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# Survey of Disabled Children Under SSI Program\*

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The Office of Research and Statistics, under a contract with Urban Systems Research and Engineering, Inc., performed a national personal survey of blind and disabled children receiving supplemental security income (SSI) benefits. The purpose of the survey was to provide descriptive characteristics of the children and their families as well as assess SSI's effect on them. The survey has provided the research community with some interesting results. Not all children in the program live in families. Almost 15 percent of the children surveyed were not living with their parents; many of them were in foster care families or group homes. SSI children live in low-income families. Almost two-thirds of them live in families with annual income (including the child's benefit) of less than \$7,000. Not only are the children handicapped, but a sizable number of children are in households where another person is also disabled and/or receiving SSI payments. Three-fourths of the families have had exposure to the welfare systems. Many of them have received or are receiving benefits from one or more of the following programs—AFDC, Medicaid, and food stamps. Many families report that they are satisfied with SSI because in many instances the amount of the benefit meets the needs of the child and the program is administered with few forms and by staff who treat them courteously. A summary of the survey report is presented in the article that follows.

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Until the onset of the supplemental security income (SSI) program in 1974, disabled children in low-income families were not eligible in their own right for any type of Federal/State financial assistance (with the exception of blind children in a few States). Even then, there was debate over whether they should be included in the SSI legislation, and the main point of disagreement was whether disabled children have greater financial needs than those of low-income children in general. Unless greater need could be shown, some legislators felt the provisions of the AFDC program for all low-income children to be adequate for the handicapped as well.

## Background

The debate over the inclusion of children in the SSI program revealed how little has been known about the situation of disabled children in poor families—what their

living expenses are, what handicaps they have, whether they receive adequate medical care, whether they attend school, what service needs they have, and what impact they have on their parents' work and financial status. Nevertheless, Congress decided to include them in the program, and 200,489 children under age 21 were receiving SSI benefits by February 1979. They constitute 5 percent of the total SSI population.

In recognition of the need to better understand this new group of beneficiaries, the Office of Research and Statistics of the Social Security Administration sponsored a baseline survey of children enrolled in the SSI program. Four areas of inquiry were established for the study:

- A basic socioeconomic and demographic descriptive analysis of SSI children and their families.
- A descriptive analysis of the disabilities of SSI children, the dysfunction that the disabilities cause, and the impact of the disability on the child's family.
- An assessment of the SSI experience and the impact of SSI benefits on handicapped children, and
- A descriptive analysis of the extent to which the other needs of SSI children beyond cash assistance are being met

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\*Survey of SSI Children, Executive Summary. Project Director for Urban Systems Research and Engineering, Inc., was Marilyn P. Rymer; Project Director for the Office of Research and Statistics was Michael C. Staren. The full report will be available early in 1980.

by the children's families and various public and private programs.

To meet these objectives, personal interviews were undertaken in the summer of 1978 with the representative payees of some 1,853 children receiving SSI benefits. Cases were selected to form a representative national sample of SSI children for the continental United States. Children were defined to be those under age 18 and not living in Medicaid institutions at the time the sample was drawn. The interviews were conducted by using a structured questionnaire. Interview time averaged around 45 minutes.

## Who Are SSI Children And What Are Their Families Like?

It is impossible to describe the average SSI child. In fact, study findings point to two significant groupings of SSI children—those living at home with their families and those living in foster care or other protective settings. Until the survey sample was drawn, the actual proportions of these groups were not known, but the sample showed that 15 percent of all SSI children are under the protective custody of State welfare departments or other social welfare agencies or institutions. This is in itself an important finding because it has not been generally recognized that such a substantial proportion of SSI children are in foster-care settings.

Since these children under protective custody (hereafter called Group B children) were found to differ significantly from those children living with their families (Group A children), survey results are presented distinguishing between the two groups.

**Characteristics of Group A children.** Group A children average 11.4 years in age. More Group A children are male (58 percent) than female (42 percent). Group A children are most likely to be white (44 percent), but the group has a greater proportion of minorities than the general or low-income populations of children. The average household size for Group A children is five persons (including the SSI child). In just over half the households (57 percent), the mother is the only parent present. One-third of the children have both parents in the home. Most live in rental housing (63 percent). Group A SSI children are more mobile than the general population with 16 percent of them having moved in the last year.

