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SSI CHILDREN

Multiple Factors Affect Families' Costs for Disability-Related Services





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The Honorable William V. Roth, Jr.
Chairman
The Honorable Daniel Patrick Moynihan
Ranking Minority Member
Committee on Finance
United States Senate

The Honorable Bill Archer
Chairman
The Honorable Charles B. Rangel
Ranking Minority Member
Committee on Ways and Means
House of Representatives

This report, entitled SSI Children: Multiple Factors Affect Families' Costs for Disability-Related Services (GAO/HEHS-99-99), responds to the mandate in Public Law 104-193, the Personal Responsibility and Work Opportunity Reconciliation Act, that we report on the disability-related expenses incurred by families of children on Supplemental Security Income (SSI) that are not covered by federal, state, and local programs serving children with disabilities. In this report, we provide data on families' total annual disability-related costs and the factors that influence the level of such costs. We also identify factors affecting families' receipt of disability-related services from other programs.

We are sending copies of this report to The Honorable Kenneth S. Apfel, Commissioner of Social Security; The Honorable Richard W. Riley, Secretary of Education; The Honorable Donna E. Shalala, Secretary of Health and Human Services; and others who are interested. We will also make copies available to others upon request.

Please contact me on (202) 512-7215 if you or your staff have any questions concerning this report. Other GAO contacts and staff acknowledgments for this report are listed in appendix III.

Cynthia M. Fagnoni
Director, Education, Workforce, and
Income Security Issues

Executive Summary

Purpose

The Congress established the Supplemental Security Income (SSI) program, which is administered by the Social Security Administration (SSA), in 1972 to provide cash payments to aged individuals and blind and disabled adults and children with limited income and resources. Families of children receiving SSI benefits may spend these cash payments for any purpose that meets a child's current and future needs, including food, clothing, shelter, and utilities, as well as disability-related services.[1] In addition to these cash payments under the SSI program, families can obtain disability-related services through other programs. From the end of 1989 through 1996, the number of children younger than 18 receiving SSI disability benefits more than tripled, from 265,000 to 955,000, and benefit payments increased from $1.2 billion to about $5.2 billion. This growth in the rolls, and allegations that some parents were coaching their children to feign disabilities in order to receive SSI benefits, caused concerns about the children's component of the SSI program.[2]

In this context, during the debate that led to the passage of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193, commonly referred to as welfare reform), some members of the Congress expressed uneasiness about how families of children on SSI used their cash benefits and introduced provisions substituting disability-related services for the cash benefits. As ultimately enacted, the law did not replace cash benefits with services for children. Instead, the law mandated that GAO study and report on the disability-related expenses incurred by families of children on SSI that are not covered by federal, state, and local programs serving children with disabilities. In response to this mandate, GAO (1) examined the disability-related costs that families of children on SSI incur and the factors that influence the level of such costs and (2) identified factors affecting families' receipt of disability-related services from programs.[3]

[1]In most cases, a disabled child's SSI benefit is paid on behalf of the child to a "representative payee," such as a parent or relative. The representative payee is responsible for determining the child's needs—defined as the immediate and reasonably foreseeable essentials for living—and for using the payments only for the child's use and benefit. Representative payees must submit reports accounting for the use of benefits when SSA asks them to do so.

[2]For GAO's report on the issue of coaching, see Social Security: New Functional Assessments for Children Raise Eligibility Questions (GAO/HEHS-95-66, Mar. 10, 1995).

[3]Disability-related services are services or items attributable to a child's disability, such as a ramp to the home of a child in a wheelchair, mobility equipment, specialty medical services, or special recreation. Families' disability-related costs are nonreimbursed expenses for disability-related services that families purchase in whole or in part out of their SSI or other family income. "Program" refers to public and private organizations and agencies providing services for free, on a sliding fee scale, or for a small copayment or deductible, to, among others, children with disabilities.

Background

In 1998, about 885,000 children received about $4.9 billion in federal SSI payments, with an average monthly amount of about $430 per child. Children may qualify for SSI if they are unmarried and meet the applicable SSI financial and disability requirements. To be considered disabled, a child younger than 18 must have a medically determinable physical or mental impairment that results in marked and severe functional limitations and that has lasted or can be expected to last for a continuous period of not less than 12 months or that can be expected to result in death.

An array of federal, state, and local programs offer a range of services and assistance to children with disabilities and their families.[4] Table 1 describes major public programs and details whether they give special consideration to children on SSI.

Table 1: Major Public Programs Serving Children With Disabilities

Program	Purpose	SSI link
Medicaid	To pay for medically necessary health care services.	Most children receiving SSI are automatically eligible for Medicaid.
Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)	To identify and treat children's health problems before they become complex or disabling and require more costly treatment.	Children receiving Medicaid, including those receiving SSI, are entitled to EPSDT services.
Medicaid's Home and Community-Based Services Waiver	To offer community-based long-term care services in order to prevent or postpone institutionalization.	Children receiving SSI are not given special consideration.
Early Intervention (part C, Individuals With Disabilities Education Act)	To enhance development and minimize and perhaps preclude later need for special education services or institutionalization.	Children receiving SSI are not given special consideration.
Special Education (part B, Individuals With Disabilities Education Act)	To ensure that all children with disabilities have available to them a free appropriate public education, through special education and related services designed to meet their unique needs.	Children receiving SSI are not given special consideration.
Children With Special Health Care Needs (title V, Social Security Act)	To provide and promote family-centered, community-based care, including care coordination services, and to aid in developing community-based systems of care; to provide rehabilitation services to children younger than 16 receiving SSI.	Children younger than 16 receiving SSI are to be referred for rehabilitation services to the state agency administering the title V program.
State family support programs	To support families in their efforts to raise their children with disabilities in the family home.	Children receiving SSI are not given special consideration.

[4]Although Medicaid serves children and adults without disabilities, GAO included the program in this group because, in most states, children on SSI are automatically eligible for Medicaid.

Results in Brief

Recent survey data show that families obtain from public programs many disability-related services for their SSI children. However, these programs do not cover the cost of all such services—families pay for some services out of their own income, which includes their children's SSI payments. Although nationwide data are not available to calculate the precise level of these expenditures, survey data on Florida families with SSI children shed some light on this question. About 87 percent of the Florida families surveyed in 1996 reported that they incurred disability-related costs. About three-quarters of these families spent $3,000 or less and half spent $1,000 or less on disability-related services over the past year. About 90 percent of the families in the Florida survey who incurred disability-related costs incurred total annual costs that were less than the maximum allowable SSI payments for the year, and about 10 percent reported costs that exceeded the maximum payments. Such data, however, do not reflect whether a child's service needs have been met. Data on expenditures do not reflect services that families needed but did not purchase because they could not afford them. Whether a family can afford to purchase services, and the need to purchase certain types of services, is affected by a family member's decision to work or stay at home to care for a child with a disability.

A variety of factors may affect families' ability to obtain services through other programs. First, SSI beneficiary status generally does not entitle a child to a program's services. Because of certain aspects inherent to the design of a program—such as eligibility criteria, the number of available service slots, and whether a program covers needed services—some SSI children do not receive services from programs. Second, because of difficulties in identifying which children need services and what services they need, some children who need services may be overlooked. Third, once a child's service needs are identified, gaining access to some program services can be difficult because of the shortage of service providers in some areas and program officials' concerns about the cost of providing some services. Finally, families play an important role in obtaining services for their children. But some families' limited knowledge of programs and services, limited ability to proactively pursue services to which they may be entitled, or lack of transportation or other supports hinders their ability to obtain services for their children.

Principal Findings

Families Incur a Wide Range of Disability-Related Costs

Families with children on SSI obtain a broad range of disability-related services. Some they obtain from programs and some they purchase themselves. Data from the 1994 and 1995 National Health Interview Survey and a 1996 Florida survey show that, collectively, families with children on SSI purchased a broad range of disability-related services.[5] In particular, about 87 percent of the Florida survey families reported purchasing disability-related services for their children and incurring a wide range of costs. The remaining 13 percent of families did not report or did not incur any disability-related costs. Families in the Florida survey reported total disability-related expenditures ranging from $10 to more than $26,000 per year. Although SSI payments may be used for any type of expenditure (such as food, clothing, or shelter) that meets the current and future needs of the disabled child, to provide a perspective on the magnitude of these costs, GAO compared annual total costs with the maximum SSI payments a family could receive for a child for a year.[6] About 90 percent of the families in the Florida survey who incurred disability-related costs incurred total annual costs that were less than the maximum allowable SSI payments for a year, and about 10 percent reported costs that exceeded the maximum payments.[7]

While it might seem from the expenditure data that SSI payments are sufficient to cover disability-related costs for most families in Florida, such data do not indicate whether a child's disability-related needs have been met or whether or the extent to which families might have purchased additional needed services had they not faced constraints on their income. Moreover, the data do not allow GAO to assess the extent to which families make tradeoffs between purchasing disability-related services and purchasing basic necessities for the entire family. In this regard, data from both surveys show that nearly 40 percent of the respondents reported that they needed but did not obtain one or more services for their children.

[5]Data are from the National Center for Health Statistics' 1994 and 1995 National Health Interview Survey, including the Disability Supplement and Disability Followback Child's Questionnaire, and the 1996 University of Florida's Institute for Child Health Policy survey of children with special health care needs.

[6]The monthly maximum SSI payment in 1996 was $470. This amount for the year was $5,640.

[7]GAO also compared families' total annual costs with the mean annual SSI payment for children in Florida in 1996, which amounted to $5,181 as of December 1996. GAO found that about 86 percent of the Florida families who incurred disability-related costs incurred total annual costs below the mean annual SSI payment.

And these data are likely to underestimate the extent to which families were unable to obtain needed services because the surveys generally asked about the need for services that were not obtained at all but rarely asked about the need for additional services that were obtained but in insufficient quantity.

From GAO's analysis of survey data and information from site visits, GAO found that a variety of factors, aside from a child's particular service needs, influence the purchase of disability-related services and, hence, the level of a family's costs for them. A key reason that some families do not purchase such services is that they cannot afford them. In the Florida survey, about 60 percent of families who were unable to obtain one or more needed services for their children reported that they did not obtain the services because they were too expensive. Another factor is employment: A family member's decision to work or stay at home to care for a child with a disability affects not only the family's income, and thus the ability to purchase services, but also the need to purchase certain services, such as some types of specialized day care, that the family member at home may now be able to provide. For example, nearly 40 percent of the families participating in the Florida survey reported that caring for a child's special needs caused someone in the family to not work. And about 40 percent of Florida survey respondents reported that family income decreased after the birth of a special-needs child.

Finally, whether families are able to obtain services from programs also affects their disability-related costs. Survey data show that public programs were widely cited as a source of full or partial funding for many of the services that families obtained for their SSI children. For example, families generally cited Medicaid and the school system as sources of full or partial payment for medical care, educational services, and therapies—such as physical or respiratory therapy. Moreover, data from both surveys show that while some programs, including Medicaid, provided certain types of services to some families, other families reported purchasing the same types of services.

Program, Service, and Family-Related Factors Affect Some Families' Receipt of Services From Programs

A variety of factors may affect some families' receipt of services through programs. First, SSI beneficiary status generally does not entitle a child to a program's services. As an illustration, children with mental impairments—that is, 64 percent of all children receiving SSI—do not meet the eligibility criteria of the title V programs in 25 states, even though children on SSI are to be referred to the state title V program for

rehabilitation services.[8] Even when a child meets a program's eligibility criteria, the child still may not be admitted to the program because the number of available slots may be filled. And once a child has been admitted, his or her service needs may still not be covered. Or, if the program covers the services, the child may not fulfill the requirements to receive them.

Second, because of difficulties in identifying which children need services and what services they need, programs may miss an opportunity to serve children. The process of identifying a child's service needs is generally separate from the process of determining that a child has a disability. Making decisions about the type and amount of services a disabled child needs is difficult: The decisions are inherently complex, and standardized methodologies to aid in making some decisions are lacking. Another difficulty, according to the results of research studies and site visit interviews with program officials and case managers, is that some service providers have an insufficient understanding about childhood disability. For instance, although teachers play a key role in identifying students in need of services and contributing to the process of determining what services they need, research results and findings from site visits indicate that some teachers are not fully prepared to play this role. Yet another difficulty concerns the screening for EPSDT services. Studies show that state Medicaid programs are not screening children for needed EPSDT services at the frequency recommended by the Secretary of the Department of Health and Human Services (HHS), which means that some children may have disability-related service needs that these programs have not identified.

