of family income, with earnings a close second. On average, SSI payments accounted for nearly half of the income for the children's families, and earnings accounted for almost 40 percent. When all sources of family income were considered, slightly more than half (54 percent) of SSI children lived in families above the poverty threshold, a notable fact given that the federal SSI program guarantees only a subpoverty level of income. However, beyond these averages there was substantial variation, with some children living in families with income well below the poverty threshold and others having income well over 200 percent of the poverty threshold. About one-third of SSI children lived in families owning a home, two-thirds lived with parents or guardians with at least one car, and about 40 percent lived with parents or guardians with zero liquid

assets. Less than 4 percent lived with adults who owned stocks, mutual funds, notes, certificates of deposit, or savings bonds.

The Social Security Administration's administrative records contain only a limited amount of information about disability diagnoses. The National Survey of SSI Children and Families supplements those records with data from an array of questions on functional limitations, self-reported health, and the perceived severity of disabilities. The data suggest that a great degree of variation in severity exists within the childhood caseload, as reflected in reports of the presence or absence of six functional limitations, perceived overall health status, and perceived impact of disability on the child's ability to do things. Overall, 36 percent of the children were reported to have had disabilities that affected their abilities to do things "a great deal," and for 21 percent their difficulties had very little or no impact. Physical disabilities were most common among children aged 0 to 5, and mental disabilities dominated the picture for the other two age groups: 6 to 12 and 13 to 17.

Virtually all SSI children are covered by some form of health insurance, with Medicaid being by far the most common source of health insurance coverage. Just as in the case of the severity of disabilities, substantial variation was reported in health care utilization among SSI children. Almost 30 percent of children had two or fewer doctor visits during the 12 months preceding the interview, and close to 50 percent had five or more doctor visits. About four-fifths of the children had no reported hospitalizations or surgeries during the previous year. More than 40 percent of the children visited an emergency room during the previous year, most of them more than once. Importantly, no out-of-pocket costs associated with medical care were reported for more than two-thirds of the children, and only about 3 percent had annual expenses exceeding $1,000 for physical and mental health care. This finding suggests that SSI payments are not used to cover medical expenses for the overwhelming majority of children.

The use of supportive therapies varied widely among SSI children: more than half reported having used physical, occupational, or speech therapy; only 8 percent used respite care for the parents or other family members. An analysis of the perception of the survey respondents shows that more than one-third of children had unmet needs for mental health counseling services, and about three-quarters of families had unmet needs for respite care. In several service categories, the proportion perceived to have had unmet service needs was around 10 percent or less. In the dominant service category of physical, occupational, and speech therapy, only 11 percent perceived to have had unmet service needs.

Introduction

The National Survey of SSI Children and Families (NSCF) is a nationally representative survey of children (aged 17 and under) and young adults (aged 18 to 23) receiving Supplemental Security Income (SSI) on the basis of a disability at the end of 2000 or who previously received or applied for SSI payments and are not currently institutionalized.[1] It is the first survey of its kind since 1978, when the SSI program was still in its infancy. The survey was designed to meet the needs of policymakers by providing comprehensive information on the characteristics of SSI children and young adults, as well as providing information on their living arrangements and their families. A useful feature of the survey is that it provides a statistically representative cross section of the SSI caseload of children and young adults. Combined with administrative records data of the Social Security Administration (SSA), the NSCF provides longitudinal data that allow for tracking the program participation patterns of a representative sample of children and young adults who were receiving SSI support at the time of the survey (between July 2001 and June 2002), as well as a representative sample of children and young adults who were receiving SSI when the 1996 welfare reform legislation was passed (Public Law 104-193).

Interviews were conducted by telephone or through in-person visits with individuals who could not complete the survey by telephone or who could not be contacted by telephone (for example, households without a telephone).[2]

Most of the information from this survey is not available elsewhere. The survey is intended to comprehensively assess the needs of SSI children and young adults, which in turn can help policymakers design policies for successful transition from dependence on support from the SSI program into continuing education or the world of productive employment. The focus of these interviews was the disabled child or young adult, but the information was provided by the parent or guardian, especially for children and cognitively impaired young adults. The interviews cover a wide array of the characteristics of the reference child or young adult, such as the nature of the disabling condition, educational attainment, and the utilization of health care and supportive services. In addition, the interviews provide information on demographics and the economic circumstances of the family. They also provide important information about the parents, such as educational attainment, employment, and the provision of care for the reference child or young adult.

Survey and SSA administrative records data each have strengths and weaknesses. For example, administrative records data on the receipt and amount of SSI payments are superior to self-reported information, especially at the individual level (Huynh, Rupp, and Sears 2002). In contrast, survey data are often a superior source of information on variables concerning the family and household that are key to policy proposals to simplify the SSI program. Because these variables are not central to the administration of the status quo SSI program, administrative records data do not provide a complete picture of family relationships (Koenig and Rupp 2003/2004). Often the combination of survey and administrative records data is superior to relying on either alone. The NSCF was therefore designed to provide data that may usefully supplement existing administrative records as sources of information on children receiving SSI payments.

Survey and administrative data are subject to potential measurement error. When comparing survey and administrative records data, it is sometimes reasonable to assume either one or the other to be a superior source (as in the examples cited above), but often the interpretation of differences is less straightforward. For example, administrative records data on disability diagnosis are affected by the practice of commonly coding the disability that is easier to document, even if some other condition is more severe in some respects. In contrast, survey measurement in this area is fundamentally affected by the respondent's perceptions, especially when it comes to conditions that are associated with social stigma, such as mental illness. Many instances of discrepancies do not imply that either one or the other source is flawed. For example, survey reports of the severity of disabilities may reflect subjective perceptions of the survey respondent and more detailed and accurate private knowledge of the reference child when compared with objective third-party reports by professionals (physicians, therapists) captured in administrative program data. However, administrative data are also affected by "moral hazard" in reporting by the applicant, while survey reports are less affected by it, if at all.[3]

In some cases survey responses may reflect measurement error arising from factors such as misunderstood or ambiguous survey questions, recall error, or interviewer error. Unfortunately, in many cases it is not immediately obvious whether a seemingly erroneous response reflects survey error or some other factor. For example, reporting a SSI benefit in a given month that is higher than the SSI federal benefit rate may simply reflect accurate reporting of the receipt of a lump-sum retroactive benefit payment. Likewise, a survey report that the child is not disabled may reflect highly subjective perceptions, but it is also possible that the child is no longer disabled or that the initial disability determination was in error because of procedural mistakes.

Given these complexities, we caution the reader to not overinterpret seemingly erroneous results from the survey either as evidence of poor survey quality or as indicative of a major problem with administrative records, the administration of the SSI program, or both. The magnitude of discrepant responses is also very relevant. If they involve a small percentage of cases, it is usually very difficult to come to a firm conclusion. If the discrepancies amount to large percentage differences, detailed assessment of the possible sources of the discrepancy would be warranted.

In this article the survey data are presented as they were recorded, and no attempt has been made to impose arbitrary edits to force consistency with data from administrative records or program rules. Ultimately, it is the responsibility of the research analyst to make an informed judgment about the magnitude and nature of potential errors.

This summary article focuses on an important subset of the survey universe, providing a statistically representative profile of noninstitutionalized disabled children aged 0 to 17 who received SSI payments (hereafter referred to as "SSI children") in December 2000.[4,5] The topics highlighted in this summary article include

- demographic characteristics,
- income and assets,
- health and disabilities, and
- health care utilization.

This summary article provides only key highlights. The survey was designed to provide a rich array of information to facilitate a series of in-depth studies by analysts at SSA, as well as by academic and private-sector researchers and policy analysts.

Demographic Characteristics

Administrative records maintained by SSA provide very reliable data on certain demographic characteristics like age and sex.[6] The age and sex distribution of SSI children in the NSCF correspond very closely with SSA administrative records (Table 1).[7] Other characteristics such as race, ethnicity, education, and household composition are unavailable or incomplete in the administrative records. We focus on those characteristics below.

SSA administrative records do not contain complete information on race (Scott 1999). The NSCF questions on race and ethnicity follow the guidelines provided by the Office of Management and Budget for collecting such information. Approximately 47 percent of SSI children were classified as "White alone," and 46 percent were classified as "Black alone" (Table 1).[8] The remaining 7 percent were of other races (American Indian or Alaska Native or Asian or Pacific Islander) or were "Multiracial." About 16 percent of SSI children were Hispanic.

SSA administrative records do not contain data on the educational attainment of SSI children or their utilization of the special education system. That data gap is filled by the NSCF. Almost 89 percent of the SSI children who were surveyed were reported to be enrolled in school, and about 70 percent participated in a special education program at some point during their schooling (Table 1).[9] Almost 68 percent had an individual education plan (IEP) at some point during their schooling.[10]

SSA data on SSI recipients' living arrangements characterize these arrangements for the payment of SSI benefits but do not reflect living arrangements from a demographic or economic perspective and thus provide an incomplete picture of family and household relationships (Koenig and Rupp 2003/2004). More than half (56 percent) of the children in the NSCF were living with their single mother (Chart 1).[11] Only about 2 percent lived with a single father. A substantial proportion (29 percent) lived in a two-parent household, and about 10 percent lived with an older relative other than their parents. Younger children, especially those under the age of 6, were far more likely to be living in two-parent households than were older children.

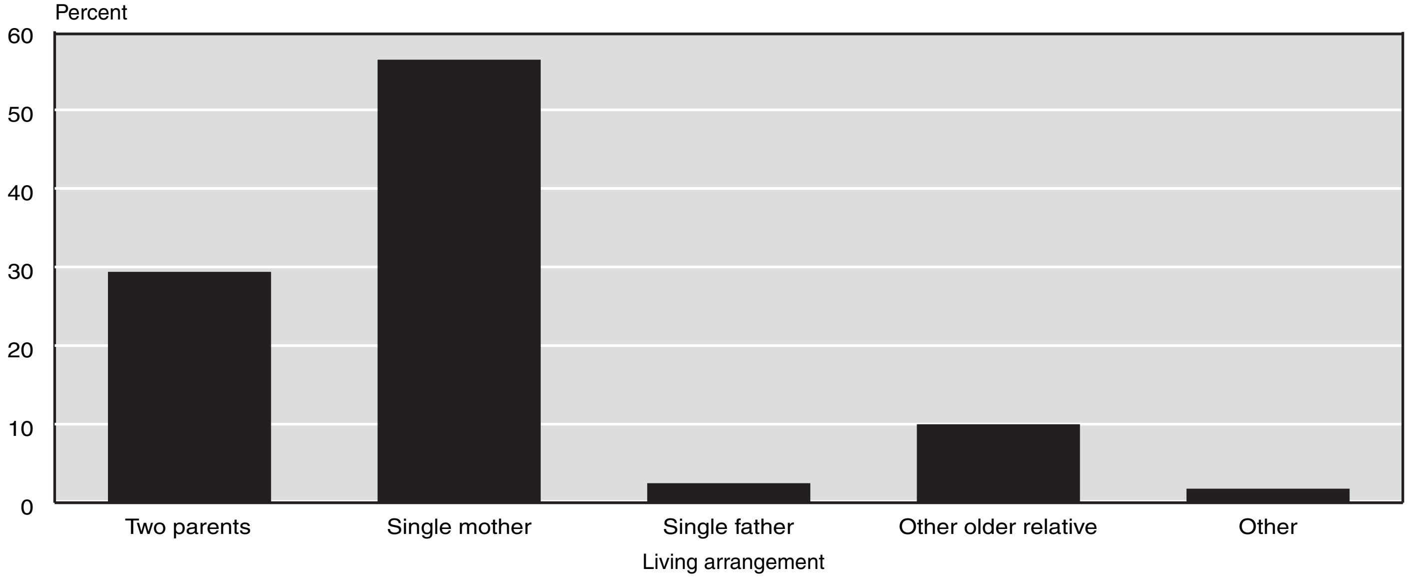
More than 50 percent of SSI children lived in households with two or three children under the age of 18 in the household, and less than a quarter lived with no other children present (Table 1). About a quarter lived in households with four or more children. A very high proportion (about half) of SSI children were living in a household reported to have at least one other individual (child or adult) with a disability.