The families of Group A children have to be poor to meet program requirements. The variation in benefit levels by State and the deeming provisions for earned income would, however, theoretically permit the families of at least some SSI children to have incomes above \$20,000. Yet study results show that most SSI children are living in very poor households. Sixty-one percent of the families had incomes of less than \$7,000 annually. Only 3 percent reported yearly incomes above \$14,000.

A key indicator of the low-income status of many of the households is that 42 percent of the cases reported receiving

income during the previous year from the AFDC program or general assistance. This degree of overlap with other income security programs was not an expected finding.

Three other annual income sources were reported frequently: Earnings (mothers in 24 percent of the households and fathers in 25 percent<sup>1</sup>); SSI payments for another household member other than the survey child (25 percent of the households); and social security, black lung, or railroad retirement benefits (24 percent of the households). Also at the point of the survey, 43 percent of the households were receiving food stamp benefits.

Among parents living with the SSI child, the father is likely to be employed while the mother is not. Fathers of most SSI children (65 percent) are not in the home, however. Their employment status was not ascertained in the study, but only 9 percent of the households received child support or alimony during the year before the survey.

The reason most mothers gave for not working was that they were needed in the home for child care. Nevertheless, the mothers of SSI children show a slightly greater labor-force participation rate than AFDC mothers (19 percent and 17 percent, respectively).

The parents of Group A children are much less educated than the general population of adults. Mothers averaged 9.6 years of school, compared with 8.8 years for the fathers. For the general population of adults, the mean is 12.4 years.

**Characteristics of Group B children.** Group B children average 12.5 years in age, just a year older than the Group A children. Like the Group A children, the majority of Group B children (59 percent) were male. Group B children show a significantly different racial distribution than Group A. A substantial majority of Group B children are white (71 percent), compared with only 44 percent of Group A children.

As mentioned earlier, most Group B children live in a foster-care setting. On the average, they have lived away from their families for 7.5 years. The average number of foster-care placements per child is 2.4. Most of these children have little or no contact with their parents, yet in almost all cases, the parents are still living. In two-thirds of the cases, the children were placed voluntarily in foster care by their families. In only 8 percent of the cases was it reported that the child would be likely to return to his/her family. Ironically, of the remaining children only 20 percent are eligible for adoption.

Payees had very little financial and work information on the parents of Group B children. Not surprisingly then, only a few children are receiving any support from their mothers or fathers. According to the survey results, more children receive social security (31 percent), State foster-care payments (30 percent), and other types of assistance (31 percent) than receive help from their parents (23 percent). Work status and income information could not be obtained from the parents of enough Group B cases to draw any reliable conclusions.

<sup>1</sup> Fathers were present only in 35 percent of the households.

## What Are the Disabilities of SSI Children?

Survey respondents were asked two key questions about the SSI child's disability—what they considered the child's main disability to be and what other disabilities (if any) the child had. The answers to these questions indicate that the majority of SSI children have multiple handicaps. Fifty-three percent of the respondents indicated that their SSI child has another handicap(s) in addition to what they consider to be the main disability.

The data on the main disabling conditions show mental retardation<sup>2</sup> to be the most frequently occurring main disability (27 percent of the cases). Fifteen percent indicated "other diseases of the nervous system" as the main handicap. This grouping covers several conditions including epilepsy, brain disease, other paralysis, meningitis, muscular dystrophy, and multiple sclerosis. Another 15 percent reported "other mental conditions" to be the main handicap. Included in this classification are psychosis, schizophrenia, neurosis, personality disorders, alcoholism, drug problems, speech defects, hearing defects, and hyperactivity. Congenital anomalies, such as spina bifida, Down's syndrome, hydrocephalus, and mongolism, were reported as the main problem by 11 percent of the cases. All other disability categories were experienced by fewer than 10 percent of the cases as the major handicap.

Analysis of the data on secondary handicaps shows that many cases (20 percent) experience "other mental conditions" as a handicap in addition to their main handicap. Twelve percent of all the survey cases said they had "other diseases of the nervous system" as a secondary handicap.

When the data on main and secondary disabilities are combined, the most frequently occurring type of disability is "other mental conditions," reported by 35 percent of the cases. Equally significant, 34 percent of the cases reported mental retardation as a handicap, either main or secondary. The third most frequently mentioned disability type was "other diseases of the nervous system" (28 percent). Sixteen percent of SSI children have congenital anomalies; 12 percent are deaf, and 10 percent have cerebral palsy. All other disability categories were experienced by fewer than 10 percent of the survey children as either a main or secondary handicap.