Third, gaining access to some program services can be difficult, even when a child's service needs are identified. A child's family may have difficulty gaining access to services because some providers—and the services they offer—are either unavailable or in short supply in some communities. For example, among national survey participants who were unable to obtain one or more needed services, about 40 percent responded that they did not obtain the service because it was unavailable. Additionally, concerns of program officials about service cost can affect a child's receipt of special education services such as technology devices. Moreover, some program officials provide only limited information to families about community resources or do not see themselves as responsible for providing information about services available from other programs.

[8]A child with a mental impairment, such as mental retardation, could qualify for a title V program if he or she has a qualifying secondary physical impairment.

Overall, families play an important role in obtaining services for their children but some are hindered by limited knowledge of programs and services, limited ability to proactively pursue services to which they may be entitled, or a lack of transportation or other supports. For example, some families do not know about program services such as respite care. In addition, case managers described some families as being hesitant to assert their rights to services because they fear retaliation against their children.

Agency Comments and GAO's Response

GAO provided copies of a draft of this report to SSA, the Department of Education, and HHS and components within HHS for their comments. Education said that the report provides a balanced treatment of the status of children receiving SSI and their families. SSA generally concurred with the draft report and noted that it is currently designing a survey of SSI children that, when completed, will collect nationwide data regarding costs of care and service utilization. SSA also said that the report provides useful information on disability-related expenditures for children with disabilities. However, the agency questioned the way in which GAO compared disability-related costs with SSI benefits. Although SSI payments may be used for any type of expenditure benefiting the child, GAO used maximum allowable SSI payments as a means of comparing disability-related costs across families. SSA expressed concern that the results of this comparison could be taken out of context, or they could be misinterpreted because many children (about 32 percent nationwide) do not receive the maximum payment. Because GAO shared these concerns, GAO presented the results of its comparison within a discussion of the limitations of the data and methods GAO used. GAO used the maximum allowable benefit amount because the survey data did not include information on the exact amount of a family's SSI payment. Moreover, about 68 percent of SSI children nationwide receive the maximum benefit, and families who receive less than the maximum benefit for a child usually have additional sources of income. GAO also added to the report a comparison of total annual costs with the mean annual SSI payment for children in Florida in 1996. GAO found that using the mean annual SSI payment yielded little or no difference in results in comparison with the results obtained from using the maximum allowable benefit. Regardless of the comparison measure used, or the representativeness of the cost data, such a comparison does not indicate whether a child's disability-related needs are met or whether families with SSI children might purchase additional needed services and, thus, incur greater costs if their incomes were higher.

SSA, Education, and components within HHS, including the Health Care Financing Administration and the Maternal and Child Health Bureau, also provided GAO with technical comments. GAO has modified the report to reflect these comments where appropriate.

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Abbreviations

CSHCN	children with special health care needs
EPSDT	Early and Periodic Screening, Diagnostic, and Treatment
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HSRI	Human Services Research Institute
IDEA	Individuals With Disabilities Education Act
IEP	Individual Education Program
NHIS	National Health Interview Survey
SSA	Social Security Administration
SSI	Supplemental Security Income
VA	Department of Veterans Affairs

Introduction

The Congress established the Supplemental Security Income (SSI) program, which is administered by the Social Security Administration (SSA), in 1972 to provide cash payments to aged individuals and blind and disabled adults and children with limited income and resources. Families of children receiving SSI payments may spend them for any purpose that meets a child's current and future needs, including food, clothing, shelter, and utilities, as well as disability-related services.[9] In addition to SSI, a number of other federal and state programs provide assistance to children with disabilities.

SSI Provides Cash Benefits to Children Who Have Disabilities and Limited Income and Resources

Children may qualify for SSI if they are unmarried and meet the applicable SSI disability, income, and financial asset requirements. To be eligible, a child younger than 18 must have "a medically determinable physical or mental impairment which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months" and must have limited income and assets.[10] Once a child is on the SSI rolls, eligibility continues until (1) death, (2) SSA determines that the child's medical condition has improved to the point that he or she is no longer considered disabled, (3) the family's finances no longer meet SSI's eligibility requirements, or (4) SSA determines that the child, upon reaching age 18, is not disabled according to adult disability criteria.[11]

Children on SSI receive cash benefits from the federal government. Additionally, most states provide a supplemental cash benefit to these children. In 1998, about 885,000 children received about $4.9 billion in federal SSI payments, with an average monthly amount of about $430 per child. Thirty-four states currently provide a supplemental cash benefit to children receiving a federal payment. These states' total state

[9]In most cases, a disabled child's SSI benefit is paid on behalf of the child to a "representative payee," such as a parent or relative. The "representative payee" is responsible for determining the child's needs—defined as the immediate and reasonably foreseeable essentials for living—and using the payments only for the child's use and benefit. Representative payees must submit reports accounting for the use of benefits when SSA asks them to. We use "family" synonymously with "representative payee."

[10]The definition of childhood disability is found in 42 U.S.C. 1382c(a)(3)(C)(i). SSA considers the parent's income and assets when deciding whether a child qualifies for SSI.

[11]SSA is to conduct continuing disability reviews of certain groups of children to determine whether a child has medically improved to the extent that the child is no longer disabled. SSA is required to review the disability status of low-birthweight babies and children younger than 18 who are likely to improve or, at the option of the commissioner, those who are unlikely to improve. SSA is also to redetermine the disability eligibility for 18-year-olds, using adult criteria for disability.

supplementation, however, is less than 6 percent of their federal and state payments.

Table 1.1 shows selected demographic characteristics of children receiving SSI. For example, the population of children on SSI is fairly evenly distributed among four age groups: 0-5, 6-9, 10-13, and 14-17. About 64 percent of children on SSI have a mental impairment, such as mental retardation, as their qualifying diagnosis. In addition, just one-fourth of all children on SSI reside in two-parent households. About 61 percent of children on SSI reside in single-parent households, nearly all headed by women. Another 13 percent of SSI children reside with other relatives or nonrelatives or in institutions or foster care. Further, nearly 70 percent of all SSI children reside in households with monthly incomes, not including SSI payments, of less than $1,000. Overall, about one-half of children receiving SSI are located in one of nine states; about one-third are concentrated as the table shows in California, New York, Florida, Texas, and Ohio.

Table 1.1: Selected Demographic Characteristics of Children Receiving SSI in December 1998

Characteristic	Number	Percent of total
Total	**885,250**	**100.0%**
Age		
0-5	174,150	19.7
6-9	222,370	25.1
10-13	251,590	28.4
14-17	237,140	26.8
Gender		
Female	323,430	36.5
Male	561,820	63.5
Diagnosed impairments[a]		
Mental impairments	523,270	63.9
Physical impairments	216,230	26.4
Other[b]	79,870	9.7
State of residency		
California	78,540	8.9
New York	70,140	7.9
Florida	59,890	6.8
Texas	50,100	5.7
Ohio	44,890	5.1
Illinois	42,420	4.8

(continued)

Characteristic	Number	Percent of total
Pennsylvania	40,340	4.6
Michigan	36,960	4.2
Louisiana	31,780	3.6
Other	430,190	48.6
Parents in household		
No parents[c]	118,650	13.4
One parent	537,000	60.7
Two parents	229,600	25.9
Monthly household income not including SSI[d]		
Zero	225,220	29.4
Less than $200	140,530	18.3
$200-$399	36,980	4.8
$400-$599	44,190	5.8
$600-$999	84,740	11.1
$1,000 or more	234,940	30.6

[a]Numbers are based on the children for whom a diagnostic code is available in SSA's Supplemental Security Record file.

[b]Includes conditions for which a diagnosis has been established but is not included in SSA's medical listing of impairments.

[c]Children with no parents in the household reside independently, with other relatives or nonrelatives, or in institutions or foster care.

[d]Includes monthly income of households headed by single adults and couples. No parental income information exists for the 118,650 children with no parents.

Sources: SSA, Children Receiving SSI (Baltimore, Md.: Office of Research, Evaluation, and Statistics, Dec. 1998), http://www.ssa.gov/statistics/ores_home.html (cited Feb. 17, 1999). Numbers projected from a 10-percent sample of children who were younger than 18 and receiving SSI benefits were drawn by SSA from its Supplemental Security Record file, Dec. 1998.

In recent years, SSI has been the focus of much congressional concern and media attention in light of unprecedented growth in the number of children receiving SSI disability benefits. From the end of 1989 through 1996, the number of children younger than 18 receiving SSI disability benefits more than tripled, from 265,000 to 955,000, and benefit payments increased from $1.2 billion to about $5.2 billion.[12] Congressional concerns also focused on media reports of allegations that some parents were

[12]See the following reports for our analyses of factors that contributed to rapid program growth during this period: Social Security: Rapid Rise in Children on SSI Disability Rolls Follows New Regulations (GAO/HEHS-94-225, Sept. 9, 1994), and Social Security: New Functional Assessments for Children Raise Eligibility Questions (GAO/HEHS-95-66, Mar. 10, 1995).

coaching their children to feign disabilities in order to receive SSI benefits.[13]

Concerned with this rapid growth and allegations of program abuse, the Congress tightened SSI program eligibility through the Personal Responsibility and Work Opportunity Reconciliation Act, enacted in August 1996. The Congress did this to help ensure that only needy children with severe disabilities receive benefits. Moreover, the allegations of coaching raised questions about the effectiveness of using cash benefits to serve children who have disabilities and limited income and resources. Therefore, an early version of the welfare reform bill passed by the House proposed substituting medical and nonmedical services for cash benefits for children on SSI. Proponents of this proposal contended that a cash benefit encourages families to keep their children disabled in order to retain the benefit and that providing services is a better way to help them. But opponents responded that the cost of rearing children with disabilities is higher than the cost of rearing children without disabilities. They indicated that without the SSI cash benefit, family income would be inadequate to cover the higher costs of providing disability-related clothing, food supplements, child care, and transportation, among other services.[14] The welfare reform law that the Congress ultimately enacted left the SSI program's cash benefit structure unchanged.[15]

Other Major Programs Provide Disability-Related Services

While SSI is designed as a cash assistance program, children on SSI may be eligible to receive a range of disability-related services—including medications, durable medical equipment, nursing services, therapies, educational services, and child care—from an array of other programs. Some of these programs were in operation before SSI was established and others began afterward. The programs that target services to children with disabilities and make the largest federal expenditures on children with disabilities are Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) and Home and Community-Based Waivers; Special Education and Early Intervention under the Individuals With Disabilities

[13]See GAO/HEHS-95-66, which states that studies we reviewed found little evidence that coaching is widespread. These studies, however, relied solely on documentation in case files and, therefore, cannot rule out coaching. In addition, see SSA Initiatives to Identify Coaching (GAO/HEHS-96-96R, Mar. 5, 1996), in which we report on two SSA initiatives to identify and process reports of parents coaching their children in order to qualify for SSI. Both initiatives identified few cases of suspected coaching, and very few of the children involved received SSI benefits.

[14]We define various disability-related services in appendix I.

[15]However, the welfare reform law did restrict the use of certain past due SSI payments benefiting children younger than 18—for example, retroactive payments for the period between application for benefits and determination of eligibility. The law requires that a child's representative payee deposit the payments in a dedicated account and limits the use of the payments to certain purposes such as job skills training or disability-related personal needs assistance or housing modifications or any other service or item the Commissioner of SSA considers appropriate, provided it benefits the child.

Education Act (IDEA); and Children With Special Health Care Needs under title V of the Social Security Act.[16]

Table 1.2 provides an overview of these programs as well as the primarily state-funded family support programs and describes their purpose, target population, financing and administration, and main service or benefit and the extent of program participation and expenditures on children. For example, title V, established in 1935 as part of the original Social Security Act, includes provisions that focus on serving children with special health care needs as part of the title's overall purpose of ensuring quality health care for mothers and children with low income or for whom the availability of health services is limited. Children younger than 16 on SSI are to be referred for rehabilitation services to the state title V program.

Table 1.2: Major Public Programs Serving Children With Disabilities

Program (and authority)	Purpose	Target population	Financing and administration	Service or benefit	Participation and expenditures on children
Children With Special Health Care Needs (title V, Social Security Act)	To provide and promote family-centered, community-based care, including care coordination, and to aid in developing community-based systems of care; to provide rehabilitation services to children younger than 16 on SSI.[a]	State-determined	A state block grant program, funded federally and with a state match; Department of Health and Human Services' (HHS) Maternal and Child Health Bureau coordinates activities at the federal level and shares information and technical assistance with the states; administered by states.	Specialty and subspecialty health care and services unavailable in most communities; services that facilitate access to health services—such as transportation and care coordination with other programs.	907,000 children with special health care needs (FY 1995); federal allocation of $545.8 million; estimated $1.3 billion in state funding for children with special health care needs, among others (FY 1997).