Income and Assets

SSA administrative records provide information on income items that are required for computing SSI eligibility and payments. Income data that are needed for economic and policy analyses—for example, parental earnings, total family income, and the share of family income from various sources—either are not available or are difficult to access in SSA records. Administrative data on assets (resources) are not available at all from SSA's regular SSI data extracts. The NSCF provides detailed data on the income sources of the SSI child, the parents of the child, and the other resident family members, as well as information on the parent's or guardian's assets and debt. Data on assets and debt include the assets and debt of any spouse or unmarried partner of the parent or guardian.

Nearly half of all SSI children in the NSCF lived in families in which their parents or guardians had no earnings (Chart 2). Among those whose parents or guardians had earnings, the level of those earnings varied substantially. About 16 percent of SSI children lived in families with monthly earnings of $2,000 or more. Among parents or guardians who had earnings, the median earned income was $1,500 per month (Table 2), or about $18,000 per year.

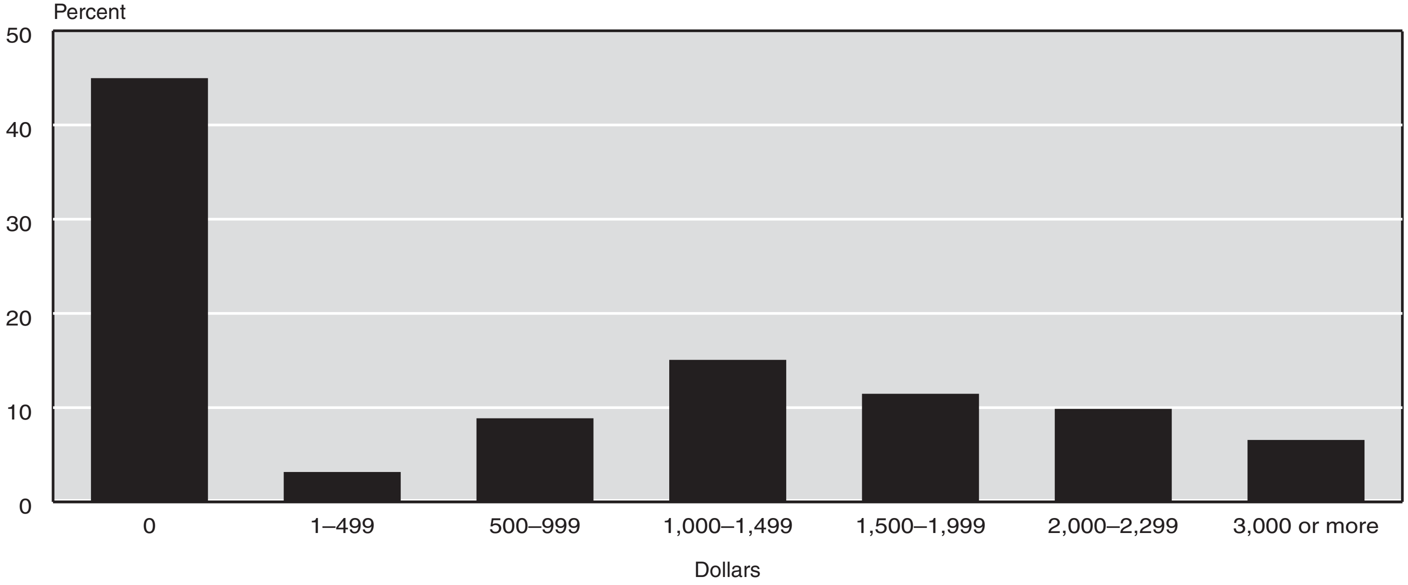
Chart 1.
Distribution of children receiving SSI by living arrangement



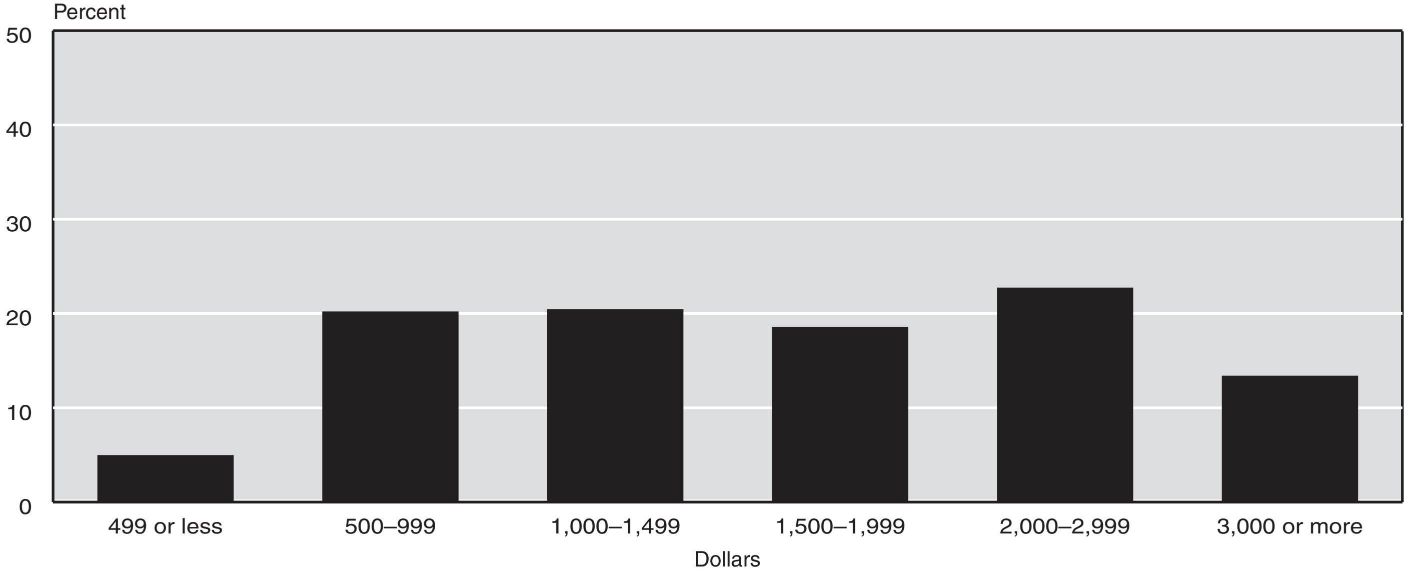
SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002. See Table 1, Note.

Chart 2.
Distribution of children receiving SSI by monthly earnings of parent or guardian and total monthly family income

Monthly earnings of parent or guardian



Total monthly family income



SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002. See Table 2.

NOTE: Chart for monthly earnings of parent or guardian (top) does not include small fraction with missing variable value.

Family income among SSI children also varied substantially. The median total family income was $1,612 per month (Table 2), or about $19,300 per year; about a quarter lived in families with less than $1,000 per month ($12,000 per year), and just over one-third lived in families with more than $2,000 per month ($24,000 per year; Chart 2). Family income includes earnings, government transfers, and other sources of cash income for all family members.

On average, SSI payments accounted for nearly 48 percent of the family income of SSI children, and earnings accounted for almost 39 percent (Chart 3).[12] Public assistance (other than SSI) and Social Security (Old-Age, Survivors, and Disability Insurance) benefits each accounted for less than 5 percent of family income, with miscellaneous other sources making up the remaining 5 percent.

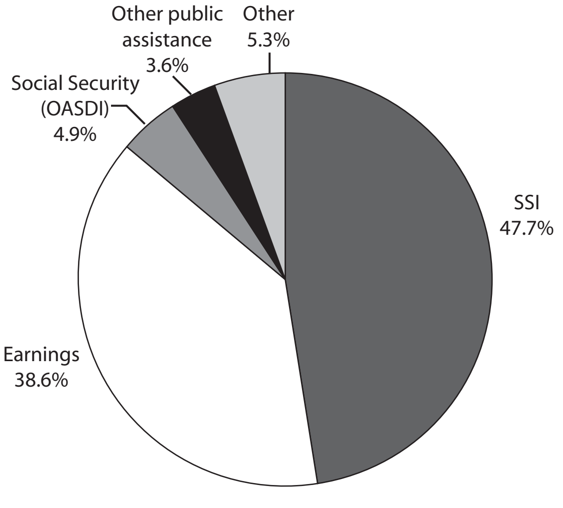
Consistent with the monthly nature of the SSI cash assistance program, family poverty status was calculated as the ratio of total monthly family income to 1/12 of the federal poverty threshold (adjusted for family size and number of related children under the age of 18). Slightly more than half (54 percent) of the children were reported to be living in families with income above the poverty threshold (Table 2), a notable fact given that the federal SSI program guarantees only a subpoverty level of income. The detailed distribution showed substantial variation, with some SSI children living in families with income well below the poverty threshold, and others living in families with income well over 200 percent of the poverty threshold.

Parents or guardians of SSI children tended to have few liquid assets and relatively modest debt (Chart 4).[13] Excluding housing and vehicles, about 40 percent of SSI children had parents or guardians with zero reported assets; another 42 percent had parents or guardians with reported assets less than $1,000. Almost 9 percent had parents or guardians with reported assets valued at $3,000 or more.[14] Half of all SSI children had parents or guardians with zero reported debt. However, almost 19 percent had parents or guardians with more than $5,000 in reported debt.

SSI children lived with parents or guardians with relatively low ownership rates of many commonly held assets (Table 2). Only about 36 percent lived with parents or guardians who owned a residence or held a mortgage on it. Only 30 percent lived with parents or guardians who had a savings account, and just over a third lived with parents or guardians who had a checking account. Less than 4 percent lived with parents or guardians who owned at least one of the following investments: stocks, mutual funds, notes, certificates of deposit, or savings bonds. In contrast, about 62 percent lived in a household in which a parent or guardian had at least one vehicle.