The disability pattern for mental retardation varies substantially for Group A and Group B children. The majority of Group B children (52 percent) reported mental retardation as their main disability, compared with only 24 percent of Group A children. Group B children are also more likely to have multiple handicaps.

The disabilities of most SSI children are apparent at an early age, according to survey respondents. Over half had handicaps diagnosed before their third birthday. Most of the respondents said that their children had been born with their disabilities.

<sup>2</sup> The categorization system of the International Classification of Diseases was used to code survey responses on types of disabilities.

A series of age-related questions were asked in the survey to assess the functional repercussions of each child's handicap(s). The questions measured the extent to which SSI children can carry out activities that nonhandicapped children do with ease, such as playing, walking, lifting objects, feeding themselves. The responses to these questions were then used to compile a dysfunction scale for SSI children by three different age groups. For each scale, the fewer points a child received, the more dysfunctional he/she was found to be.

SSI children aged 0–4 averaged only 2.0 points out of a possible 6 points. Most of the survey children in this age group, for example, cannot take part in ordinary play.

Children aged 5–18 averaged 7.1 out of 12 points, thus faring somewhat better than the younger age group. One-third of these children, however, are not able to take part in ordinary play. Over half have trouble walking several blocks or climbing several flights of stairs. In fact, almost half need more help in bathing, eating, dressing, or going to the toilet than one would expect for children their age.

A 2-point scale was used for children aged 16 and older, with the average score at 0.8 points. Just over a third of these older SSI children are not able to do any type of work, including housework or odd jobs.

One of the most interesting disability-related survey findings is the high incidence of other disabled persons in the families of SSI children:

- 21 percent of SSI children have handicapped parents (either one or both)
- 24 percent of SSI children have a handicapped sibling.

In fact, 15 percent of the Group A children had another sibling receiving SSI payments. This high incidence of multiple SSI children in households was an unexpected survey result.

## How Well Is SSI Working For Children?

Two major issues are involved in asking this question: (1) the adequacy of SSI benefits and (2) the administrative performance of the program with regard to children. The highlights of the findings in these areas are presented below.

**Adequacy of SSI benefits.** Congressional debate over including children in the SSI program mainly focused on whether or not disabled children have greater financial needs than other low-income children. Survey results indicate that indeed there are extra costs involved in caring for disabled children. Transportation, clothes, and medical care were the three major types of extra expense cited by survey respondents, with around 20 percent of the sample reporting extra costs in these areas in the month before the survey. Although expenditures for school, babysitting, and special equipment were not reported by as many survey respondents, for those who did report them they were expensive.

Cost data were not collected on all types of "extra"

monthly expenses since some—such as clothing and transportation—are experienced normally by all children. It is thus difficult to isolate the extra costs for a handicapped child. Estimates were obtained for several other expense categories. Results show that, overall, each SSI child averages monthly extra out-of-pocket expenses of \$7.08 for health care costs, \$4.69 for school, \$4.40 for babysitting, \$3.31 for special equipment, and \$8.21 for other expenses—according to their payees. The total monthly extra cost comes to \$27.69. It is important to note that this is an overall average and that some handicapped children in fact have no extra monthly expenses while others have substantially more than this average.

These cost data substantiate the contention that disabled children cause their parents to incur extra costs in providing for their care. Some question does arise as to whether the extra costs are equal to the difference between the SSI benefit level and the benefit level available to low-income children on AFDC. Even if the extra costs documented through the survey are doubled or tripled to account for the extra costs not estimated (such as transportation and clothing), the difference between the two levels is still substantial. To illustrate, the highest marginal amount paid in AFDC for the second child in a low-income family of three in July of 1978 was \$81 in Connecticut. The SSI benefit for a disabled child at this time was \$189, a difference of \$108. Survey results do not show the extra costs of raising a handicapped child to be nearly that high. Therefore, although the survey data substantiate that disabled children have extra maintenance costs, they also point to the continuing inadequacy of the benefits paid to low-income children on AFDC. Until that inadequacy is rectified, SSI children are in some ways a favored group of low income children according to Federal income security policy.

Respondents were directly questioned about the adequacy of the SSI grant for meeting their disabled children's needs, and two-thirds of the Group A payees indicated that the SSI grant does cover the basic costs of care. Group B respondents were not so inclined, with only 38 percent reporting the payment level to be adequate.