(continued)

[16]Although Medicaid serves children and adults without disabilities as well, children on SSI are automatically eligible for Medicaid in most states. The Medicaid law refers to EPSDT as a set of items and services within the Medicaid program. However, common usage refers to EPSDT as a program. In this report, we refer to EPSDT as a program within Medicaid.

Program (and authority)	Purpose	Target population	Financing and administration	Service or benefit	Participation and expenditures on children
Medicaid (title XIX, Social Security Act)	To pay for medically necessary health care services.	Low-income children and women, low-income persons who are blind or disabled, and low-income elderly persons.	Jointly funded by federal and state governments; federal oversight by HHS's Health Care Financing Administration (HCFA); administered by state Medicaid programs.	Federal law requires the states to offer certain services, including hospital, physician, and nurse practitioners' services; the states can offer other benefits such as occupational therapy and dental services.	15.3 million children; $15.7 billion in federal and state expenditures (FY 1997).
Medicaid's EPSDT (title XIX, Social Security Act)	To identify and treat children's health problems before they become complex or disabling and require more costly treatment.	Children younger than 21 on Medicaid.	Same as above.	Age-appropriate screenings and immunizations, follow-up diagnostic services, and medically necessary treatment services.	6.4 million children; $1.6 billion in federal and state expenditures (FY 1997).
Medicaid's Home and Community-Based Services Waiver (title XIX, Social Security Act)[b]	To offer community-based long-term care services in order to avoid institutionalization.	State-determined.	Same as above.	Range of social and supportive services.	7,568 children; $252.4 million in federal and state expenditures (calendar year 1997).
Early Intervention (part C, IDEA)	To enhance development and minimize and perhaps preclude later need for special education services or institutionalization.	Children from birth to 3 years who manifest developmental delays or have a state-defined condition likely to cause a delay.	Jointly funded by federal, state, and local governments. Federal Department of Education develops guiding rules and regulations, provides technical assistance to the states, and monitors them. Administered by states.	Among the services offered are diagnostic evaluations, special instruction, therapies, psychological services, social work services, care coordination, and transportation.	187,348 children; federal allocation of $309 million; estimated $3.6 billion in state and local expenditures (FY 1997).[c]

(continued)

Program (and authority)	Purpose	Target population	Financing and administration	Service or benefit	Participation and expenditures on children
Special Education (part B, IDEA)	To ensure that all children with disabilities have available to them a free and appropriate public education through special education and related services designed to meet their unique needs.	Children from 3 through 21; broad federal guidelines for categorical disability criteria (specific assessment tools are determined locally).[d]	Same as above.	Identification and assessment of disabling conditions; specially designed instruction; and transportation and developmental, corrective, and other supportive services (e.g., psychological services, therapies, audiology, and mobility services) needed to help a child benefit from special education.	5.8 million children; federal appropriation of $3.1 billion; estimated $38.9 billion in state and local expenditures (FY 1997).[c]
State family support programs	To support families in their efforts to raise their children with disabilities in the family home.	State-determined.	Primarily state-funded; typically administered through a state's developmental disabilities authority.	A range of services, including respite care, home and vehicle modifications, equipment, therapies, care coordination, and cash subsidies.	281,000 families of children and adults with disabilities; $525 million in expenditures on both adults and children (FY 1996).[e]

[a]It is up to the states to define "rehabilitation services," and their definitions vary substantially. The states are not required to provide a specific amount of funds for children younger than 16 on SSI when Medicaid is unable to provide assistance. Theoretically, a state could determine that no money is a reasonable amount, according to Maternal and Child Health Bureau legal opinions.

[b]Currently the more than 200 waiver programs serve more than 250,000 people of all ages. Federal regulations permit waiver programs to serve the elderly and people with disabilities, including people with physical disabilities, developmental disabilities, mental retardation, or mental illness. Data are unavailable on the number of children served across all waivers. However, the most recently available data show that 36 waivers are targeted exclusively to children. Information in the table on participation is limited to 26 of these 36 waiver programs and on expenditures to 23, because data are unavailable for the remaining waivers.

[c]Little information is available on state and local expenditures on Early Intervention and Special Education services. An estimate prepared by the Urban Institute in 1996 indicates that the federal portion of Early Intervention and Special Education expenditures is about 8 percent. We used this figure to estimate state and local expenditure amounts. (See Laudan Y. Aron, Pamela J. Loprest, and C. Eugene Steuerle, Serving Children With Disabilities: A Systematic Look at the Programs (Washington, D.C.: The Urban Institute Press, 1996).

[d]Children aged 3 through 5 and 18 through 21 are eligible for special education if allowed under state law.

[e]David Braddock and others, The State of the States in Developmental Disabilities, 5th ed. (Washington, D.C.: American Association on Mental Retardation, 1998), pp. 41-42. In gathering data, the researchers defined "family support" as any community-based service administered or financed by the state mental retardation and developmental disability agency that provided for vouchers, direct cash payments to families, reimbursement, or direct payments to service providers that the state agency itself identified as family support.

Medicaid, established in 1965, pays for health services for low-income children and adults with disabilities, among others. Children on SSI are generally eligible for Medicaid coverage.[17] In 1967, the Congress established the EPSDT benefit to ensure that children eligible for Medicaid receive representative and comprehensive health services. These benefits are more comprehensive than benefits included in a state's Medicaid plan (within federal guidelines, each state defines its own benefit package). Medicaid also operates the Home and Community-Based Services Waiver Program.[18] The program gives states, through a waiver, the option to offer services that go beyond the health and health-related benefits that have been the principal focus of Medicaid, including a wide range of social and supportive services.

In addition, IDEA, which dates from 1975, is the main federal legislation supporting the educational rights of children with disabilities.[19] Under IDEA's Early Intervention Program, infants and toddlers younger than 3 who have a substantial developmental delay (or who are at risk of delay) are entitled to receive services to maximize their development. About 12 percent of the children on SSI who are younger than 3 receive Early

[17]The states may link eligibility for Medicaid with SSI in one of three ways. First, the law allows automatic Medicaid eligibility when a person becomes entitled to SSI. Thirty-two states and the District of Columbia have elected this option. Second, states may impose Medicaid eligibility criteria that are more restrictive than SSI criteria as long as the states do not choose criteria that are more restrictive than those they were using for Medicaid on January 1, 1972 (before the implementation of SSI). The 11 states that have chosen this option are known as "section 209(b)" states, after the section of the Social Security Amendments of 1972 that established it. Third, in the remaining 7 states, SSI recipients are eligible for Medicaid, but they must file a separate application with the state agency that administers Medicaid. The Balanced Budget Act of 1997 created title XXI of the Social Security Act, referred to as the Child Health Insurance Program, to expand health insurance for low-income children previously ineligible for Medicaid. Children on SSI are generally not eligible for this program because they are generally eligible for Medicaid.

[18]This program is also called the section 1915(c) waiver program, for the section of Medicaid law in which it is authorized.

[19]In 1975, the Congress passed the Education for All Handicapped Children Act (P.L. 94-142), which was later amended and renamed the Individuals With Disabilities Education Act.

Intervention services.[20] IDEA's Special Education Program makes available to all children with disabilities who are 3 through 21 a free appropriate public education—in the least restrictive environment possible—that meets their unique needs regardless of the type or severity of disability. About 60 percent of the children on SSI who are 3 or older receive Special Education services.[21]

Finally, most states operate one or more family support programs. While these primarily state-funded programs vary in the groups they target and the services they offer, one of their main goals is to support families in their efforts to raise their children with disabilities at home. Services they offer include supportive services such as respite care, home and vehicle modifications, physical and occupational therapies, adaptive equipment, and recreation, as well as financial assistance and care coordination.

Objectives, Scope, and Methodology

Acknowledging the substantial programs that assist children with disabilities, the Senate report accompanying an early version of the welfare reform bill stated that the children's component of the SSI program required further examination.[22] Specifically, the report stated that the issue of whether families of children on SSI incur expenses related to a child's disability needed to be addressed, as well as the effect of these programs on the cash needs of families with disabled children. Indeed, only one survey, conducted more than 20 years ago, has assessed families' costs for disability-related services for children receiving SSI, although

[20]Based on a sample of families with children on SSI who participated in the National Center for Health Statistics' 1994 and 1995 National Health Interview Survey, including the Disability Supplement and Disability Followback Child's Questionnaire. Participants were asked whether their children younger than 3 had received any type of special education services for infants and very young children with special needs during the past 12 months. The survey noted that for a child younger than 3, special education is a program designed to meet the individual needs of infants and very young children who have special needs. It may include services at home, at a hospital, or somewhere else.

[21]Based on a sample of families with children on SSI who participated in the National Center for Health Statistics' 1994 and 1995 National Health Interview Survey, including the Disability Supplement and Disability Followback Child's Questionnaire. Participants were asked whether their children had received any type of special education services or benefits for children with special needs paid for by the public school system during the past 12 months. The survey noted that for children aged 3 or older, special education is a program designed to meet the individual needs of children age 3 and older with special needs. It may take place at a regular school, a special school, or a private school or at home or a hospital.

[22]S. Rep. No. 104-96 (1995).

numerous studies have addressed this issue indirectly.[23] In the conference report accompanying the welfare reform bill, the Congress stated that it might address the issue of SSI benefits for children in the future. To help inform any future deliberations on this issue, the Congress mandated in the welfare reform law that we study and report on the disability-related expenses that families of children on SSI incur that are not covered by federal, state, and local programs serving children with disabilities.

To address this mandate, we (1) examined the disability-related costs that families of children on SSI incur and the factors that influence the level of such costs and (2) identified factors affecting families' receipt of disability-related services from programs.

To examine families' disability-related costs and the factors affecting the level of such costs, we analyzed responses by families with children younger than 18 on SSI in two surveys.[24] One was the National Center for Health Statistics' 1994 and 1995 National Health Interview Survey (NHIS), including the Disability Supplement and Disability Followback Child's Questionnaire. The other was the University of Florida's Institute for Child Health Policy 1996 survey of Florida children with special health care needs.[25] The data from both surveys have some limitations. For example, because the NHIS did not ascertain information on SSI receipt for

[23]Many studies that have addressed costs for disability-related services concentrated on populations other than children receiving SSI benefits, such as Medicaid beneficiaries or people with particular impairment types. Studies have also assessed total disability-related costs, regardless of who pays for the services. Studies that focused on children receiving SSI covered issues other than disability-related costs, such as access to health care and items families purchase with the SSI benefit. The one survey that identified disability-related costs for children on SSI was conducted in 1978. (See Urban Systems Research and Engineering, Inc., Survey of Blind and Disabled Children Receiving Supplemental Security Benefits, SSA publication 13-11728, prepared by Marilyn Rymer and others (Baltimore, Md.: SSA, Jan. 1980).) The survey data were later analyzed by Social and Scientific Systems, Inc., and Mathematica Policy Research, Inc. (See Myles Maxfield, Jr., and Allen Kendall, Disabled Children in the Supplemental Security Income Program (Washington, D.C.: SSA, Division of Supplemental Security Studies, June 30, 1981).)

[24]Disability-related costs occur when families pay for disability-related services or items, either entirely or in part, with their own family income. Their income may come from a number of sources, including a child's SSI cash benefit. Consistent with the definitions used by the two surveys, families' disability-related costs do not include expenditures reimbursed by an insurance company or other source. We define "disability-related services" as the services or items that are attributable to a child's disability. These services include, for example, a ramp to the home of a child in a wheelchair, mobility equipment for a child with cerebral palsy, or specialty medical services for a child with severe asthma.

[25]The Florida survey was developed as part of a study that examined children receiving Medicaid as well as those enrolled in managed care organizations. See E.A. Shenkman and B.V. Vogel, Managed Care: Implications for Families' Out-of-Pocket Expenses When Caring for Children With Special Health Care Needs (Gainesville, Fla.: University of Florida, Institute for Child Health Policy, May 1998). Grant 95A5PE273A, funded by HHS Assistant Secretary of Planning and Evaluation. Both the NHIS and the Florida survey were conducted before the tightening of SSI eligibility requirements by the welfare reform law in August 1996.