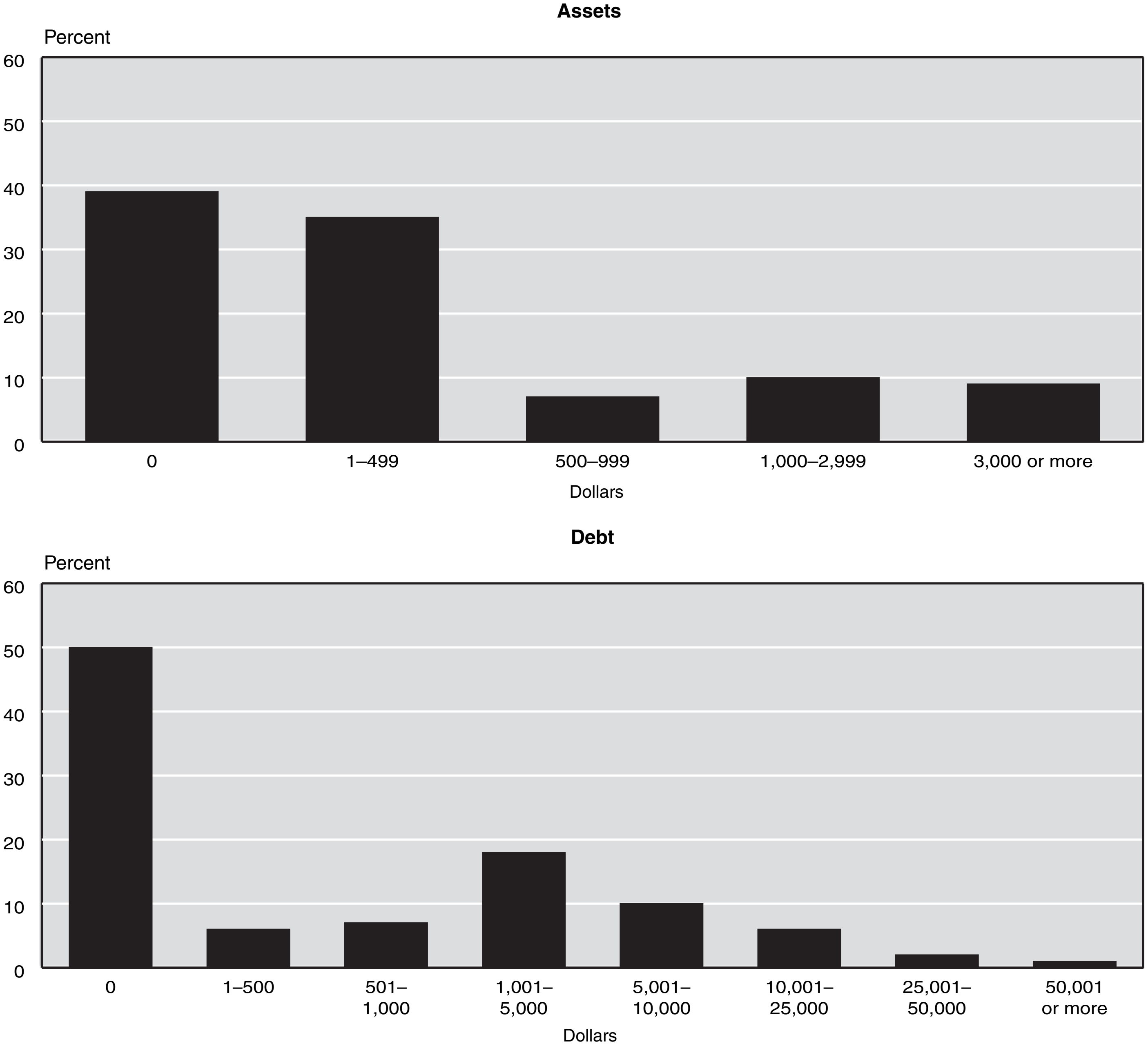
Family participation in government assistance programs other than the SSI program is shown in Chart 5. Just over 14 percent of SSI children lived in families receiving public assistance payments other than those from the SSI program (for example, Temporary Assistance for Needy Families and general assistance), 13 percent in families that received Social Security

Chart 3.
Average share of family income of children receiving SSI, by source



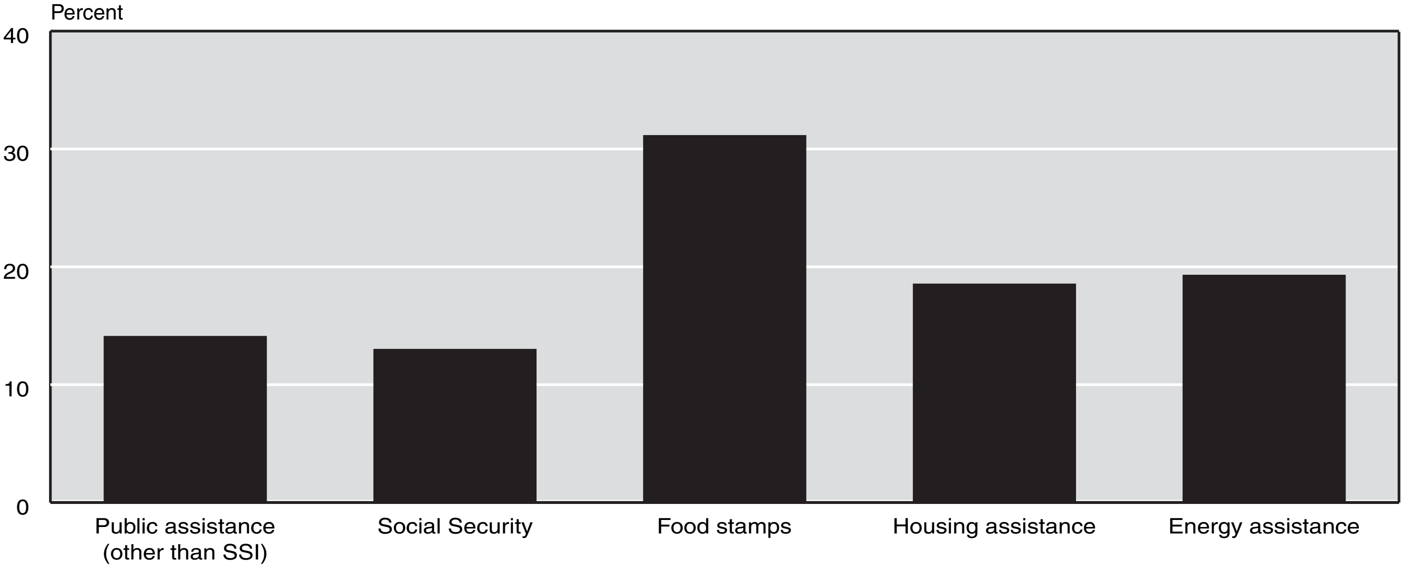
SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002. See Table 2.

Chart 4.
Distribution of children receiving SSI by reported total liquid assets and total debt of parent or guardian



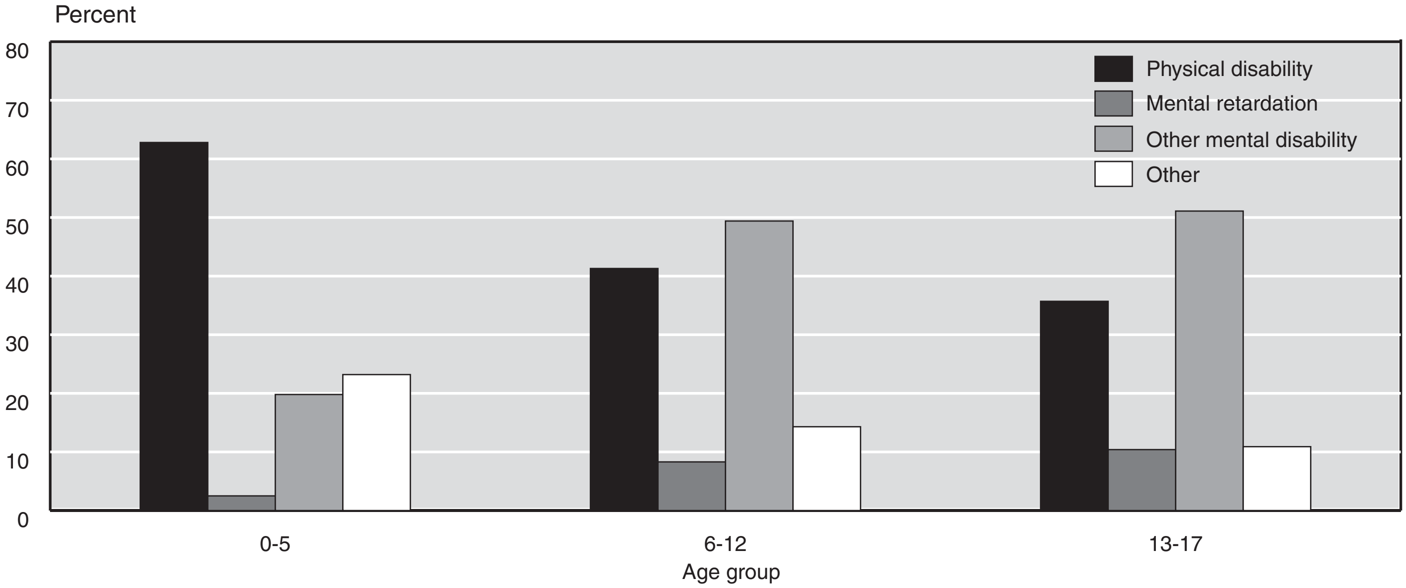
SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002. See Table 2.

Chart 5.
Percentage of families of children receiving SSI with income from other government programs



SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002. See Table 2.

Chart 6.
Percentage of children receiving SSI with reported physical, mental, or other disabilities, by age group



SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002. See Table 3.

NOTE: Chart does not include small fraction with missing variable value.

(OASDI), 31 percent in families receiving food stamps, nearly 19 percent in families with housing assistance (residence in public housing or subsidized rent), and just over 19 percent in families receiving energy assistance.

Health Status

Although SSA administrative records contain data on the child's disability diagnosis at the time of application for SSI benefits and at the point of continuing disability reviews, information is not collected on the general health status of SSI recipients, their functional limitations, or the severity of their disabling condition(s). From the NSCF, data are available on the disabling condition, general health status, functional limitations, and severity of disability for SSI children. As discussed in the Introduction, these data are based on the subjective perceptions of the survey respondent.

Disabling conditions were classified as physical, mental, and other, on the basis of up to three conditions reported by the NSCF respondent. The categories are not mutually exclusive. In other words, if a respondent reported mental retardation and a mobility impairment, the child would be counted in both the mental disability category and the physical disability category. Within the mental disability category, two subgroups were distinguished: mental retardation and other mental disorders (which includes all mental disorders except mental retardation).

Overall, parents or guardians reported that 50 percent of SSI children had a mental disability, and about 44 percent had a physical disability (Table 3). Eight percent of all SSI children reported mental retardation; 44 percent reported a mental disability other than mental retardation. Substantial age differences were evident within this overall distribution. For preschool-aged SSI children, physical disabilities were the most frequent, while for SSI children aged 6 to 12 and 13 to 17, mental disabilities were clearly dominant (Chart 6).[15] About 28 percent of SSI children reported more than one disabling condition (not shown).

Around 39 percent of SSI children were reported by the parent or guardian to be in poor or fair health (Chart 7). However, a nontrivial minority—about 27 percent—were reported to be in excellent or very good health. Differences were small in perceived general health status among the three age groups (Table 3).

Respondents were asked to ascertain the presence or absence of six kinds of functional limitations for SSI children aged 6 to 17: getting into or out of bed, getting around inside the home, using or getting to the toilet, eating, bathing or showering, and dressing.[16] Sixty-one percent of SSI children aged 6 to 12 were reported to have none of these six functional limitations (Table 3). An even higher portion of teenagers (77 percent) aged 13 to 17 were reported to have none. At the other end of the scale, about 20 percent of SSI children aged 6 to 12 were reported having three to six of these functional limitations (Table 3). The proportion of teenagers aged 13 to 17 with three to six functional limitations was much lower, about 12 percent. Among SSI children in both age groups (6 to 12 and 13 to 17) who reported one or more of the six functional limitations covered in the NSCF questionnaire, the mean and median number of reported functional limitations was three (Table 3).

Among SSI children between the ages of 6 and 12, the parent or guardian reported that 10 percent needed help getting into or out of bed, 9 percent needed help getting around the house, 17 percent needed help using or getting to the toilet, and 14 percent needed help eating (Chart 8). A much larger percentage needed help bathing or showering (34 percent) and dressing (33 percent).