**Administrative performance.** The SSI program appears to be working reasonably well, according to survey respondents. Relatively few cases (10 percent) experienced problems with the application process. Also few (13 percent) reported any problems after they received their first SSI check.

Cases having previous experience with State welfare agencies were asked to compare the two programs, and the majority (80 percent) gave SSI a more favorable review. Although many said they liked SSI better than welfare because the benefits are higher, even more reported they preferred SSI because the general attitudes of the people at the SSI office are better and because SSI takes less time, fewer forms, and is less confusing.

Survey results pointed to two areas in which SSA's performance appears to warrant improvement. First, only 2

percent of all survey cases reported that they received any emergency assistance from SSA while their applications were being processed. A \$100 emergency grant is supposed to be available to all cases needing it, and some 10 percent of the cases said they were experiencing an emergency at the point of application. It appears that this benefit is not being properly administered, since most of the cases were not even aware of its availability.

A second area in which SSA could improve is in its role as information and referral source for SSI children. Only 6 percent of the payees for Group A children said SSA had told them about other programs or agencies that they didn't know about before.

### **What About the Other Needs of SSI Children?**

The needs of disabled children do not end with cash assistance. Certainly their needs for health care, education, and social services are an important concern in making sure that they are able to achieve their full potential. Survey questions delved into each of these areas to assist in future planning efforts with regard to low-income handicapped children.

**Health care.** In the Congressional hearings leading to the passage of SSI, it was acknowledged that a critical need for handicapped children is adequate health care. Survey results show that SSI children utilize medical services at a considerably greater rate than nonhandicapped children. On the average, the SSI child visits a physician 11.4 times a year. Nonhandicapped children under age 6 years see a physician about 6.3 times a year, while those aged 6–16 only average three visits a year.<sup>3</sup> The SSI child is also hospitalized about once every 2 years on the average.

In spite of these higher utilization rates, some survey results suggest that the health care available to SSI children may not be fully adequate. First of all, 15 percent of the children surveyed do not receive Medicaid benefits. States have several options regarding Medicaid eligibility, and some have chosen not to extend it to disabled children. Some of these children said they were able to get free medical care elsewhere, but it appears that 11 percent of all SSI children remain without medical coverage.

Second, when asked if there was any service, treatment, or thing that the SSI child was doing without because of a lack of money, 11 percent of the respondents indicated that their child was doing without needed health care. In fact, additional health care was the most frequently mentioned unmet need due to cost.

**Education.** Increasing emphasis has been placed in recent years on the importance of education to handicapped children, and particularly "mainstreaming" them—that is, getting them into a school setting with nonhandicapped children when possible. Survey findings indicate that almost all SSI children of school age are enrolled in an educational

<sup>3</sup> 1976 data from National Center for Health Statistics.

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or training program; few are attending regular classes with nonhandicapped children. For the children aged 6 and older, just over half are in special schools for the handicapped, with most of the remainder in regular public schools. Most SSI children in regular schools are not "mainstreamed." Instead, the majority spend the day in special classes for the handicapped.

For the children under age 6, 60 percent attend school, with an additional 27 percent reported by their payees as too young to be in any school. As with the older children, most (63 percent) are in special schools for the handicapped. Only 11 percent of the younger in-school SSI children surveyed are in a Head Start program.

**Social Services.** The social service status of SSI children is a final area of concern. Payees were asked whether their SSI child was now receiving or had ever received certain types of social services. The most frequently reported public social service for Group A children turned out to be supportive health services—that is, assistance in obtaining medical care—with 25 percent of the children utilizing this service. Counseling and transportation were the most frequently used public services by Group B children, again

with a 25 percent utilization rate. Survey data suggested no strong pattern of service-utilization change since the implementation of SSI.

Respondents were also asked whether there were any unmet social service needs. The service need most frequently mentioned for both groups of children was for recreation services such as camp.

## Conclusion

The SSI Children Survey has made available a considerable amount of descriptive information on SSI children for use by policymakers and program analysts. The findings reviewed in this summary have been directed to the basic research questions that prompted the study. Still further analysis can be undertaken with the data to investigate in greater depth particular policy concerns. A public use data tape has been prepared that combines the survey data on each child with selected data from the child's SSI record file. This data base provides a significant opportunity for thorough research in the future regarding policies that may affect handicapped children in low-income families.