12.5 percent of the children who were younger than 18 and included in the 1994 and 1995 surveys, the children receiving SSI included in the NHIS may not be representative of SSI children nationwide. Moreover, because the Florida survey consists of data from a random sample of Florida children receiving Medicaid, the SSI children in the Florida survey may not be representative of all SSI children in Florida. In addition, data in both surveys were self-reported and some respondents may not have been able to recall with precision the amount they spent on a particular service over a year. Moreover, some respondents may not have known which entity or entities paid for a service.

For both surveys, adults in families provided responses about their children's receipt of a set of disability-related services. We analyzed data on 450 children from the NHIS and 208 children from the Florida survey.[26] Because the set of services in the NHIS did not include several disability-related services that a family might need to purchase, or did not ask about the costs associated with some services, we did not use the NHIS data to estimate total family costs. Because the Florida survey is more comprehensive than the NHIS in the scope of disability-related services covered by survey questions, we used the Florida survey data to estimate family costs. The Florida survey asked each family how much it paid for individual services that the child with the greatest health care needs received during the past year. Total family disability-related costs were calculated by summing the individual service costs reported for the child. Findings from the Florida data may not be representative of children receiving SSI nationwide. Nevertheless, the age ranges and gender composition of the SSI children in the Florida survey were generally similar to those of the population of children on SSI nationwide. Moreover, more than half of the children in both groups lived in single-parent families. And, although the prevalence of some impairment types varied significantly among the two groups, they generally had a similar range of impairment types.

To provide a perspective on the magnitude of families' disability-related costs, we compared the annual total costs of Florida survey participants with the maximum SSI payments a family could receive for a child for a year. Although SSI payments may be used for any type of expenditure benefiting the child, this analysis provides a basis for comparing costs across families. We used the maximum allowable benefit amount because

[26]The group of 450 children from the NHIS was composed of children whom family members identified as receiving SSI and whose family members responded to the 1994 or 1995 Disability Followback Child's Questionnaire. For these 450 children, we analyzed responses to questions contained in the Disability Followback, the Disability Supplement, and other parts of the survey.

the Florida survey did not contain information on the exact amount of a family's SSI payment. Although 32 percent of SSI children nationwide received less than the maximum benefit at the end of 1996, the families who do not receive the maximum benefit usually have sources of income in addition to their children's SSI payments. As a result, these families' total income usually equals or exceeds the level of maximum allowable payments. At the time of the Florida survey in 1996, the annual maximum allowable SSI payment for one child was $5,640.[27]

To identify factors affecting families' receipt of disability-related services from programs, we focused our review on programs that target and have the largest federal expenditures for children with disabilities.[28] These programs are Medicaid's EPSDT and waiver programs, IDEA's Special Education and Early Intervention programs, and the title V program. In our analysis of these and other federal, state, and local programs, we reviewed research studies and interviewed program officials, experts, and advocacy groups on disabled children's access to program services. Also, we made site visits to Mississippi, New Hampshire, and Texas to interview families and case managers of children receiving SSI, representatives of community organizations, and state and county program officials.[29] We used a list of 38 disability-related services that we derived from the NHIS and Florida survey to help collect and analyze information gathered during our site visits (appendix I lists and defines the 38 services). We performed a content analysis of the site visit data to identify factors that affect families' receipt of disability-related services from programs. To meet our evidentiary threshold to be considered a "factor," an issue had to be raised by two or more types of groups interviewed during site visits (for example, program officials, case managers, families, representatives of community organizations) in two or more states. We did not identify the extent to

[27]We also compared total annual costs for Florida families with the mean annual SSI payment for children in Florida in 1996. The mean annual SSI payment for children in Florida amounted to $5,181 as of December 1996.

[28]In this report, "program" refers to public and private programs, organizations, and agencies that provide services and items for free, on a sliding fee scale, or for a copayment or deductible that benefit, among others, children with disabilities. Programs include, for example, federal, state, and local agencies, nonprofit community service organizations, and for-profit private companies conducting charity work. An example of a for-profit private company conducting charity work is a utility company discounting the utility bill for a family with low income whose child with a disability requires higher than normal electricity usage.

[29]We chose these states because the proportions of their state populations younger than 18 that receive SSI benefits were high (Mississippi), medium (Texas), and low (New Hampshire). Within each state, we chose one county with a large general population and some type of community organization focused on childhood disability with whose representatives we could work to arrange group interviews. Service providers (for example, community mental health center staff) sometimes attended our meetings with representatives of community organizations.

which any of the factors affect access to program services for children on SSI.

We did our work between November 1997 and April 1999. We did not verify the accuracy of the responses to either the NHIS or Florida survey, but the administrators of both surveys used various procedures to ensure the reliability of the survey data. We performed our work in accordance with generally accepted government auditing standards.

Families Incur a Wide Range of Disability-Related Costs

Families with children on SSI obtain a broad range of disability-related services, some from programs and some by purchasing them themselves. Data from the NHIS and Florida survey show that families purchased a broad range of disability-related services such as specialized day care, medical devices, and physical therapy.[30] In addition, data from the Florida survey show that the families' costs for these services varied widely. While the vast majority of the families in Florida incurred annual costs that were less than the maximum allowable SSI payments for a year, a small proportion of families incurred costs that greatly exceeded these payments. However, expenditure data do not indicate whether a child's disability-related needs have been met or whether families might have purchased additional services had they not faced constraints on their income. Other survey data and findings show that a key reason some families do not purchase services is that they cannot afford them, thus affecting the level of disability-related costs they incur. In addition, a family member's employment status and whether families obtain services from programs affect the level of their costs.

Families Purchase a Broad Range of Services

Data from the NHIS and Florida survey show that families with children on SSI obtain a broad range of disability-related services. While families obtain many of these services from programs, families may also purchase services. For example, about 87 percent of the Florida families surveyed reported that they purchased disability-related services for their SSI children, such as special diet or formula, special or additional clothing, or modifications to the home.[31] Tables 2.1 and 2.2 show that—for many of the services asked about in the NHIS and for almost every service asked about in the Florida survey—some proportion of families reported that they had incurred disability-related costs during the previous year. For example, at least half of the families in the Florida survey who provided transportation to or from service providers or obtained specialized day care, home-related services, special diet or formula, medical supplies, special or additional clothing, diapers (for use beyond the usual age), or assistive technologies (for example, devices to assist speech) reported purchasing these services over the past year.

[30]Families may purchase disability-related services or items entirely, or they may pay for only a portion of a service's cost, the difference being paid for by other sources.

[31]The remaining 13 percent of families did not report or did not incur any disability-related costs. The 87 percent figure may overstate the proportion of families reporting the purchase of disability-related services to the extent that the purchase of doctor visits, hospital care, or a van or car was not related to a child's disability and a family purchased no other disability-related service.

Table 2.1: Percentages of SSI Children in the NHIS Who Received Disability-Related Services and Whose Families Paid for Them Over the Past Year

Service	Percent of SSI children who received disability-related services[a]	Percent of service-receiving children whose families paid for services[b]
Medical care and therapy		
Doctor visits for conditions lasting at least 12 months	37.6	[c]
Home visits by a doctor	0.4	0
Visiting nurse	5.0	0
Social work services	14.5	1.3
Medications for conditions lasting at least 12 months	28.5	[c]
Mental health services[d]	18.3	4.5
Physical therapy	17.7	3.4
Occupational therapy	12.2	2.1
Audiologist services	9.3	10.2
Recreational therapist services	4.1	8.4
Speech therapy	27.7	0
Respiratory therapy	4.9	0
Hospital visits for regular treatments	7.8	[c]
Personal care		
Respite or substitute care[e]	7.0	9.1
Personal attendant services	2.4	0
Helpers[f]	47.6	5.0
Transportation		
Transportation services	15.3	12.3
Modify a van or car	1.0	[c]
Education		
Reader or interpreter	1.6	0
Special education	57.8	[c]
Physical education or recreation	17.5	[c]
Home		
Home modifications	22.9	[c]
Equipment and supplies		
Assistive devices and technologies[g]	31.8	7.5
Special diet	8.4	[c]
Other		
Services from a center for independent living	1.8	18.9

(Table notes on next page)

[a]Percentages are based on 450 weighted cases from the National Center for Health Statistics' 1994 and 1995 National Health Interview Survey, including the Disability Supplement and Disability Followback Child's Questionnaire. Sampling errors at the 95-percent confidence level for the percentages of SSI children receiving services did not exceed plus or minus 6 percentage points.

[b]We considered a family to have paid for a service if a parent or other family member in the household used his or her own income or the child's SSI cash benefit, either entirely or in part. These percentages should be interpreted with caution given the small sample sizes upon which many were based.

[c]Data are not available because questions about who paid for the service were not asked.

[d]Includes services for mental health or substance abuse in inpatient or outpatient settings or mental health community support programs. Payment information was not collected for community support programs.

[e]Payment information was collected only on paid employees of the family.

[f]Includes services received during the past 2 weeks rather than the past 12 months and includes services provided by family members. Payment information was collected only for up to four helpers per family.

[g]Includes medical devices and implants; payment information was collected only for medical devices.

Table 2.2: Percentages of SSI Children in the Florida Survey Who Received Disability-Related Services and Whose Families Paid for Them Over the Past Year

Service	Percent of SSI children who received disability-related services[a]	Percent of service-receiving children whose families paid for services[b]
Medical care, therapy, and insurance		
Doctor visits in a clinic or office[c]	85.6	13.9
Hospital care[c]	39.4	6.3
Skilled nursing services	17.3	8.8
Medications for CSHCN[d]	77.4	32.7
Counseling services	22.1	6.5
Higher health insurance premiums	3.8	[e]
Additional health insurance	1.9	[e]
Physical therapy	40.4	4.7
Occupational therapy	33.7	2.9
Speech therapy	41.8	1.2
Respiratory therapy	10.1	15.0
Personal care		
Respite or substitute care	22.1	47.7
Specialized day care	2.9	60.0
Personal attendant services	9.1	21.1

(continued)

Service	Percent of SSI children who received disability-related services[a]	Percent of service-receiving children whose families paid for services[b]
Transportation		
Transportation to and from CSHCN providers[d]	77.4	92.4
Emergency transportation	13.5	22.2
Purchase a van or car for CSHCN[c,d]	17.8	92.3
Education		
Educational services for CSHCN[d]	19.2	30.0
Home		
Extra charges on telephone bills	43.8	98.9
Extra charges on electric or other utility bills	29.8	100.0
Home modifications	13.0	87.5
Equipment and supplies		
Assistive technologies	15.9	50.0
Home or durable medical equipment	34.6	26.8
Special diet or formula	27.4	52.7
Special or additional clothing	16.8	94.4
Diapers beyond the usual age	36.1	76.3
Medical supplies (e.g., bandages)	30.3	67.2
Other		
Other	13.9	96.6

[a]Percentages are based on 208 cases in the University of Florida's Institute for Child Health Policy 1996 survey of children with special health care needs. Sampling errors at the 95-percent confidence level for the percentages of SSI children receiving services did not exceed plus or minus 7 percentage points.

[b]We considered a family to have paid for a service if a parent or other family member in the household used his or her own income or the child's SSI cash benefit, either entirely or in part. These percentages should be interpreted with caution given the small sample sizes upon which many were based.

[c]Some responses may include amounts for the receipt of or payment for services that are not specifically related to a child's disability.

[d]CSHCN stands for children with special health care needs.

[e]Data are not available because questions about who paid for the service were not asked.

Families' Costs Vary Widely

Data from the Florida survey show that the families who obtained disability-related services by purchasing them incurred a wide range of costs.[32] These families reported total costs ranging from $10 to more than $26,000 over the past year when all service expenditures are included, even some that were not necessarily attributable to the child's disability. Three-fourths of these families reported total annual costs of less than $3,000, half of the families reported total annual costs of $1,000 or less, and one-quarter of the families reported costs of $350 or less over the past year.

When services that are not necessarily attributable to a child's disability (that is, doctor visits in a clinic or office, hospital care, and the purchase of a car or van) are excluded from the analysis, families reported total annual expenditures ranging from $2 to $11,700.[33] Three-fourths of these families reported total annual costs of less than $1,782, half of the families reported total annual costs of $840 or less, and one-quarter of the families reported costs of $325 or less over the past year.