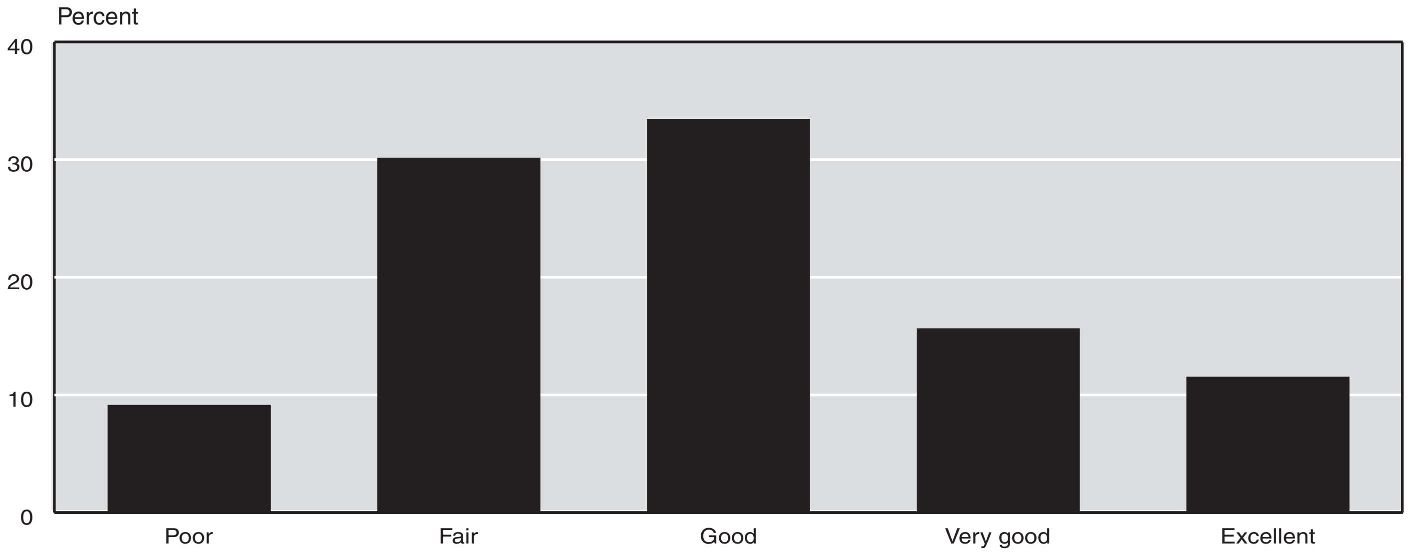
Among SSI teenagers (aged 13 to 17), 7 percent needed help getting into or out of bed, 6 percent needed help getting around the house, and 10 percent needed help using or getting to the toilet. Eight percent needed help eating, 19 percent needed help bathing or showering, and 18 percent needed help dressing.[17]

About 36 percent of children receiving SSI payments were perceived by their parents or guardians to have disabilities that affected their ability to do things "a great deal" (Chart 9). In contrast, 21 percent were perceived to have disabilities that had "very little" or no impact on their ability to do things. As Table 3 shows, the overall pattern was very similar for the three age groups of children.

Health Care Utilization and Expenses

Health care utilization is a topic of great importance in studies of SSI children. Childhood disabilities often lead to extensive health care needs and expenses. Most SSI children are covered by Medicaid, which pays for most of their health care. However, it is not known whether they receive all of the health care services they need and what the reasons are for any unmet needs. In addition, little is known about their out-of-pocket medical expenses. SSA administrative records do not contain any information on this topic. Utilization data are collected in other national surveys, but the sample of SSI children is often too small in such surveys to study health care utilization in any detail. In addition to utilization data, the NSCF collects data on perceived health care needs and perceived unmet health care needs among SSI beneficiary children, as well as information on out-of-pocket expenses related to disability.

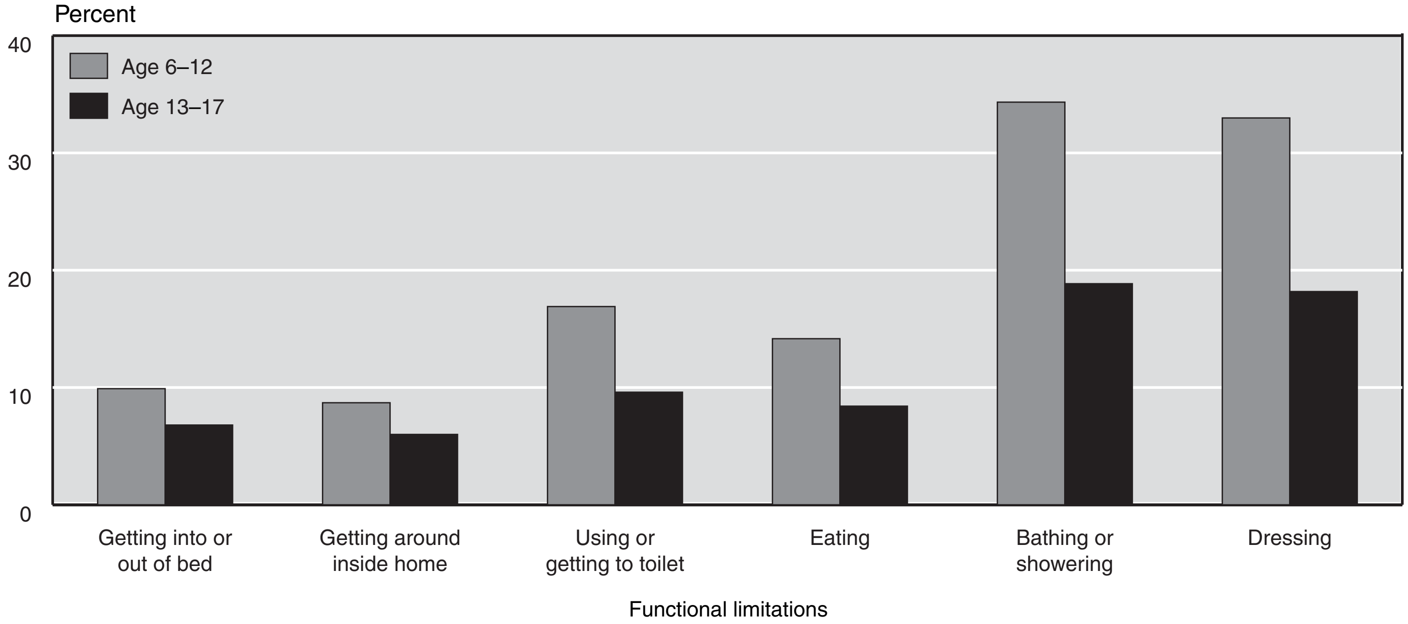
Chart 7.
Distribution of children receiving SSI by reported health status



SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002. See Table 3.

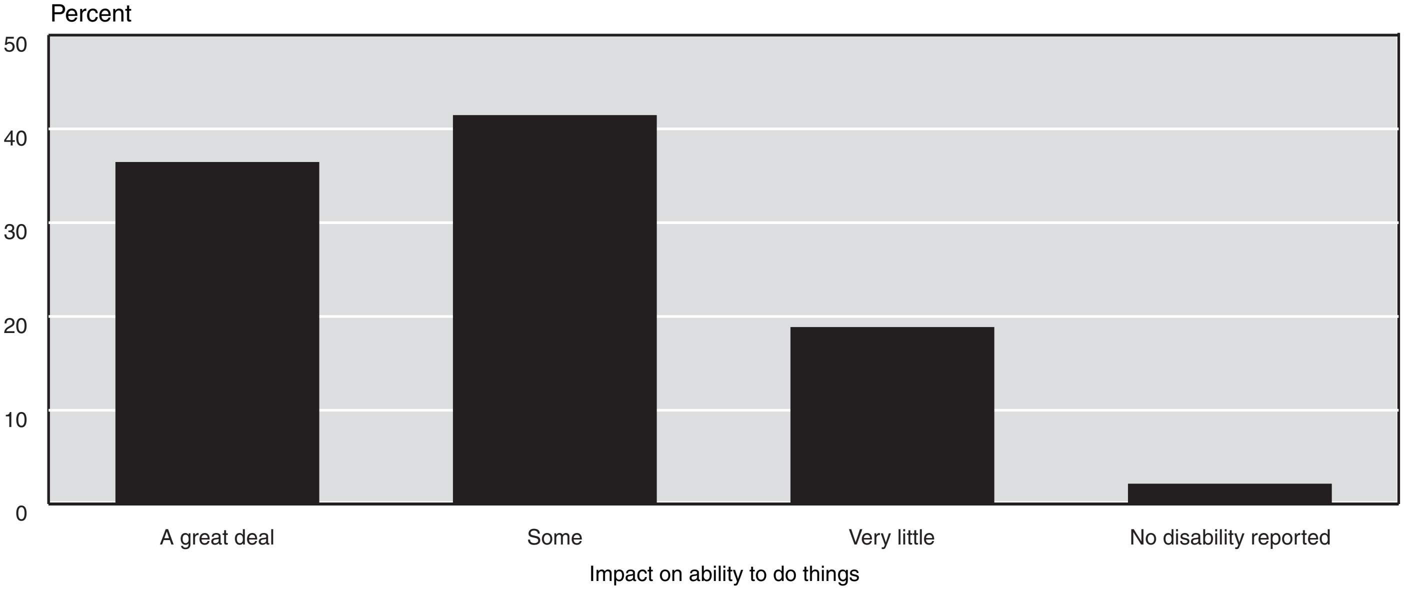
NOTE: Chart does not include small fraction with missing variable value.

Chart 8.
Percentage of children receiving SSI with reported need for help with specific activities, by age group



SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002. See Table 3.

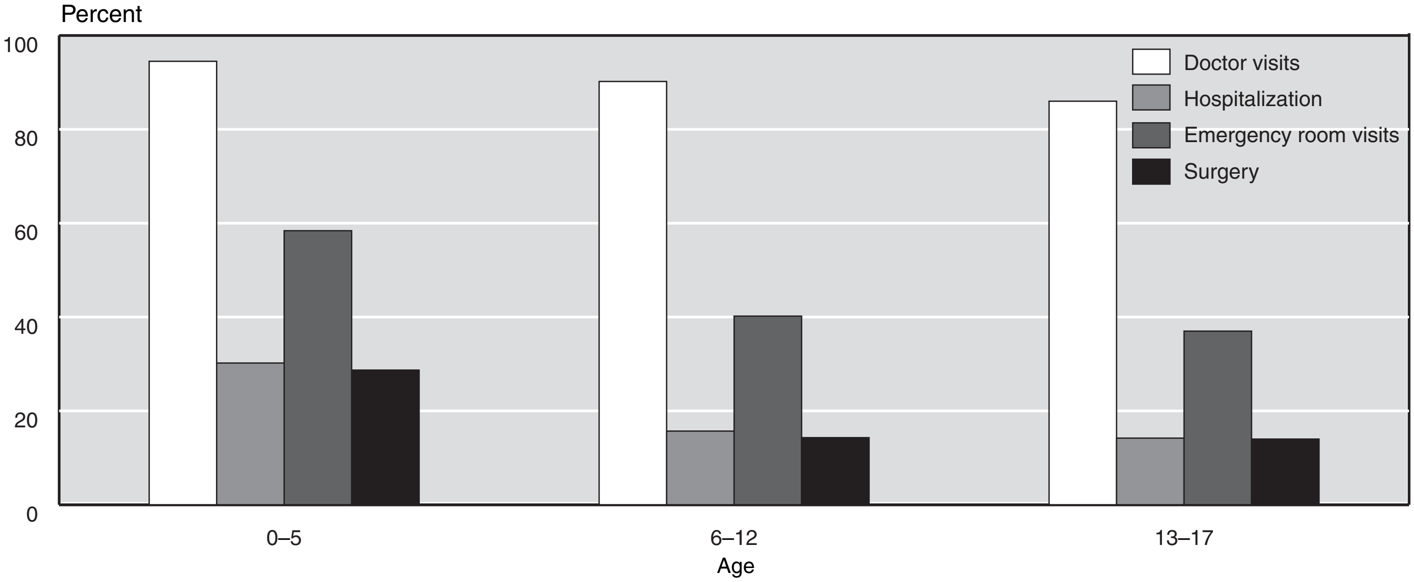
Chart 9.
Distribution of children receiving SSI by perceived impact of disability on child's ability to do things



SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002. See Table 3.

NOTE: Chart does not include small fraction with missing variable value.