Although SSI payments may be used for any type of expenditure benefiting the child, to provide a perspective on the magnitude of these costs, we compared total annual costs with the maximum SSI payments a family could receive for a child for a year.[34] The Florida data show that of the families who incurred disability-related costs, about 90 percent reported total annual costs below the annual maximum allowable SSI payment.[35] Moreover, about half of the families reported costs of less than 20 percent of the maximum SSI payment. However, about 10 percent of the families reported expenditures that exceeded the maximum SSI payment. Included in these calculations are families' reported costs for services that are not necessarily attributable to a child's disability. When these services are excluded from the calculations, about 95 percent of the families reported

[32]We did not calculate total families' disability-related costs from NHIS data because the survey did not ask respondents about a comprehensive range of services and what they spent for them, as did the Florida survey.

[33]Some or all expenditures for doctor visits in a clinic or office, hospital care, and the purchase of a car or van may be attributable to a child's disability. But because the data do not allow us to segregate the costs of the services that are or are not attributable to a child's disability, we present total annual costs of Florida families in two ways: both including and excluding the costs of these services.

[34]The monthly maximum SSI payment in 1996 was $470. This amount for the year was $5,640.

[35]When we compared total annual costs for Florida families who incurred disability-related costs with the mean annual SSI payments for children in Florida in 1996, we found that about 86 percent of these families incurred total annual costs less than the mean SSI payments for the year. The mean annual SSI payments for children in Florida amounted to $5,181 as of December 1996.

annual disability-related costs below the annual maximum SSI payment.[36] About 5 percent of the families, however, still reported disability-related costs that exceeded the maximum SSI payment.

This pattern from the Florida data may not be representative of all SSI families in the United States. However, this data pattern is consistent with the nationwide pattern of disability-related expenditures presented in a 1981 study by Social and Scientific Systems, Inc., and Mathematica Policy Research, Inc. That study, which was based upon a survey of a national sample of SSI families, found that 5 percent of the families reported costs exceeding their monthly SSI payment, while nearly 80 percent had an SSI payment that exceeded their costs by more than $100 per month.[37]

Nevertheless, while it might seem from the data that the SSI payment covers disability-related costs for most families in Florida, such data do not indicate whether a child's disability-related needs have been met. Because expenditure data reflect only actual purchases, we are unable to determine whether or the extent to which families with SSI children might have purchased additional needed services, and thus incurred greater costs, had their incomes been higher.[38] For example, the data do not allow us to determine the extent to which what was purchased reflects a tradeoff between disability-related services and basic necessities such as food, clothing, and shelter for the entire family. Because families can use the monthly SSI payment for any type of purchase that benefits the disabled child, some families may decide that they can use only a portion

[36]About 95 percent of the families who incurred costs also reported annual disability-related costs less than the 1996 mean annual SSI payments for children in Florida.

[37]To examine the disability-related costs incurred by families with SSI children, researchers for Urban Systems Research and Engineering, Inc., selected from SSA's Supplemental Security Record a stratified random sample of about 2,500 children receiving SSI as of December 1977, who were living in the continental United States and were not living in institutions paid by Medicaid. The researchers completed about 1,850 interviews, for a response rate of 74 percent. Social and Scientific Systems, Inc., and Mathematica Policy Research, Inc., analyzed these data as part of their own study on the costs families said they incurred on a particular set of disability-related services. This set of services, however, was not comprehensive, since it did not include such common disability-related services as transportation and special diet and clothing. Because the survey did not ask families about a comprehensive range of services, its results may understate disability-related costs. In addition, 29 percent of the families reported being unable to afford certain disability-related services for their children. Specifically, 39 percent of the families reported that they needed additional health services, and 25 percent reported that they needed additional special equipment. These findings might be different if data were collected today, because advances in medicine and technology in the almost two decades since this study have resulted in new treatments and services for children with disabilities. See Urban Systems Research and Engineering, Survey of Blind and Disabled Children Receiving Supplemental Security Benefits, and Maxfield and Kendall, Disabled Children in the Supplemental Security Income Program.

[38]Data from the NHIS show that about 53 percent of the children on SSI live in a household with a monthly income below the federal poverty level. Monthly income includes transfer payments such as SSI. The data exclude the 12 percent of children in the sample for whom poverty status was unknown.

of the SSI benefit for purchasing disability-related services and that the remainder should go toward purchasing other necessities such as food, clothing, or shelter.

In this regard, data from both surveys show some families reporting that they do not obtain needed services for their children. About 38 percent of the respondents in the Florida survey, and about 39 percent of the respondents in the NHIS, reported that they needed but did not obtain one or more services for their children. These survey data, however, likely do not reflect the full extent to which families needed but did not obtain services. The surveys generally asked families about services needed but not obtained at all but rarely asked about the need for additional services that families had already obtained but in insufficient quantity.

Multiple Factors Affect Families' Level of Costs

A variety of factors, aside from the particular service needs of a child, influence families' purchase of services and, hence, their level of disability-related costs. A key reason that some families do not purchase needed services is that they cannot afford them. Another factor is a family member's decision about employment, which affects not only a family's income, and thus its ability to purchase services, but also its need to purchase certain types of disability-related services. Finally, whether or not families are able to obtain services from programs also influences the level of their costs.

Service Affordability Affects the Purchase of Services

A key reason why some families do not purchase services that they do not obtain from programs is that they cannot afford them. In the Florida survey, about 60 percent of families there who were unable to obtain one or more needed services for their children reported that they did not obtain them because they were too expensive. Similarly, 31 percent of the NHIS respondents who were unable to obtain needed services stated that they did not obtain them because they were too expensive. In addition, families and case managers we interviewed during our site visits mentioned service expense as a key issue in families' being able to purchase needed services.

Employment Decisions Can Affect the Purchase of Services

Family employment decisions can influence the level of disability-related costs. A family member's decision to work or stay at home to care for a child with a disability affects not only the family's income, and thus its ability to purchase services, but also its need to purchase certain types of

services, such as specialized day care or certain types of physical or occupational therapy, that the family member at home may now be able to provide. Labor market participation studies suggest that, in making a decision about employment, a family member compares his or her potential wage with the availability, cost, and quality of child care and other services provided by the market and with the cost and quality of care and services that other family members, friends, or other community sources provide.[39] The family member also weighs the public benefits, such as SSI and Medicaid, that could be obtained. For example, the child's SSI benefits provide some offset to earnings lost by staying at home, and other assistance programs, such as Medicaid, may cover a child's needed services at little or no cost to the family. Such assistance could make the family better off economically than it would be if the family member worked for low wages.

In families with children, a family member whose wage earning potential is relatively low is less likely to be employed than a family member whose earnings potential is high. Moreover, the tendency for a lower-wage earner to choose to remain at home is likely to be greater in families with disabled children whose care needs may be greater or more expensive or who may be more difficult to place in market-based child care arrangements. For example, a parent with a disabled child may choose to quit work, reduce the number of hours he or she works, or make other work-related changes in order to care for the child at home if market-based child care, including specialized care related to the child's disability, is too expensive or not available.

In the NHIS and Florida survey, many families reported that caring for a child's special health care needs reduced family employment. Almost one-third of the respondents in the NHIS said their children's health was a reason that someone in the family had not taken a job in order to care for a child. Moreover, about one-fifth of the NHIS respondents indicated that someone in their family had quit working or worked fewer hours because of a child's health. Similarly, nearly 40 percent of the families participating in the Florida survey reported that caring for their children's special needs caused someone in the family to not work, 33 percent reported turning down a job, and 20 percent reported working less.

[39]See, for example, Child Care: Child Care Subsidies Increase Likelihood That Low-Income Mothers Will Work (GAO/HEHS-95-20, Dec. 30, 1994), p. 3, and Rachel Connelly, "The Effect of Child Care Costs on Married Women's Labor Force Participation," Review of Economics and Statistics, Vol. 74, No. 1 (Feb. 1992), pp. 83-90.

Case managers, community organization representatives, and families we interviewed during our site visits described two key factors that contributed to some family members' working less or quitting work to care for their children. First, a shortage of some services, particularly specialized day care, causes some family members to forgo paid work in order to care for the children themselves. Second, the care-giving demands on some family members—for example, the need to take a child to multiple medical appointments or to make unanticipated visits to the child's school or day care center during normal work hours—lessens the feasibility of work.

A decision to not work or to reduce working hours can affect both the ability to purchase services, through the resulting loss in earnings, and the need to purchase some types of services. Survey data show that the presence of a child with special needs in a family can reduce family income. About 40 percent of the Florida survey respondents reported that family income decreased after the birth of a special-needs child. Of the families whose income decreased, 50 percent reported a decrease of $600 or more a month and half of these reported a decrease of $1,400 or more. Three-quarters of the families with a decrease in income reported that the decrease continued for more than 12 months. In addition, about 15 percent of the NHIS respondents reported having severe financial problems during the past year because of a child's health. Moreover, although the total extent of caregiving is not known from the survey data, 46 percent of the families in the Florida survey reported that someone in the household provided therapies or other health-related care for their children. In families in which a member has chosen to not work and to provide services, such as certain types of specialized day care, family expenditures for these services are lower than if the family had purchased them.

Whether or Not Families Obtain Services Through Programs Affects Their Costs

Whether or not families are able to obtain services through programs also affects the disability-related expenses they incur. Tables 2.3 and 2.4 show that public programs were widely cited as a source of full or partial funding for many of the services that families obtained for their SSI children. For almost every disability-related service included in the NHIS and Florida survey, some proportion of families with SSI children reported public programs as sources of payment for services obtained during the previous year. For example, more than half of the respondents in the NHIS who obtained social work services, the services of a visiting nurse, physical therapist services, audiologist services, mental health services, respiratory therapy services, or personal attendant services for their

children reported Medicaid as a source of payment. Also, more than half of the families in the Florida survey who obtained counseling services, skilled nursing services, medications for a child's special health care needs, respiratory therapy, home or durable medical equipment, emergency transportation, doctor visits in a clinic or office, or hospital care for their children reported Medicaid as a source of payment.[40]

Table 2.3: Percentages of SSI Children in the NHIS Who Received Disability-Related Services and the Public and Private Sources That Paid for Them Over the Past Year

Service	Percent of SSI children who received disability-related services[a]	Percent of service-receiving children who received services from public or private sources[b]					
		Medicaid	Rehabilitation program	School system	Other public source[c]	Private health insurance	Other private source[d]
Medical care and therapy							
Doctor visits for conditions lasting at least 12 months	37.6	[e]	[e]	[e]	[e]	[e]	[e]
Home visits by a doctor	0.4	0	100.0	0	100.0	0	0
Hospital visits for regular treatments	7.8	[e]	[e]	[e]	[e]	[e]	[e]
Visiting nurse	5.0	87.4	3.1	3.1	12.6	3.8	0
Social work services	14.5	57.6	8.2	12.3	28.2	3.6	3.5
Medications for conditions lasting at least 12 months	28.5	[e]	[e]	[e]	[e]	[e]	[e]
Mental health services[f]	18.3	64.0	1.0	6.2	8.2	6.8	0
Physical therapy	17.7	52.6	3.6	44.8	8.8	3.4	5.1
Occupational therapy	12.2	37.2	2.7	59.9	6.7	3.6	1.7
Audiologist services	9.3	69.3	5.4	34.8	3.6	13.4	0
Recreational therapist services	4.1	18.8	17.8	56.2	17.3	8.4	4.9
Speech therapy	27.7	27.4	0.9	72.8	3.8	0.7	0.6
Respiratory therapy	4.9	92.2	0	0	23.3	3.9	0
Personal care							
Respite or substitute care	7.0	[e]	[e]	[e]	8.3[g]	[e]	42.1[h]
Personal attendant services	2.4	71.9	10.9	9.3	27.6	0	18.4
Helpers[i]	47.6	3.2	2.4	4.3	3.5	0	0.6
Transportation							
Transportation services	15.3	20.8	7.7	52.8	13.2	0	0
Modify a car or van	1.0	[e]	[e]	[e]	[e]	[e]	[e]

(continued)

[40]The questions relating to hospital care and doctor visits in a clinic or office were phrased in such a manner that one cannot determine the extent to which those services were related to the child's special health care needs.

Service	Percent of SSI children who received disability-related services[a]	Percent of service-receiving children who received services from public or private sources[b]					
		Medicaid	Rehabilitation program	School system	Other public source[c]	Private health insurance	Other private source[d]
Education							
Special education	57.8	[e]	[e]	[e]	[e]	[e]	[e]
Reader or interpreter	1.6	17.6	10.9	56.2	0	0	0
Physical education or recreation	17.5	[e]	[e]	[e]	[e]	[e]	[e]
Home							
Home modifications	22.9	[e]	[e]	[e]	[e]	[e]	[e]
Equipment and supplies							
Assistive devices and technologies	31.8	[e]	[e]	[e]	[e]	[e]	[e]
Special diet	8.4	[e]	[e]	[e]	[e]	[e]	[e]
Other							
Services from a center for independent living	1.8	21.4	9.2	5.9	59.6	18.9	0

[a]Percentages are based on 450 weighted cases from the National Center for Health Statistics' 1994 and 1995 National Health Interview Survey, including the Disability Supplement and Disability Followback Child's Questionnaire. Sampling errors at the 95-percent confidence level for the percentages of SSI children receiving services did not exceed plus or minus 6 percentage points.

[b]These percentages should be interpreted with caution given the small sample sizes upon which many were based.

[c]Excludes the Department of Veterans Affairs (VA) and other military programs. For two services, less than 3 percent of those receiving the services reported VA or other military programs as sources of payment. For the remaining services, no respondent reported VA or other military programs as sources of payment.

[d]Excludes family members not in the household and the parents' employers. No respondent reported family members not in the household as a source of payment for any service. For three services, less than 4 percent of those receiving the services reported a parent's employer as a source of payment. For the remaining services, no respondent reported a parent's employer as a source of payment.

[e]Data are not available because questions about who paid for the service were not asked.

[f]Includes services for mental health or substance abuse in inpatient or outpatient settings or mental health community support programs. Payment information was not collected for community support programs.

[g]Includes only responses to "any other source" of payment, which may include some private funding.

[h]Includes only responses to "a paid employee of an organization or business," some of which may receive public funding.

[i]Includes services received during the past 2 weeks rather than the past 12 months and includes services provided by family members. Payment information was collected only for up to four helpers per family.

Table 2.4: Percentages of SSI Children in the Florida Survey Who Received Disability-Related Services and the Public and Private Sources That Paid for Them Over the Past Year

Service	Percent of SSI children who received disability-related services[a]	Percent of service-receiving children who received services from public or private sources[b]						
		Medicaid	Rehabilitation program	School system	Title V	Other public source[c]	Private health insurance	Other private source[d]
Medical care, therapy, and insurance								
Doctor visits in a clinic or office[e]	85.6	76.7	0	0	31.3	3.3	20.0	1.7
Hospital care[e]	39.4	84.1	0	0	33.8	2.5	25.0	3.8
Skilled nursing services	17.3	64.7	0	12.1	23.5	12.1	9.1	3.0
Medications for CSHCN[f]	77.4	85.0	0	0	17.0	1.9	13.8	1.3
Counseling services	22.1	60.9	4.3	26.1	10.9	10.9	8.7	0
Higher health insurance premiums	3.8	[g]	[g]	[g]	[g]	[g]	[g]	[g]
Additional health insurance	1.9	[g]	[g]	[g]	[g]	[g]	[g]	[g]
Physical therapy	40.4	47.7	0	48.9	21.2	9.4	8.2	1.2
Occupational therapy	33.7	39.1	0	64.8	13.0	8.6	4.3	1.4
Speech therapy	41.8	25.6	0	70.5	4.7	4.6	2.3	0
Respiratory therapy	10.1	73.7	0	0	15.8	0	15.8	0
Personal care								
Respite or substitute care	22.1	17.8	2.2	0	8.9	34.8	2.2	2.2
Specialized day care	2.9	0	0	0	20.0	80.0	0	0
Personal attendant services	9.1	42.1	0	21.1	10.5	25.0	0	0
Transportation								
Transportation to and from CSHCN providers[f]	77.4	8.3	0.6	0	2.4	1.8	0.6	0
Emergency transportation	13.5	76.7	0	0	17.2	0	26.7	3.4
Purchase a van or car for CSHCN[e,f]	17.8	0	0	0	0	2.6	0	5.1

(continued)

Service	Percent of SSI children who received disability-related services[a]	Percent of service-receiving children who received services from public or private sources[b]						
		Medicaid	Rehabilitation program	School system	Title V	Other public source[c]	Private health insurance	Other private source[d]
Education								
Educational services for CSHCN[f]	19.2	7.5	0	56.1	2.5	12.5	2.5	0
Home								
Extra charges on telephone bills	43.8	1.2	0	0	0	2.4	0	0
Extra charges on electric or other utility bills	29.8	1.6	0	0	1.6	1.6	0	0
Home modifications	13.0	0	0	0	8.3	20.0	0	4.2
Equipment and supplies								
Assistive technologies	15.9	3.1	3.1	37.5	9.4	3.1	3.1	9.4
Home or durable medical equipment	34.6	52.8	0	0	50.0	1.4	15.1	4.2
Special diet or formula	27.4	28.1	0	0	13.8	22.4	1.8	0
Special or additional clothing	16.8	6.1	0	0	6.1	0	0	0
Diapers beyond the usual age	36.1	11.7	0	0	7.8	15.6	2.6	1.3
Medical supplies (e.g., bandages)	30.3	34.4	1.6	0	26.2	1.6	8.1	1.6
Other								
Other	13.9	10.7	0	3.7	7.4	0	3.7	0

[a]Percentages are based on 208 cases in the University of Florida's Institute for Child Health Policy 1996 survey of children with special health care needs. Sampling errors at the 95-percent confidence level for the percentages of SSI children receiving services did not exceed plus or minus 7 percentage points.

[b]These percentages should be interpreted with caution given the small sample sizes upon which many were based.

[c]Excludes VA and other military programs. For five services, no more than 3 percent of those receiving the service reported VA or other military programs as sources of payment. For the remaining services, no respondent reported VA or other military programs as sources of payment.

[d]Excludes family members not in the household as a source of payment. For 11 services, less than 5 percent of those receiving the services reported family members not in the household as a source of payment. For the remaining services, no respondent reported family members not in the household as a source of payment.

[e]Some responses may include amounts for the receipt of or payment for services that are not specifically related to a disability.

[f]CSHCN stands for children with special health care needs.

[g]Data are not available because questions about who paid for the service were not asked.

In addition, more than half of the respondents in the NHIS who obtained services such as occupational therapist services, services from a speech therapist or pathologist, or recreational therapist services for their children reported the school system as a source of payment. And more than half of the families in the Florida survey who obtained occupational therapy, speech therapy, or educational services related to special health care needs (such as tutoring, books on tape, and sensory integration) for their children reported the school system as a source of payment.

Data from both surveys also show that while some families obtained services that were funded in whole or part by a program, other families purchased the same types of services. For example, many families in both surveys reported Medicaid as a source of payment for a number of disability-related services, yet some families also reported purchasing these same types of services. A variety of factors discussed in chapter 3 may affect a family's ability to obtain services through programs.

Program, Service, and Family-Related Factors Affect Families' Receipt of Program Services

A variety of factors affect families' receipt of services through programs. (See table 3.1.) First, SSI beneficiary status generally does not entitle a child to a program's services. Because of certain aspects inherent to the design of a program—such as eligibility criteria, the number of available service slots, and whether it covers needed services—some SSI children may not receive services from particular programs. Second, because of difficulties in identifying who needs services and what services they need, programs may not be serving some children. Third, once children's service needs are identified, their gaining access to some program services that are in short supply can be difficult. Overall, families play an important role in obtaining services for their children. Yet some families' limited knowledge of program options and their rights to them, limited ability to proactively pursue services for their children, or lack of transportation or other supports hinders their ability to play this role, which may result in their not acquiring some services.

Table 3.1: Factors Affecting Families' Receipt of Services From Programs

Factor	Aspect
Program design	Program eligibility criteria Number of available service slots Service coverage
Identifying eligible children and their needs	Challenges in making service decisions Insufficient understanding of childhood disability Screening for services less frequently than HHS recommends
Gaining service access	Provider shortages Program officials' concerns about service costs Limited help gaining access to program services
Families' circumstances	Limited knowledge of program options and legal rights Limited ability to proactively pursue services Lack of transportation and other supports facilitating access

Program Design May Affect Whether Children Receive Services

Some children, despite their SSI beneficiary status, do not receive services from programs because of certain aspects inherent to program design.[41] An SSI child may not meet the eligibility criteria to qualify for a program. Even when a child qualifies, he or she still may not be admitted to the program because the service slots may be filled. Moreover, once a child has been admitted to a program, it may not cover a service that the child needs. Or if the service is covered, the child may not fulfill requirements to receive it.

[41]We were unable to identify the extent to which any of these aspects of program design affect access to program services for children on SSI, because the programs in large part do not track program participation by whether a child is an SSI recipient.

A Child May Not Meet Program Eligibility Criteria

Even when children are SSI recipients, they may not meet the eligibility criteria that a program uses to screen admissions. For example, in most states, children on SSI automatically qualify for Medicaid. In 11 states, however, children must meet more restrictive disability, income, and asset standards than those required to qualify for SSI benefits. As a consequence, some of the children on SSI in those 11 states may be ineligible for Medicaid, although SSA and HCFA officials told us they do not know the size of the ineligible population.

Children on SSI are also not automatically eligible for the Special Education or Early Intervention programs. Regardless of whether children receive SSI benefits, to qualify for Special Education, they must undergo a separate assessment to determine whether they have one of several broad qualifying disabilities—such as mental retardation—or, in some states, experience a developmental delay.[42] Any child assessed as having a qualifying disability or delay must also demonstrate that special educational services are needed in order to receive an appropriate education. Eligibility for Early Intervention requires an infant or toddler to be developmentally delayed as defined by the state or have a condition likely to cause a delay.[43] As a result, a child receiving SSI may not be found eligible for these programs.

Further, children younger than 16 on SSI do not automatically qualify for title V services, even though they are to be referred to the state title V program for rehabilitation services. Rather, children on SSI must meet the individual state title V program's eligibility criteria. For example, in about 38 states, children on SSI—like all other applicants—must have at least one of several specific conditions to be eligible for the title V program.[44] But among these states, some of the more prevalent impairment types among the population of children on SSI do not qualify a child for title V services. In fact, children with mental retardation or other mental impairments

[42]To qualify for Special Education, a child must generally be aged 3 through 21. Children aged 3 through 5 and 18 through 21 are eligible for special education if allowed under state law. Some states and localities, at their discretion, also provide services to children 3 through 9 who are experiencing a developmental delay.

[43]Eligibility for Early Intervention requires that a child be younger than 3 years old.

[44]To obtain these data, we performed an analysis of findings from a 1997 survey of state title V programs conducted by the Institute for Child Health Policy at the University of Florida. The Institute collected data on eligibility criteria and scope of services from 50 state title V programs and the District of Columbia's title V program. We confirmed our analysis of this survey with 44 state title V programs and the District of Columbia's program. Among the remaining six programs, three did not reply to our request for confirmation, and we did not reanalyze data on three programs that generally do not serve children on SSI. See Institute for Child Health Policy, University of Florida, Directory of State Title V CSHCN Programs' Eligibility Criteria and Scope of Services (Gainesville, Fla.: May 1997).

(accounting for 64 percent of all children receiving SSI) do not qualify for the program in 25 states.[45]

Some Children Are Not Admitted to Programs Because Service Slots Are Limited

A child who meets a program's eligibility criteria might not be admitted to the program if the service slots are filled. In our site visits, programs offering specialized day care, respite care, and summer recreation were identified as having a limited number of slots. In contrast, other programs, such as EPSDT and Special Education, admit all entitled individuals.

Programs with a limited number of available slots use various approaches to decide which qualifying children to select for admission. For example, a 1995 survey of 58 state family support programs by the Human Services Research Institute found that they used one or more approaches to select children: 16 percent selected all who applied, half made "first come, first served" selections, 36 percent made selections on the basis of "need" according to the program's definition (for example, severity of a child's disability or family coping skills or stress level), and 10 percent used a lottery.[46]

If the number of available slots is limited, children either may not be admitted to a program or may be placed on a waiting list, which, if sufficiently lengthy, may effectively mean some will not be admitted to the program. About half of the family support programs in 1995 had a waiting list, and one-quarter had a waiting list of 400 or more families. A Texas family support program had a waiting list of nearly 10,200 in 1996. And among the 13 percent of NHIS respondents who tried to obtain additional Special Education services, nearly one-quarter said that their children had been on a waiting list for one or more Special Education services during the previous year.