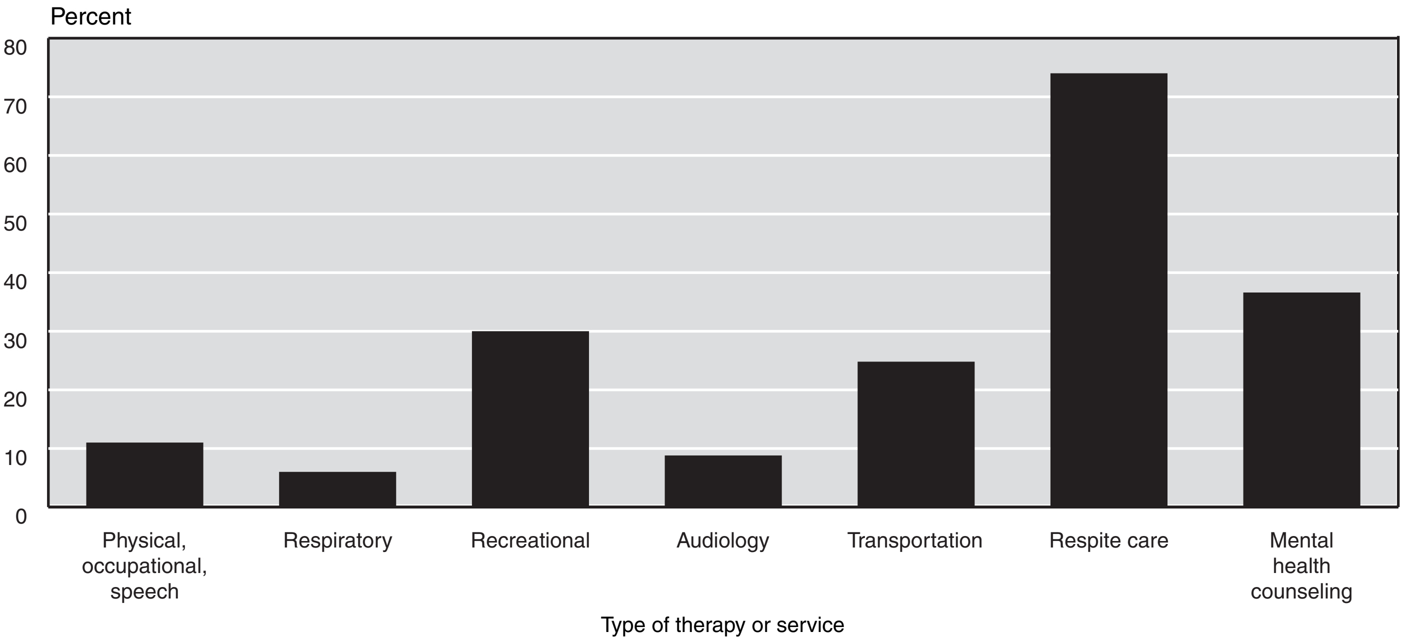
Chart 10.
Percentage of children receiving SSI reported to have had at least one doctor visit, hospitalization, emergency room visit, or surgery during the 12 months before the interview, by age group



SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002. See Table 4.

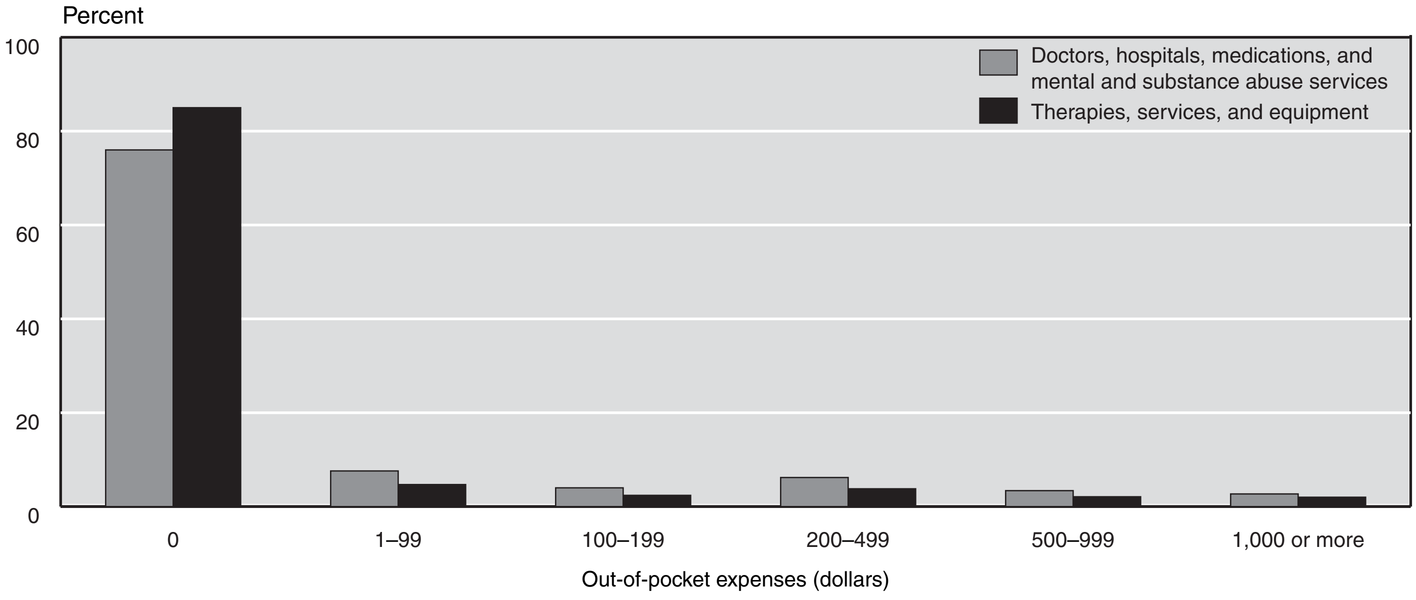
NOTE: The number of doctor visits, hospitalizations, emergency room visits, and surgeries were not reported for a small number of children in the survey.

Chart 11.
Percentage of children receiving SSI with perceived unmet needs for therapy or service among those with reported needs for therapy or service



SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002. See Table 4.

Chart 12.
Distribution of out-of-pocket expenses for health care services, therapies, and equipment among SSI children during the 12 months before the interview, by amount and type of expenditure



SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002. See Table 4.

Almost all SSI children had some form of health insurance: more than 90 percent had Medicaid coverage, 14 percent were covered through the State Children's Health Insurance Program (SCHIP), and close to 15 percent had private insurance (Table 4).[18] These numbers included children who had more than one type of health insurance, such as Medicaid and private insurance or Medicaid and SCHIP in states that provide dual eligibility for the two programs.

About 90 percent of SSI children visited the doctor at least once during the previous 12-month period (Table 4). Forty-three percent had at least one emergency room visit. Only 18 percent had at least one hospitalization, and 17 percent had at least one surgery during the previous 12-month period. Health care utilization varied significantly by age group. Thirty percent of SSI children aged 0 to 5 had at least one hospitalization (Chart 10) compared with 15 percent of children between the ages of 6 and 17 (authors' calculations based on Table 4). A higher proportion (95 percent) of SSI children aged 0 to 5 were reported to have had at least one doctor visit during the previous year, compared with 88 percent of children aged 6 to 17 (authors' calculations based on Table 4).

More than half of SSI children reported receiving physical, occupational, or speech therapy (Table 4). This was the most frequently reported service category. About 23 percent reported receiving audiology therapy, less than 20 percent reported receiving transportation services, and less than 15 percent reported receiving one of the following three categories of services: recreational therapy, respite care services, or mental health counseling.[19] About 40 percent of SSI children reported receiving more than one of the seven services or therapies presented in Table 4, with those aged 0 to 5 being the most likely to have received multiple services or therapies and those aged 13 to 17 the least likely (not shown).

One of the unique features of the NSCF is that it collects information not only on service utilization but also on perceived need for services. Overall, the reported proportion of children perceived as needing various categories of services ranged from 58 percent for physical, occupational, and speech therapy to 15 percent for respiratory therapy. The ranking of perceived need for services in the various categories did not differ greatly across age groups (Table 4). However, younger children needed physical, occupational, or speech therapy, as well as audiology therapy services, at a much greater rate than did older children. In contrast, the reported frequency of the need for transportation services was about the same for the three age groups, and the perceived need for mental health counseling was somewhat higher in the two older age groups.

Combining the data on actual service utilization and perceived need for services provides a picture of perceived unmet service needs among SSI children. Not all of the children who claimed to need specific services were reported to have received them. For some services, unmet need did not appear to be a major issue. Less than 11 percent of SSI children with perceived needs for physical, occupational, or speech therapy; respiratory therapy; and audiology therapy did not receive them (Chart 11). However, unmet need appeared to be a more substantial concern with respect to other services. For example, nearly 37 percent of SSI children who reported needing mental health counseling did not receive that service. The rate for respite care was even higher—the parents or guardians of 74 percent of SSI children had a perceived need for respite care but did not receive it.

Out-of-pocket health care expenses were measured during the 12 months before the survey for doctor visits, hospital stays, and prescription medicines; physical, occupational, speech, respiratory, recreational, and audiology therapies; transportation services; respite care; mental health care or counseling; and durable medical equipment. For more than 68 percent of SSI children, their parents or guardians did not report any out-of-pocket expenses for the child's health care in those categories during the previous 12 months (Table 4). Among the almost 32 percent who reported out-of-pocket health care expenses in one or more of those categories, the mean amount was $840 and the median was $200 (not shown). Less than 3 percent reported out-of-pocket expenses exceeding $1,000 in either of the two major categories—doctor visits, hospital stays, prescription medications, and mental health care and substance abuse services; and therapies, transportation and respite care services, and durable medical equipment—in the previous 12 months (Chart 12).

Concluding Observations

This article is the first stage of empirical analysis of data from the NSCF. Although the findings are diverse, we conclude our analysis with two overall observations. First, the NSCF provides a rich array of information that adds value to the data that can be obtained from SSA's administrative records on the SSI childhood disability program. Second, the results indicate that disabled children receiving income support from the SSI program are an enormously heterogeneous population. This is true on many different dimensions. Most important, the nature and severity of disabling conditions varies substantially. As a result, the financial needs, health care needs, and service needs of the childhood disability caseload also vary substantially. In addition, the family environment of

SSI children varies in ways that are not directly related to the nature and severity of the child's disabling conditions. Some children live in families with a single parent, others in two-parent families or with grandparents. A very high proportion of SSI children, about half, live in a household with at least one other person reported to have disabilities. While almost half of SSI children live in families without a wage earner, a nontrivial minority live in families whose earnings represent a large proportion of family income. Because of differences in a broad array of family variables, family income relative to the official poverty threshold also varies greatly.

This heterogeneity of the population of SSI children with disabilities presents substantial challenges for the SSI program, as well as for the broader safety net serving these children and their families. From this perspective, it is not surprising that the disabled children portion of the SSI program has been the subject of controversy and policy debates over the years. SSI is a cash assistance program; however, the diversity of the target population suggests the need to consider a broader array of in-kind programs and services as potential tools for serving the needs of children with disabilities. Thus, research on program interactions, the service needs of SSI children, and the interaction of the SSI program with broader social forces such as labor markets and family dynamics will help to inform the policy debate.

This need for comprehensive information is a fundamental reason why further research using the NSCF database is so promising. This article provides a bird's-eye view of the data and only scratches the surface concerning a number of promising research directions. Future research using the NSCF may focus on topics such as

- the utilization of special education and other school-based services by SSI disabled children;
- the relationship between various dimensions of disabilities, service needs, and out-of-pocket medical expenses, especially as they pertain to physical and mental disabilities;
- the effects of the child's disability on parental employment and earnings;
- employment outcomes and educational attainment of young adult SSI recipients; and
- the relationship between family structure and labor market variables and SSI financial eligibility for children.

Given the wealth of information in the NSCF database, these and other topics can be fruitfully explored in more detailed and focused analyses by researchers of the Social Security Administration, as well as by other analysts in the broader policy evaluation and academic research community. This new data set will contribute to the policy debate by supporting research on the design of more efficient and better-targeted policies to serve the needs of children with disabilities, on the long-term implications of such policies on program cost, on moving SSI children with disabilities toward financial independence, and on the productive potential of children with disabilities.