[45]A child with a mental impairment, such as mental retardation, can qualify for a title V program if he or she has a secondary physical impairment that qualifies the child for the program. According to our analysis of the Institute for Child Health Policy survey of state title V programs, some title V programs use other types of eligibility criteria, as follows: the child's condition results in impaired growth, development, or limited functioning or other factors related to the severity of the condition (35 programs); nonintervention by the program may lead to a disabling condition or the child's condition may put him or her at risk for a disability or handicap (26 programs); the child's condition requires a particular treatment or is amenable to treatment (32 programs); the child's condition lasts for a certain period of time (28 programs); needed services are available (7 programs); the child's condition affects the family (6 programs).

[46]John Agosta and Kerri Melda, Results of a National Survey of Family Support Programs for People With Disabilities and Their Families (Salem, Ore.: Human Services Research Institute, 1995).

Service Coverage Can Affect Service Receipt

Once a child is admitted to a program, it may not cover all the disability-related services that he or she needs. The largest federal and state programs serving children with disabilities generally do not cover home-related services (extra telephone and utility charges and home modifications), certain supplies (diapers needed by a disabled child who is beyond the usual age for using them and special diet or formula and clothing), respite care, over-the-counter medications for disability-related conditions, and expenses related to the purchase or modification of a vehicle beyond what a family would normally spend. (See appendix II for a summary of the services covered by the programs in our study.) For example, EPSDT and Special Education typically do not cover any of these services. Similarly, with the exception of respite care and special clothing, Early Intervention does not cover these services. In addition, the Medicaid Home and Community-Based Waivers and title V programs allow the states to determine the scope of covered services, and many of the states have opted not to cover these services.

Even when a program covers a needed service, a child may not meet the eligibility requirements to receive it. Programs use a range of requirements that must be met in order to obtain a service. For example, in order for a child to receive a Medicaid service in a state, including an EPSDT service, the service must be "medically necessary." Medical necessity is defined and assessed by each state's Medicaid program and therefore can vary from state to state. Similarly, a Special Education service must be deemed "educationally necessary" owing to a child's impairment for the child to receive it.

Difficulties in Identifying Eligible Children and Their Needs May Hinder Families in Obtaining Services

Because of difficulties in identifying which children need services and what services they need, programs may miss serving some children who need services. First, making decisions about the type and amount of services a child needs is difficult: The decisions are inherently complex, and standardized methodologies to aid in making some decisions are lacking. Second, according to the results of research studies and site visit interviews with program officials, case managers, and community organizations, some providers who deliver health and educational services lack a sufficient understanding of childhood disability. Finally, state Medicaid programs are not screening children for needed EPSDT services at the frequency recommended by the Secretary of HHS, which means that some children may have disability-related service needs that the program has not identified.

Difficulties in Making Service Decisions Can Lead to Discrepant Views on Which Services Are Necessary

Making decisions about the type and amount of services that are necessary for children with disabilities can be difficult. Research studies and experts generally agree that the service needs of children with disabilities are highly individualized, which makes the task of determining their need for services inherently complex.[47] Exacerbating this difficulty is the lack of a clear scientific consensus on the appropriate service interventions for some disabilities.[48] For example, title V program directors have said that managed care plans have differing interpretations of what is medically necessary for children and have called for better definitions of medical necessity for early intervention services.[49] To the extent that a standardized methodology for determining service need is unavailable, program officials can have difficulty knowing the precise type and amount of services and items necessary to meet a child's needs. In such instances, professional judgment is significant in decisionmaking. For instance, HCFA officials told us that decisions Medicaid makes about the medical necessity of certain services, such as assistive technology, diapers, recreational therapy, and personal care for a child with mental illness, involve professional judgment and could thus lead to divergent decisions among program officials.[50] When program officials disagree, one may decide that a child needs a particular service while another may reach the opposite conclusion. Moreover, in several instances during our site visits, we also heard divergent views between program officials and providers (such as physicians) about whether a service is necessary.

[47]Two children with the same disability could have quite different service needs. The individualized nature of need stems from the multiple factors that influence need, including severity of impairment, functional level, the characteristics of the families, and broader physical and social environments.

[48]Some experts have noted that disability in children has not been the focus of much scientific study. For instance, the cause, progression, and effect of some impairments are not well understood, and the tools to measure these concepts have not been well developed.

[49]Margaret McManus and others, Strengthening Partnerships Between State Programs for Children With Special Health Needs and Managed Care Organizations (Washington, D.C.: Maternal and Child Health Policy Research Center, Mar. 1996). This 50-state mail survey of title V programs, prepared for the HHS Maternal and Child Health Bureau, focused on the critical issues concerning managed care initiatives.

[50]Discrepant views also occur over whether the benefit derived from a service is primarily educational or medical. For example, assistive technologies, such as augmentative communication devices, are subject to debate and disagreement as to whether they have primarily an educational or a medical benefit.

Some Providers' Insufficient Understanding of Childhood Disability May Hamper Effective Service Determination

According to research studies and interviews we conducted with program officials, case managers, and community organizations, some providers who deliver health and educational services to children lack sufficient understanding of childhood disability. Consequently, programs may not identify some children with disabilities who need services or may not provide services to children who may be eligible for them.

Teachers, for example, play a key role in identifying students who need Special Education services and in helping to determine what services they need. But some teachers may not be fully prepared to play this role. For example, the National Longitudinal Transition Study, which collected nationwide data between 1987 and 1990, found that only 19 percent of regular education teachers received training on the needs of disabled students.[51] In addition, Alabama's Supreme Court held in 1993 that some school districts could not offer certain programs to children with disabilities because there were no qualified staff to teach them. As a result, local authorities were unable to ensure that even minimum standards in instruction for children with disabilities were being met.[52] Similarly, in 1994 during field hearings on IDEA, several witnesses stressed the need for teacher preparation in learning about disabilities and working with students who have them.[53] The 1997 amendments to the IDEA state that "over 20 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by . . . supporting high-quality, intensive professional development for all personnel who work with" children with disabilities.[54] Yet the Department of Education has stated that there is "convincing evidence of a national substantial chronic shortage of special education teachers who are fully certified in their positions."[55]

[51]Congressional Research Service, Special Education: Issues in the State Grant Program of the Individuals With Disabilities Education Act (Washington, D.C.: Mar. 20, 1995), pp. 30-31. The National Longitudinal Transition Study is the most current information on educational outcomes for students with disabilities.

[52]Opinion of the Justices, No. 338, 624 So.2d 107 (Ala. 1993).

[53]Equal Educational Opportunity and Nondiscrimination for Students with Disabilities: Federal Enforcement of Section 504, Equal Educational Opportunity Project Series, Vol. II (Washington, D.C.: United States Commission on Civil Rights, Sept. 1997), p. 262.

[54]Amendments to the Individuals With Disabilities Education Act, P.L. 105-17, title I, June 4, 1997.

[55]Department of Education, Twentieth Annual Report to Congress on the Implementation of the Individuals With Disabilities Education Act (Washington, D.C.: 1998), p. vi.

Screening for Needed Services Is Not Always Conducted at the Recommended Frequency

State Medicaid programs do not always screen children for EPSDT services at the frequency recommended by the Secretary of HHS. Therefore, some children with disabilities may have needs for services that the program has not identified and that they may thus not be receiving. The screening component of EPSDT is designed to identify children's health problems before they become more complex or disabling and require more costly treatment. Specifically, each state's EPSDT program must provide age-appropriate health assessments—that is, screening examinations—according to a schedule the program establishes.

However, research has consistently shown that state EPSDT programs did not achieve HHS's goal of providing 80 percent of the annual scheduled screening examinations by 1995.[56] A review of EPSDT operations between 1989 and 1997 found that the program "has never met its objective to ensure that children received continuous and comprehensive medical care. EPSDT participation rates—even for the basic screening examinations—have been low throughout the history of the program."[57] Also, in 1998, we reported that 81 percent of children receiving Medicaid benefits had not been previously screened for blood lead toxicity.[58]

Gaining Access to Needed Program Services Is Sometimes Difficult

Even when a child's service needs are identified, gaining access to some program services can be difficult. A child's family may have difficulty gaining access to services because some providers and the services they offer are either unavailable or in short supply in some communities. Additionally, program officials' concerns about service cost can affect a child's access to special education services. Further, service access may be hindered because program officials do not always help families gain access to related programs' services.

[56]The Omnibus Budget Reconciliation Act of 1989 (P.L. 101-239) required the states to establish timetables for well-child examinations consisting of medical, dental, vision, and hearing screens for each child covered by EPSDT. In response to the act, the Secretary of HHS set the goal that state EPSDT programs were to provide 80 percent of the annual screening services recommended for each age group by 1995. Although research has consistently shown that EPSDT programs did not achieve their screening goals, some researchers have noted that EPSDT participation rates tend to understate the number of screening examinations provided by Medicaid, as providers can either fail to correctly report a visit as an EPSDT screening examination or fail to report the visit at all.

[57]A. Sardell and K. Johnson, "The Politics of EPSDT Policy in the 1990s: Policy Entrepreneurs, Political Streams, and Children's Health Benefits," The Milbank Quarterly, Vol. 76, No. 2 (1998), p. 179.

[58]Medicaid: Elevated Blood Lead Levels in Children (GAO/HEHS-98-78, Feb. 20, 1998). We based this study on data from the National Health and Nutrition Examination Survey, Phase 2 (1991-94).

Providers Are in Short Supply

Some providers and the services they offer are either unavailable or in short supply in some communities, hindering access to services. The Florida and NHIS survey results indicate that some disability-related services are unavailable to some families who need them. Among the families in the Florida survey who were unable to obtain one or more needed services for their children, 23 percent said they did not obtain a needed service because it was unavailable. And among NHIS participants who were unable to obtain needed services, about 40 percent responded that they did not obtain a service because it was unavailable.

Experts and representatives from community organizations and case managers with whom we met during our site visits told us that provider shortages reduce service availability and, thus, family access to services. For example, in our site visits, a range of services were mentioned as being in short supply: specialized day care; respite care; occupational, speech, and physical therapies; care coordination; transportation; special education; special equipment; and mental health and physician services. Likewise, title V program directors in a 50-state survey most frequently cited overall shortages in pediatric specialty providers when asked about their concerns regarding pediatric managed care.[59] Moreover, as noted earlier, the Department of Education maintains that the shortage of fully certified special education teachers is a chronic national problem.[60]

In addition, we heard during our site visits that shortages of some services—Early Intervention services, transportation, specialized day care, respite care, and medical services—are more pronounced in rural than in other areas. Researchers have found similar problems in rural areas of the country. For example, title V directors reported that shortages in pediatric specialty providers were particularly acute in rural states.[61]

Program Officials' Concerns About Costs Can Limit Access to Special Education Services

Research studies and information from our site visits indicate that the concerns program officials have about service cost can affect a child's receipt of special education services. Because some disability-related services are expensive, concerns about their cost may limit children's access to them. For example, the U.S. Commission on Civil Rights reported that the cost of assistive technologies is a particular concern of

[59]McManus and others, Strengthening Partnerships Between State Programs.

[60]Department of Education, Twentieth Annual Report to Congress on the Implementation of the Individuals With Disabilities Education Act.

[61]McManus and others, Strengthening Partnerships Between State Programs.

school officials and that technology devices and services for students in special education programs can be a major expenditure for local school districts. Difficulties in funding these services can prevent schools from using technology in educating students with disabilities.[62]

During our site visits, program officials, case managers, and representatives from community organizations told of instances in which concerns about cost affected a child's receipt of services. In order for a child to receive services through the Special Education program, the IDEA requires that a local team prepare an Individualized Education Program (IEP) detailing the specific special education and related services, supports, and aids needed for the child to receive an appropriate education. In some cases, the teams responsible for determining the child's special education service needs and preparing the child's IEP exclude a service—such as assistive technology used for communication—from the IEP because of its cost.

Some Programs Do Not Help Families Gain Access to Services From Other Programs

Experts note that some program officials provide only limited information to families about community resources or do not see themselves as responsible for providing information about services available from other programs. In addition, we found during our site visits that some programs do not refer children with disabilities to other programs. For example, several case managers discussed school systems that did not refer children with disabilities to the state agency that provides vocational rehabilitation, although these children had reached an appropriate age for school-to-work transition planning. Moreover, case managers are often assigned to families but focus primarily on services offered by their own program and are not always aware of services from other programs.

[62]Equal Educational Opportunity and Nondiscrimination for Students with Disabilities, pp. 311-12.