Notes

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[1] In December 2000, almost 13,000 children in the Supplemental Security Income (SSI) program, or 1.5 percent of the childhood caseload, lived in Medicaid institutions.

[2] Mathematica Policy Research, Inc., developed and implemented the survey under a competitively awarded contract with the Social Security Administration. The NSCF questionnaire, User's Manual, and Public-Use File are available at http://www.socialsecurity.gov/disabilityresearch/nscf.htm.

[3] *Moral hazard* in this context refers to the incentive that applicants face to exaggerate the severity of disabilities in order to increase the probability of a successful award. The concept of moral hazard refers to an important technical term in economics denoting circumstances conducive to opportunistic behavior. (See Eatwell, Milgate, and Newman, 1991, Volume 3: 549–551.)

[4] We calculate age as of December 2000, which corresponds to the point of sample selection. At the time of the interview, between July 2001 and June 2002, these sample members were 6 months to 18 months older. Thus, some of the sample members will have aged out of the younger age groups (0–5, 6–12) and into the older age group (13–17) by the time of the interview. Also, some of the sample members will have aged out of our sample completely (that is, reached the age of 18). In addition, we define children receiving SSI (or SSI children) as those who received an SSI payment in December 2000. By the time of the interview, a small proportion of these children were no longer receiving SSI support. Unless otherwise noted, we use these sample definitions throughout the article.

[5] Other important groups in the survey universe include young adults receiving SSI at the time of the survey, children and young adults receiving SSI at the time of welfare reform, and former SSI recipients and denied applicants. Davies and Rupp (2005/2006) provide additional details.

[6] The characteristics of SSI children based on administrative data are presented in two annual reports by SSA's Office of Policy: *Children Receiving SSI* and the *SSI Annual Statistical Report*. Both reports are available at http://www.socialsecurity.gov/policy.

[7] Tables 1 through 4 provide means, percentages, and percentage distributions for the characteristics discussed in the article. Appendix Tables 1 through 4 provide standard errors for selected characteristics presented in Tables 1 through 4. The standard errors in the appendix tables were calculated using a Taylor-series linearization, which accounts for the complex sample design of the NSCF.

[8] Ireys and others (2004, 21) report that the NSCF estimate of the proportion of children receiving SSI who were classified as "Black/African American" is substantially and statistically significantly higher than corresponding estimates from three national surveys, including the Survey of Income and Program Participation (SIPP). Correspondingly, the NSCF estimate of the proportion classified as "White" is lower. We believe that the NSCF estimate is superior for two reasons. First, SSI children are sampled from SSA administrative records, which provide a much more accurate measure of SSI recipient status than the other three surveys in which SSI recipient status may be measured with substantial error. This is important because of the statistical association between race and SSI recipient status. Our interpretation is supported by the fact that once SSI recipient status is established by SSA administrative records rather than by survey reporting, the SIPP estimate of the percentage classified as "Black" comes fairly close to the NSCF estimate. Using SIPP data matched to SSA records, Table 35 in *SSI Annual Statistical Report*, *2004* (2005, 85) reports that 43 percent of SSI children are "Black." Second, according to Ireys and others (2004, Appendix Table 1), the questionnaire item on race in each of the other three surveys lists "White" first; however, the NSCF questionnaire, following OMB guidelines, lists "White" as the last specific race category. Listing "White" first may result in an underestimate of the proportions in the other race categories.

[9] Note that a small portion of cases (about 6 percent) had a missing value on this variable. In general, the percentages in the text were expressed relative to the total and therefore were lower-bound estimates of the unobserved true sample proportions.

[10] The individual education plan (IEP) is a written plan for educational services, which is developed for students with special needs.

[11] To simplify the presentation, the charts in this article do not show the percentage of respondents with missing data for the variable of interest. In most cases, the percentage of respondents with missing data for a given variable is quite small. Readers are referred to the tables for details on the missing data for the relevant variables.

[12] The median total SSI payment for the family of a child receiving SSI overall and for all three age groups was $531 (Table 2). This equals the federal benefit rate (FBR) in 2001 for individual units. The average, of course, is higher but does not reach the level of the FBR for couples in 2001 ($796).

[13] The definition of total liquid assets includes the value of checking accounts, savings accounts, stocks, notes, certificates of deposit, mutual funds, bonds, cash, household items valued in excess of $500, burial accounts, and other assets. The values of the home and vehicles of parents or guardians are excluded from this measure.

[14] The fact that almost 9 percent of SSI children in the NSCF had parents or guardians with $3,000 or more in reported assets might seem puzzling, given that the SSI resource threshold is $2,000 for individuals and $3,000 for couples. Several factors explain this puzzle. First, the measure of assets reported here included items such as household goods and burial funds that would be at least partially excluded when calculating SSI resource eligibility. If those items were removed from the assets of parents or guardians, only 4.3 percent would have reported assets of $3,000 or more. Second, reporting error and imputation error may have affected the NSCF estimates of parent or guardian assets. If all cases were excluded for which total parent or guardian assets were imputed, only 5.3 percent would have reported assets of $3,000 or more. If household items, burial funds, and imputed cases were removed, only 2.7 percent would have reported assets of $3,000 or more.

[15] The distribution of disabilities reported by NSCF respondents differed from SSA administrative data on disability diagnosis for the NSCF sample members in two major areas: the percentage reporting mental retardation and the percentage reporting a physical disability. Compared with the NSCF data presented in Table 3, SSA administrative data identified 61.8 percent of SSI children with a mental disability (including 32.5 percent with mental retardation and 29.2 percent with a mental disability other than mental retardation), 25.4 percent with a physical disability, 7.7 percent with a disability other than mental or physical, and 5.1 percent with a missing disability diagnosis code. If the children identified as mentally retarded in SSA administrative data were removed from the sample, the distribution of disabilities in the NSCF matched very closely the distribution of disabilities in SSA administrative data. This finding might suggest that some respondents were reluctant to report that their child was mentally retarded or that they did not consider mental retardation to be a health condition.

[16] These questions were based on standard survey definitions of functional limitations and did not necessarily reflect program definitions.

[17] Ireys and others (2004, 30) find substantially higher percentages of SSI children who were reported to have had functional limitations than those that we found here. The differences in the estimates are primarily because of different definitions of the analysis sample. Our analysis of the data shows that Ireys and others (2004) reported the percentage of SSI children with a given functional limitation conditional on

reporting the presence of any functional limitation. This is not documented in their report, and it gives the (false) impression that a very large fraction of SSI children have functional limitations. We correctly present the unconditional percentage of SSI children with a given functional limitation.

[18] Ireys and others (2004, 40) report that the estimated proportion of SSI children with Medicaid coverage is substantially higher than the corresponding estimates from three major national surveys. All of these differences are statistically significant. We believe that the NSCF numbers are more accurate for two reasons. First, as previously noted, the measurement of SSI recipient status is more accurate in the NSCF. Second, the *SSI Annual Statistical Report, 2004* (2005, 85) reports that 93 percent of SSI children are covered by Medicaid, a number slightly higher than the NSCF estimate. The 93 percent figure was derived from SIPP data that were matched to SSA administrative records. A logical edit was applied to assign Medicaid coverage to SSI children in states in which all SSI recipients are categorically eligible for SSI.

[19] Respite care services are services provided to parents or other family members to allow them to take a break from the daily responsibilities associated with caring for a child with disabilities.

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Table 1.
Demographic characteristics of children receiving SSI and their families, by age of child

Characteristic	All ages		Number, by age group			Percentage distribution, by age group		
	Number	Percentage distribution	0–5	6–12	13–17	0–5	6–12	13–17
Total	791,954	100.0	154,492	357,538	279,924	100.0	100.0	100.0
			Sex, race, and ethnicity					
Sex								
Male	506,117	63.9	91,419	236,071	178,628	59.2	66.0	63.8
Female	285,838	36.1	63,073	121,468	101,297	40.8	34.0	36.2
Race								
One race reported								
White	373,802	47.2	72,988	167,266	133,548	47.2	46.8	47.7
Black	366,129	46.2	66,567	166,021	133,541	43.1	46.4	47.7
American Indian or Alaska Native	13,202	1.7	2,291	7,537	3,374	1.5	2.1	1.2
Asian or Pacific Islander	9,717	1.2	2,820	4,208	2,688	1.8	1.2	1.0
Multiracial	29,105	3.7	9,826	12,505	6,774	6.4	3.5	2.4
Ethnicity								
Hispanic	128,690	16.3	27,858	62,253	38,579	18.0	17.4	13.8
Not Hispanic	663,264	83.8	126,634	295,285	241,345	82.0	82.6	86.2
			Education					
Currently enrolled in school								
Yes	701,864	88.6	95,367	352,664	253,832	61.7	98.6	90.7
No	48,814	6.2	18,147	4,874	25,793	11.8	1.4	9.2
Missing	41,276	5.2	40,977	0	299	26.5	0	0.1
Special education								
Ever received								
Yes	547,531	69.1	58,805	271,207	217,519	38.1	75.9	77.7
No	197,453	24.9	53,320	84,393	59,739	34.5	23.6	21.3
Missing	46,971	5.9	42,366	1,938	2,666	27.4	0.5	1.0
Received in the past 12 months								
Yes	472,596	59.7	58,805	271,207	142,584	38.1	75.9	50.9
No	182,353	23.0	53,320	84,393	44,639	34.5	23.6	16.0
Missing	137,005	17.3	42,366	1,938	92,701	27.4	0.5	33.1
Individual education plan								
Ever had one								
Yes	536,360	67.7	64,049	272,375	199,936	41.5	76.2	71.4
No	255,594	32.3	90,443	85,163	79,988	58.5	23.8	28.6
Currently has one								
Yes	484,568	61.2	58,258	254,016	172,294	37.7	71.1	61.6
No	236,373	29.9	54,070	89,507	92,797	35.0	25.0	33.2
Missing	71,013	9.0	42,165	14,015	14,833	27.3	3.9	5.3

(Continued)

Table 1.
Continued

Characteristic	All ages		Number, by age group			Percentage distribution, by age group		
	Number	Percentage distribution	0–5	6–12	13–17	0–5	6–12	13–17
				Household				
Living arrangement								
Two parents	231,672	29.3	57,604	101,630	72,437	37.3	28.4	25.9
Single mother	445,555	56.3	87,384	206,008	152,163	56.6	57.6	54.4
Single father	18,773	2.4	779	9,886	8,108	0.5	2.8	2.9
Other older relative	78,388	9.9	8,463	36,881	33,044	5.5	10.3	11.8
Other	13,818	1.7	260	1,839	11,718	0.2	0.5	4.2
Missing	3,749	0.5	0	1,295	2,454	0	0.4	0.9
Number in household								
Two	88,342	11.2	15,132	33,899	39,311	9.8	9.5	14.0
Three	182,145	23.0	37,535	78,010	66,600	24.3	21.8	23.8
Four	204,626	25.8	46,097	92,278	66,251	29.8	25.8	23.7
Five	154,622	19.5	27,805	76,498	50,319	18.0	21.4	18.0
Six	80,455	10.2	15,210	35,709	29,536	9.8	10.0	10.6
Seven	41,846	5.3	7,155	20,625	14,066	4.6	5.8	5.0
Eight or more	38,072	4.8	5,559	20,519	11,994	3.6	5.7	4.3
Missing	1,847	0.2	0	0	1,847	0	0	0.7
Number under age 18 in household								
One	179,003	22.6	36,408	64,722	77,873	23.6	18.1	27.8
Two	239,156	30.2	53,485	105,419	80,251	34.6	29.5	28.7
Three	188,346	23.8	34,854	95,283	58,209	22.6	26.7	20.8
Four	91,519	11.6	16,906	41,034	33,579	10.9	11.5	12.0
Five or more	80,706	10.2	11,050	45,942	23,713	7.2	12.9	8.5
Missing	13,225	1.7	1,788	5,138	6,299	1.2	1.4	2.3
Other household members with disability								
Yes	387,430	48.9	59,187	179,358	148,885	38.3	50.2	53.2
No	396,273	50.0	95,305	176,431	124,537	61.7	49.4	44.5
Missing	8,252	1.0	0	1,749	6,503	0	0.5	2.3

SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002.

NOTE: The absolute numbers in the table refer to estimated population totals. These numbers are derived by applying an appropriate weight to each sample observation and rounding the result to an integer number. Therefore subgroup numbers may not add to the total in some cases.

Table 2.
Monthly family income, assets, and debt of parents or guardians among children receiving SSI, by age of child (in percent unless otherwise noted)

Characteristic	All ages	Aged 0–5	Aged 6–12	Aged 13–17
		Income		
Total family income				
Distribution by dollar amount				
0	0.6	0.4	0.1	1.2
1–499	4.4	3.0	4.6	4.8
500–999	20.2	24.1	19.4	19.0
1,000–1,499	20.4	19.0	19.3	22.5
1,500–1,999	18.5	18.6	18.7	18.2
2,000–2,999	22.7	21.6	24.6	20.9
3,000 or more	13.3	13.3	13.3	13.4
Mean among all children receiving SSI (dollars)	1,818	1,808	1,853	1,780
Median among all children receiving SSI (dollars)	1,612	1,607	1,687	1,545
SSI benefits of family [a]				
Distribution by dollar amount				
1–99	2.3	3.2	2.0	2.3
100–299	6.5	5.0	6.2	7.6
300–499	20.7	21.7	21.2	19.4
500–699	44.5	50.9	44.3	41.3
700–899	3.8	3.3	3.5	4.6
900 or more	22.2	15.9	22.8	24.7
Mean among recipients (dollars)	672	609	689	684
Median among recipients (dollars)	531	531	531	531
Earnings of parent or guardian				
Percentage distribution by dollar amount of earnings				
0	44.9	42.3	43.6	47.9
1–499	3.1	2.9	3.3	2.9
500–999	8.8	8.7	8.8	8.9
1,000–1,499	15.0	18.1	15.4	12.6
1,500–1,999	11.4	9.4	13.1	10.3
2,000–2,999	9.8	9.2	10.0	9.8
3,000 or more	6.5	9.3	5.8	6.0
Missing	0.6	0	0	1.7
Percentage distribution by presence of earnings				
With earnings	54.5	57.7	56.4	50.4
Without earnings	44.9	42.3	43.6	47.9
Missing	0.6	0	0	1.7
Mean among those with earnings (dollars)	1,770	1,843	1,745	1,759
Median among those with earnings (dollars)	1,500	1,452	1,513	1,522
Social Security income of family				
Percentage receiving	13.0	6.4	12.4	17.4
Mean among recipients (dollars)	654	710	629	666
Median among recipients (dollars)	561	700	546	561
Other public assistance of family [b]				
Percentage receiving	14.1	13.8	13.9	14.5
Mean among recipients (dollars)	372	340	401	353
Median among recipients (dollars)	300	300	300	290
Average share of family income from—				
SSI	47.7	46.0	47.4	49.0
Earnings of parent or guardian	38.6	41.8	39.3	35.7
Social Security	4.9	2.6	4.2	7.1
Other public assistance	3.6	3.7	3.7	3.6
Other	5.3	5.9	5.5	4.6

(Continued)

Table 2.
Continued

Characteristic	All ages	Aged 0–5	Aged 6–12	Aged 13–17
		Income (cont.)		
Poverty status of family				
Distribution by poverty status				
Below poverty threshold	44.3	45.4	44.5	43.5
At or above poverty threshold	53.8	53.4	53.9	53.8
Missing	1.9	1.2	1.6	2.6
Distribution by percentage of poverty threshold				
Below 50	15.7	17.8	15.5	14.8
50–99	28.6	27.6	28.9	28.8
100–149	26.0	25.9	25.3	27.1
150–199	15.8	14.0	17.8	14.3
200–299	9.2	9.9	8.5	9.5
300 or more	2.8	3.6	2.4	2.8
Missing	1.9	1.2	1.6	2.6
In-kind transfers of family (percentage receiving)				
Food stamps	31.1	36.6	30.5	28.9
Mean among recipients (dollars)	236	235	249	218
Median among recipients (dollars)	200	200	217	186
Housing assistance	18.5	17.2	19.4	18.1
Energy assistance	19.3	17.2	20.5	18.8
		Assets and debt		
Total liquid assets of parent or guardian [c]				
Distribution by dollar amount				
0	39.1	38.4	38.9	39.8
1–499	34.8	34.1	35.5	34.4
500–999	6.9	7.6	6.8	6.5
1,000–2,999	10.4	10.2	10.7	10.1
3,000 or more	8.8	9.8	8.0	9.2
Mean among all children (dollars)	1,546	1,838	1,316	1,679
Median among all children (dollars)	20	25	20	20
Total debt of parent or guardian [d]				
Distribution by dollar amount				
0	50.0	43.5	51.1	52.2
1–500	5.9	6.2	5.7	6.0
501–1,000	6.9	7.7	7.3	5.9
1,001–5,000	18.4	23.5	17.3	17.1
5,001–10,000	9.7	10.2	9.7	9.3
10,000–25,000	6.4	6.8	6.5	5.9
25,001–50,000	1.8	1.6	1.5	2.4
50,001 or more	0.9	0.5	0.8	1.2
Assets owned by parent or guardian				
Home	36.0	36.2	35.9	36.0
Vehicle	61.6	63.7	62.5	59.2
Investments [e]	3.5	6.0	3.1	2.7
Checking account	36.6	35.8	37.0	36.5
Savings account	30.0	31.3	30.7	28.6

SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002.

NOTE: All income amounts reported in this table are monthly values. Information on assets and debt refer to the month before the interview or the month of the interview. Assets and debt items include assets and debt of parent or guardian and of spouse or partner of the parent or guardian.

a. Data on SSI are restricted to families reporting SSI receipt. Although the sample was drawn from the population of children receiving SSI, 7 percent reported that they were no longer receiving SSI income support at the time they were interviewed. The distribution for this variable was limited to the remaining 93 percent of the observations.

b. "Other public assistance" includes Temporary Assistance for Needy Families (formerly Aid to Families with Dependent Children), general assistance or relief, and other welfare payments received by family members.

c. "Total liquid assets of parent or guardian" includes checking accounts, savings accounts, stocks, notes, certificates of deposit, mutual funds, bonds, cash, household items valued in excess of $500, burial accounts, and other assets. This variable does not include the value of the home or vehicle.

d. "Total debt of parent or guardian" includes debt from credit cards, medical debts, and loans. It excludes vehicle debt and mortgage.

e. "Investments" refers to stocks, mutual funds, bonds, certificates of deposit, and notes.

Table 3.
Disability and health status of children receiving SSI, by age of child

Characteristic	All ages	Aged 0–5	Aged 6–12	Aged 13–17
		Percentage distribution		
Reported general health status				
Poor	9.1	8.3	9.8	8.6
Fair	30.1	31.3	30.8	28.5
Good	33.4	34.2	31.4	35.7
Very good	15.6	17.5	14.8	15.6
Excellent	11.5	8.5	13.0	11.2
Missing	0.3	0.4	0.3	0.4
Severity of health condition				
High	53.5	51.5	54.7	52.9
Moderate	32.5	32.0	33.5	31.5
Mild	9.7	10.2	9.2	10.0
No health condition reported	2.3	4.1	1.2	2.8
Missing	2.1	2.2	1.5	2.7
Disability affects ability to do things—				
A great deal	36.4	33.7	38.1	35.8
Some	41.4	40.5	43.7	39.0
Very little	18.8	20.8	16.3	20.8
No disability reported	2.1	3.7	1.0	2.5
Missing	1.3	1.3	0.9	1.8
Number of functional limitations reported—				
Zero	a	a	61.3	77.3
One	a	a	6.0	5.3
Two	a	a	12.2	5.8
Three to six	a	a	20.5	11.6
Mean number of limitations among children with one or more limitations	a	a	3	3
		Percentage reporting		
Type of disability [b]				
Any physical disability	43.5	62.8	41.3	35.7
Any mental disability	50.4	21.7	56.0	59.2
Mental retardation	7.9	2.5	8.3	10.4
Mental disability (other than mental retardation)	44.2	19.8	49.4	51.1
Other	14.8	23.2	14.3	10.9
None reported	0.4	0.4	0.3	0.6
Missing	2.8	4.5	1.3	3.9
Functional limitations				
Need help [c]—				
Getting in or out of bed	a	a	9.9	6.8
Getting around inside home	a	a	8.7	6.0
Using or getting to toilet	a	a	16.9	9.6
Eating	a	a	14.2	8.4
Bathing or showering	a	a	34.3	18.9
Dressing	a	a	33.0	18.2

SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002.

a. Data on functional limitations were collected only for NSCF sample members aged 6 or older.

b. Up to three health problems or conditions were coded in the NSCF. Because sample members can have more than one health problem or condition, the disability categories and subcategories are not mutually exclusive. Therefore, the percentages do not add to 100.

c. Sample members may need help with more than one function. Therefore, the categories under "Functional limitations, Need help" are not mutually exclusive and exhaustive, and percentages do not add to 100.

Table 4.
Health insurance, health service utilization, and out-of-pocket expenses among children receiving SSI, by age of child

Characteristic	All ages	Aged 0–5	Aged 6–12	Aged 13–17
		Health insurance		
Percentage distribution by coverage				
Yes	98.3	98.6	98.8	97.6
No	1.7	1.4	1.2	2.5
Percentage reporting specified type of insurance [a]				
Medicaid	90.4	90.1	90.1	90.9
SCHIP	14.0	15.7	14.2	12.9
Private	14.8	17.6	14.2	13.8
		Health service utilization		
Percentage distribution by number of doctor visits in the past 12 months				
Zero	6.6	2.2	6.3	9.4
One	10.3	3.6	11.1	13.1
Two	11.4	7.3	12.5	12.2
Three	10.0	8.9	9.7	11.1
Four	9.5	8.0	9.4	10.3
Five or more	48.4	66.8	47.7	39.3
Missing	3.8	3.3	3.4	4.6
Percentage distribution by number of hospitalizations in the past 12 months				
Zero	81.4	68.6	84.1	85.0
One	7.9	11.6	7.2	6.6
Two	3.7	6.0	3.5	2.6
Three or more	6.4	12.6	5.0	4.9
Missing	0.7	1.3	0.3	0.8
Percentage distribution by number of emergency room visits in the past 12 months				
Zero	56.0	39.7	58.5	61.9
One	16.1	18.5	16.4	14.4
Two	10.9	13.9	10.7	9.5
Three or more	15.6	25.9	13.1	13.1
Missing	1.4	2.0	1.3	1.2
Percentage distribution by number of surgeries in the past 12 months				
Zero	82.5	70.5	85.2	85.7
One	11.9	18.1	10.0	10.7
Two	2.6	4.9	1.9	2.3
Three or more	2.5	5.7	2.3	1.0
Missing	0.5	0.8	0.5	0.3
Percentage reporting services or therapies received [a]				
Physical, occupational, speech	51.3	65.5	58.0	34.9
Respiratory	13.7	26.5	12.6	7.9
Recreational	12.9	15.9	14.0	9.9
Audiology	22.7	34.7	24.6	13.6
Transportation	19.3	19.9	19.3	19.1
Respite care	7.5	9.0	8.4	5.5
Mental health counseling	13.7	11.6	14.6	13.8

(Continued)

Table 4.
Continued

Characteristic	All ages	Aged 0–5	Aged 6–12	Aged 13–17
Percentage reporting perceived need for services or therapies [a]				
Physical, occupational, speech	57.5	70.8	63.7	42.3
Respiratory	14.5	27.4	13.7	8.5
Recreational	18.4	19.6	20.6	15.0
Audiology	24.9	37.1	27.1	15.2
Transportation	25.7	25.3	25.9	25.6
Respite care	28.6	29.5	31.5	25.0
Mental health counseling	21.6	18.6	22.9	21.8
Percentage reporting unmet need among those with perceived need [a]				
Physical, occupational, speech	10.9	7.6	9.0	17.4
Respiratory	5.9	3.4	7.7	6.5
Recreational	29.9	19.0	32.0	34.0
Audiology	8.7	6.6	9.2	10.4
Transportation	24.7	21.7	25.3	25.5
Respite care	73.9	69.6	73.3	77.8
Mental health counseling	36.5	37.3	36.2	36.6
		Out-of-pocket expenses		
Percentage distribution of presence of out-of-pocket expenses for health care, therapies, services, or equipment				
Yes	31.6	38.3	30.0	30.0
No	68.4	61.7	70.0	70.0
Percentage distribution by dollar amount of out-of-pocket expenses for doctors, hospitals, medications, and mental and substance abuse services [b]				
0	76.0	70.7	77.4	77.3
1–99	7.6	7.1	7.5	7.8
100–199	4.0	5.2	4.1	3.3
200–499	6.2	8.6	5.8	5.4
500–999	3.4	4.6	3.3	2.9
1,000 or more	2.7	3.9	1.8	3.3
Percentage distribution by dollar amount of out-of-pocket expenses for therapies, services, or equipment [c]				
0	85.0	80.4	85.7	86.8
1–99	4.7	6.5	3.9	4.8
100–199	2.4	2.9	2.5	2.0
200–499	3.8	4.8	3.5	3.5
500–999	2.1	2.8	2.4	1.3
1,000 or more	2.0	2.7	2.0	1.7

SOURCE: National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002.

a. Sample members may report on more than one category. The categories are not mutually exclusive and exhaustive, and the percentages do not add to 100.

b. Amount that was paid in past 12 months on physical health care (includes doctor visits, hospital stays, prescription medications) and mental health care (includes both inpatient and outpatient care).

c. Sample members' total out-of-pocket expenditures for all services or equipment in the past 12 months (includes physical, occupational, or speech therapy; respiratory therapy; recreational therapy; audiology therapy; transportation services; respite care; mental health counseling; and durable medical devices).

Table A-1.
Estimated standard errors of selected demographic characteristics of children receiving SSI, by age of child

Characteristic	All ages	Aged 0–5	Aged 6–12	Aged 13–17
		Sex, race, and ethnicity		
Percentage male	0.6	2.2	0.9	1.4
Percentage black alone	2.7	3.5	2.8	3.2
Percentage Hispanic	1.9	2.3	2.1	2.0
		Education		
Percentage currently enrolled in school	0.6	1.9	0.4	0.8
Percentage receiving special education				
Ever	1.1	2.2	1.6	1.4
In the past 12 months	1.1	2.2	1.6	1.3
Percentage with an individual education plan at time of interview	1.4	2.1	1.6	2.0
		Family and household		
Percentage living with—				
Two parents	1.4	2.2	1.9	1.8
Mother only	1.4	2.6	1.6	1.8
Percentage in—				
Two-person household	0.5	1.3	0.8	0.8
Three- or four-person household	1.0	2.1	1.4	1.5
Percentage with—				
One person under age 18 in household	0.9	1.9	1.1	1.4
Five or more persons under age 18 in household	0.8	1.2	1.2	0.9
Percentage living with other household member with disability	0.9	2.1	1.5	1.5

SOURCE: Authors' calculations from the National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002.

NOTE: The standard errors were calculated using a Taylor-series linearization, which accounts for the complex sample design of the NSCF.

Table A-2.
Estimated standard errors of selected variables for monthly family income, assets, and debt of parents or guardians among children receiving SSI, by age of child

Characteristic	All ages	Aged 0–5	Aged 6–12	Aged 13–17
		Income		
Total family income				
Percentage with less than $1,000	1.1	2.0	1.6	1.2
Percentage with $2,000 or more	1.3	2.5	1.6	1.7
Mean among all children receiving SSI (dollars)	35.3	57.8	47.5	42.0
Total SSI benefits of family [a]				
Percentage with less than $300	0.6	1.2	0.8	0.9
Percentage with $900 or more	0.7	1.9	0.9	1.4
Mean among recipients (dollars)	10.0	18.6	13.9	15.8
Earnings of parent or guardian				
Percentage with no earnings	1.1	1.8	1.6	1.4
Percentage earning $1,500 or more	1.2	2.1	1.5	1.6
Mean among those with earnings (dollars)	41.6	77.8	54.8	59.9
Social Security income of family				
Percentage receiving	0.7	1.3	1.0	0.8
Mean among recipients (dollars)	20.6	54.3	36.0	23.7
Other public assistance of family [b]				
Percentage receiving	0.8	1.7	0.9	1.3
Mean among recipients (dollars)	21.6	29.6	31.5	32.2
Average share of family income from—				
Earnings of parent or guardian	0.8	1.4	1.3	1.2
SSI	0.8	1.4	1.1	1.2
Poverty status of family				
Percentage in poverty	1.3	2.0	1.7	1.6
Percentage below 50% of poverty threshold	0.8	1.6	1.3	1.2
Percentage above 200% of poverty threshold	0.9	1.7	1.0	1.3
In-kind transfers of family				
Food stamps				
Percentage receiving	1.1	2.0	1.3	1.6
Mean among recipients (dollars)	6.1	14.1	9.9	8.0
Housing assistance (percentage receiving)	0.9	1.9	1.3	1.3
Energy assistance (percentage receiving)	1.3	1.8	1.5	1.6

(Continued)

Table A-2.
Continued

Characteristic	All ages	Aged 0–5	Aged 6–12	Aged 13–17
		Assets and debt		
Total liquid assets of parent or guardian [c]				
Percentage with no assets	1.0	2.2	1.3	1.3
Percentage with $3,000 or more	0.6	1.5	0.9	0.8
Mean among all children receiving SSI (dollars)	167.4	424.8	199.7	237.8
Total debt of parent or guardian [d]				
Percentage with no debt	1.3	2.2	1.4	1.8
Percentage with debt of $5,001 or more	1.0	1.8	1.2	1.6
Assets owned by parent or guardian (percentage owning)				
Home	1.2	2.2	1.5	1.5
Vehicle	1.7	2.6	1.9	2.3
Investments [e]	0.5	1.4	0.6	0.5
Checking account	0.9	2.2	1.3	1.3
Savings account	1.2	2.7	1.3	1.6

SOURCE: Authors' calculations from the National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002.

NOTES: The standard errors were calculated using a Taylor-series linearization, which accounts for the complex sample design of the NSCF.

All income amounts reported in this table are monthly values. Information on assets and debt refer to the month before the interview or the month of the interview.

a. Data on Supplemental Security Income (SSI) is restricted to families reporting SSI receipt. Although the sample was drawn from the population of child SSI recipients, 7 percent reported that they were no longer receiving income support at the time they were interviewed.

b. "Other public assistance" includes Temporary Assistance for Needy Families (formerly Aid to Families with Dependent Children), general assistance or relief, and other welfare payments received by family members.

c. "Total liquid assets of parent or guardian" includes checking accounts, savings accounts, stocks, notes, certificates of deposit, mutual funds, bonds, cash, household items valued in excess of $500, burial accounts, and other assets. This variable does not include the value of the home or vehicles.

d. "Total debt of parent or guardian" includes debt from credit cards, medical debts, and loans. It excludes vehicle debt and mortgage.

e. "Investments" refers to stocks, mutual funds, bonds, certificates of deposit, and notes.

Table A-3.
Estimated standard errors of selected characteristics of disability and health status of SSI children, by age of child

Characteristic	All ages	Aged 0–5	Aged 6–12	Aged 13–17
Percentage with[a]—				
Any physical disability	0.8	1.8	1.3	1.4
Mental disability (other than mental retardation)	0.8	1.4	1.3	1.3
Percentage with reported general health status as—				
Poor or fair	1.2	2.2	1.7	1.3
Very good or excellent	1.0	1.7	1.6	1.0
Percentage with severity of health condition reported as—				
High	1.2	2.7	1.7	1.5
Mild or not reporting a health condition	0.7	1.6	1.0	1.0
Functional limitations				
Percentage needing help—				
Getting in or out of bed	b	b	0.9	0.7
Getting around inside home	b	b	0.8	0.6
Using or getting to the toilet	b	b	0.9	1.0
Eating	b	b	1.2	0.8
Bathing or showering	b	b	1.2	1.2
Dressing	b	b	1.4	1.1
Percentage with—				
Zero limitations	b	b	1.3	1.2
Three to six limitations	b	b	1.2	1.1
Percentage reported by parent or guardian that disability affects ability to do things—				
A great deal	1.2	1.9	1.5	1.5
Very little or no disability reported	0.8	1.9	1.0	1.2

SOURCE: Authors' calculations from the National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002.

NOTE: The standard errors were calculated using a Taylor-series linearization, which accounts for the complex sample design of the NSCF.

a. Up to three health problems or conditions were coded in the NSCF. Because sample members can have more than one health problem or condition, the disability categories are not mutually exclusive.

b. Data on functional limitations were collected only for NSCF sample members aged 6 or older.

Table A-4.
Estimated standard error of variables for health insurance, health service utilization, and out-of-pocket expenses among children receiving SSI, by age of child

Characteristic	All ages	Aged 0–5	Aged 6–12	Aged 13–17
		Health insurance		
Percentage with specified type of insurance				
Medicaid	1.0	1.5	1.4	1.0
SCHIP	1.5	2.2	1.7	1.3
Private	0.7	1.8	1.0	1.0
		Health service utilization		
Percentage with doctor visits in the past 12 months numbering—				
Two or less	1.0	1.2	1.5	1.7
Five or more	1.1	1.9	1.4	1.7
Percentage with at least one hospitalization in the past 12 months	0.6	1.8	0.9	1.0
Percentage with emergency room visits in the past 12 months numbering—				
Zero	0.9	2.0	1.2	1.6
Three or more	0.6	2.3	0.9	0.9
Percentage with at least one surgery in the past 12 months	0.6	2.0	0.9	0.9
Percentage receiving specified services or therapies				
Physical, occupational, speech	1.2	2.4	1.5	1.3
Respiratory	0.6	1.7	1.0	0.7
Transportation	0.8	2.0	1.3	1.1
Respite care	0.6	1.5	0.9	0.7
Mental health counseling	0.7	1.2	1.0	1.0
Percentage with perceived need for specified services or therapies				
Physical, occupational, speech	1.1	2.3	1.4	1.4
Respiratory	0.6	1.7	1.0	0.8
Transportation	1.0	2.2	1.4	1.1
Respite care	1.1	1.7	1.4	1.4
Mental health counseling	0.7	1.6	1.2	1.1
		Out-of-pocket expenses		
Percentage with any out-of-pocket expenses for health care, therapies, services, or equipment	1.0	1.9	1.6	1.5
Percentage with amount of out-of-pocket expenses for doctors, hospitals, medications, and mental and substance abuse services as [a]—				
$0	0.9	1.8	1.4	1.6
$200 or more	0.7	1.7	0.9	1.2
Percentage with amount of out-of-pocket expenses for therapies, services, or equipment as [b]—				
$0	0.8	1.8	1.0	1.1
$200 or more	0.6	1.2	0.8	0.7

SOURCE: Authors' calculations from the National Survey of SSI Children and Families (NSCF), interviews conducted between July 2001 and June 2002.

NOTE: The standard errors were calculated using a Taylor-series linearization, which accounts for the complex sample design of the NSCF.

a. Amount that was paid in past 12 months on physical health care (includes doctor visits, hospital stays, and prescription medications) and mental health care (includes inpatient and outpatient care).

b. Sample members' total out-of-pocket expenditures for all services or equipment in the past 12 months (includes physical, occupational, or speech therapy; respiratory therapy; recreational therapy; audiology therapy; transportation services; respite care; mental health counseling; and durable medical devices).