Limited Program Knowledge and Other Circumstances Impede Some Families From Obtaining Program Services

Some families' limited knowledge of programs and services, limited ability to proactively pursue services, or lack of transportation or other supports hinder their ability to obtain services for their children, which may then not be acquired. According to evidence from research studies and site visits, families who are knowledgeable about program services and procedures and proactive in pursuing them are more successful in obtaining services for their children than those who are not.[63] For instance, when programs do not refer children with disabilities to other programs that provide needed services, families have a greater responsibility to identify those programs and arrange for service delivery. However, we learned from our site visits, review of research studies, and interviews with experts that some families lack this knowledge and ability to be proactive in obtaining services. For example, some families do not know about services that programs offer. Thus, these families may be unaware that disability-related services, such as respite care, exist, or the families may pay for services because they do not realize that a program covers them. Still other families are unfamiliar with their legal rights to services and the procedures established to protect those rights. Finally, some families are unfamiliar with the steps, procedures, and terminology needed to gain access to program services.

In addition, our site visits and research show that some families are described as being unable to be proactive, hesitant to question decisions of professionals, "reluctant to speak up" and share information, or increasingly "apathetic" about securing services as their children grow older. Some families are reportedly hesitant to assert their rights to services because they fear retaliation against their children or do not want the stigma of accepting public benefits. Other families simply lack the time and energy to dedicate to pursuing services for their children. One family, for example, spoke to us of being "too tired to try to pursue" services that might be helpful. And some parents with a cognitive or physical limitation are not fully able to aggressively seek and gain access to services for their children.

[63]For example, a study of the implementation of federal policy for young children with disabilities found that the following family factors influenced the amount and nature of services provided to a child: knowledge of programs serving children with disabilities and how to gain access to services within these programs, ability to advocate persistently for the child's and family's needs, and resourcefulness in pursuing these ends. The absence of these factors was sometimes associated with fewer services, while their presence was associated with more and higher-quality services. Gloria L. Harbin and others, Implementing Federal Policy for Young Children with Disabilities: How Are We Doing?, a publication of the Early Childhood Research Institute on Service Utilization (Chapel Hill, N.C.: Frank Porter Graham Child Development Center, Mar. 1998). The Institute is funded by the Department of Education, Office of Special Education Programs, under a cooperative agreement (H024T0002) with the University of North Carolina and Rhode Island College.

Finally, we learned during our site visits that some families lack transportation or other supports needed to help obtain program services. For example, some families do not own a car, do not have access to reliable and accessible public transportation, or do not have friends or family who are willing and able to provide transportation assistance. Indeed, lack of transportation is an important factor causing families to miss appointments with service providers. Moreover, some families do not have telephones, making it difficult for them to contact providers or an ambulance in an emergency and increasing the difficulty case managers have in maintaining contact with them.

38 Disability-Related Services Used in Collecting and Analyzing Site Visit Data

Service	Definition
Medical and therapy	
Doctor visits in a clinic or office	Self-defined; excludes mental health services and hospital or emergency room visit
Home visits by a doctor	Self-defined; excludes mental health services
Hospital care	Includes inpatient and outpatient hospital care; excludes mental health services
Skilled nursing services (RN/LPN), including visiting nurse	Professional nursing care in the home for children with extensive personal and medical needs
Dental care	Self-defined
Prescription medication	Self-defined
Over-the-counter medication	Self-defined
Counseling or mental health services, including social work	Inpatient and outpatient psychological or social therapy or counseling provided by a psychologist, psychiatrist, social worker, counselor, or clergy member
Health insurance	Higher premiums or additional insurance
Physical therapy	Examination, treatment, and instruction in order to detect, assess, prevent, correct, alleviate, and limit physical disability, bodily malfunction, and pain from injury, disease, and any other bodily or mental condition
Occupational therapy	The use of any occupation for remedial purposes; the use of selected tasks to restore, reinforce, and enhance performance, facilitate learning of skills and functions essential for adaptation and productivity, diminish or correct pathology, and promote and maintain health
Audiology	Therapy for impaired hearing
Recreational therapy	Self-defined
Speech therapy	Identification, assessment, and rehabilitation of speech or language disorders such as articulation, stuttering, or delayed language
Respiratory therapy	Treatment, management, and care of patients with respiratory problems (e.g., aerosol therapy, use of nebulizer, ventilation)
Child care	
Respite care	Substitute care for child with chronic illness or disability so primary caregiver is temporarily freed from responsibility
Specialized day care	Care or supervision for approximately 8 hours per day in a special setting, after which the child returns home in the afternoon or the evening; care provided by a person trained to handle medical emergencies or perform special health procedures

(continued)

Service	Definition
Personal attendant services, home health aide, or special help and supervision	A professional trained to help parents with the care of a chronically ill or disabled child in the home or with household tasks; a personal care attendant provides services such as bathing, dressing, and lifting child and is an employee of a health care agency
Services from a center for independent living	Self-defined
Transportation	
Transportation	Provide transportation to and from a doctor or service provider for reasons related to special health care needs or disability; excludes emergency transportation
Emergency transportation	Helicopter or ambulance
Purchase a van or car to transport a child with special health care needs	Self-defined; excludes modifications to a van or car
Modify a van or car to transport a child with special health care needs	Installing special equipment because of a child's impairment or health problem. Includes hand controls, hand rails, straps, specialized handles, ramps, or lifts; power controls for windows, mirrors, seat, or steering; automatic transmission; air conditioning; a button that opens the door; a large trunk or storage area
Education	
Educational services related to special health care needs	Tutoring, books on tape, extra books, modified pens, adaptive backpack, sensory integration, etc.
Reader or interpreter	Self-defined
School-to-work transition	Services to facilitate a disabled child's entry into the workforce
Home	
Extra telephone charges	Self-defined
Extra electric or other utility charges	Self-defined
Home modifications	Widened doorways or hallways; ramps or street-level entrances; railings; automatic or easy-to-open doors; accessible parking or drop-off site; bathroom or kitchen modifications; elevator, chair lift, or stair glide; alerting devices, etc.
Equipment and supplies	
Assistive technologies	Computers, learning aids, devices to assist speech, hearing aids, etc.

(continued)

Service	Definition
Home or durable medical equipment	Respirator, nebulizer, inhaler, ventilator, suction machine; intravenous pump; feeding pump; wheelchair; specialized seating, pads; batteries, chargers, remote controls for environment or lifts, lights, computer; oxygen; portable equipment and set-ups; walking aids, braces, crutches, walkers; scooters; other types of braces; nonallergenic bedding; special pillows, leg rolls or props, etc.
Special diet or formula	Ensure, Pedialyte, pureed baby foods or other products; high-calorie or nutrition drinks; homemade food (cost of ingredients); adaptive straws, drinking glasses, specialized utensils, etc.
Special or additional clothing	Adaptive clothing or tailoring; adaptive shoes, Velcro strips instead of laces, built-up heels, etc.
Diapers beyond the usual age	Self-defined
Implants	Ear vent tube; shunt to drain fluid; artificial joint; implanted lens; implanted pin, screw, nail, wire, rod, plate; artificial heart valve; pacemaker; silicone implant; infusion pump; cochlear implant; other organ implant, etc.
Medical supplies	Bandages or tape; distilled water; saline solution; suction catheters; gastronomy tubes; feeding tubes; syringes; dip sticks to check urine; gauze pads; skin creams; alcohol; cotton swabs, balls; urinals; chux pads; lambskin; tracheostomy and supplies; catheters and bags, etc.
Recreation	
Special recreation or physical education	Self-defined
Coordination of care	
Coordination of services	The professional coordination of services for families with children with chronic conditions or disabilities. Includes coordinating all medical care, which means keeping in touch with the child's doctors or therapists who know the results of tests and treatments and are aware of the child's prescription medicines. Also includes arranging nonmedical care (such as social services and personal care services), special education services, and transportation to appointments and evaluating service needs.

Sources: GAO's compilation of services and their definitions based on the 1994 and 1995 National Health Interview Survey, including the Disability Supplement and Disability Followback Child's Questionnaire, and the University of Florida's Institute for Child Health Policy 1996 survey of Florida children with special health care needs.

Disability-Related Services Covered by Selected Programs

Service	Medicaid				Percent of state title V programs (n=21)	Percent of state family support programs (n=44)
	EPSDT	Number of waivers	Special Education[a]	Early Intervention[a]		
Medical and therapy						
Doctor visits in a clinic or office	Yes	0	No[b]	No[b]	62%	84%[c]
Home visits by doctor	Yes	0	No	No[b]	14	84[c]
Hospital care	Yes	0	No	No	52	84[c]
Skilled nursing services (RN/LPN), including visiting nurse	Yes	15	No	Yes	43	84[c]
Dental care	Yes	1	No	Yes	62	84[c]
Prescription medication	Yes	2	No	No	62	84[c]
Over-the-counter medication	No	0	No	No	48	84[c]
Counseling or mental health services, including social work	Yes	8	Yes	Yes	43	84[c]
Health insurance	No	0	No	No	14	84[c]
Physical therapy	Yes	2	Yes	Yes	62	84[d]
Occupational therapy	Yes	2	Yes	Yes	62	84[d]
Audiology	Yes	1	Yes	Yes	57	[e]
Recreational therapy	Yes	0	Yes	No	14	89[f]
Speech therapy	Yes	1	Yes	Yes	62	84[d]
Respiratory therapy	Yes	0	No	No	33	84[d]
Child care						
Respite care	No	24	No	Yes	29	100
Specialized day care	No	0	Yes	No	10	[e]
Personal attendant, home health aide, or special help and supervision	Yes	20	Yes	No	5	[g]
Services from a center for independent living	No	0	No	[g]	0	[g]
Transportation						
Transportation	Yes	5	Yes	Yes	52	[e]
Emergency transportation	Yes	0	No	No	33	[e]

(continued)

Service	Medicaid		Special Education[a]	Early Intervention[a]	Percent of state title V programs (n=21)	Percent of state family support programs (n=44)
	EPSDT	Number of waivers				
Purchase a van or car to transport a child with special health care needs	No	0	No	No	0	[e]
Modify a van or car to transport a child with special health care needs	No	1	No	No	19	89[h]
Education						
Educational services related to special health care needs	No	0	Yes	Yes	14	[g]
Reader or interpreter	No	0	Yes	Yes	33	[g]
School-to-work transition	No	0	Yes	[g]	10	[g]
Home						
Extra telephone charges	No	0	No	No	19	61[i]
Extra electric or other utility charges	No	0	No	No	14	61[i]
Home modifications	No	16	No	No	24	89[h]
Equipment and supplies						
Assistive technologies	Yes[j]	0	Yes	Yes	52	91[k]
Home or durable medical equipment	Yes[j]	15	No	No	67	91[k]
Special diet or formula	No[j]	9	No	No[l]	76	61[i]
Special or additional clothing	No[j]	0	No	Yes	24	61[i]
Diapers beyond the usual age	No[j]	0	No	[g]	48	61[i]
Implants	Yes[j]	0	No	Yes[m]	52	[e]
Medical supplies	Yes[j]	0	No	No	57	84[c]

(continued)

Service	Medicaid		Special Education[a]	Early Intervention[a]	Percent of state title V programs (n=21)	Percent of state family support programs (n=44)
	EPSDT	Number of waivers				
Recreation						
Special recreation or physical education	No	0	Yes	[g]	10	89[f]
Coordination of care						
Coordination of services	Yes	21	Yes	Yes	81	73

[a]Services meet (yes) or do not meet (no) the minimum requirements contained in the Individuals With Disabilities Education Act and accompanying federal regulations. According to Department of Education officials, however, any service can be provided if judged to be necessary and included in the Individualized Education Program (for Special Education) or Individualized Family Service Plan (for Early Intervention).

[b]Doctor visits are covered only for diagnostic or evaluation purposes.

[c]Data were included under the medical expenses and health insurance category on the Human Services Research Institute (HSRI) survey.

[d]Data were included under the specialized therapies category on the HSRI survey.

[e]Data were unavailable from the HSRI survey.

[f]Data were included under the recreation category on the HSRI survey.

[g]Not applicable.

[h]Data were included under the home and vehicle modification category on the HSRI survey.

[i]Data were included under the household expenses category on the HSRI survey.

[j]While federal regulations at 42 CFR 440.70(b)(3) provide that coverage of "medical supplies, equipment, and appliances suitable for use in the home" be included as part of the Medicaid home health benefit, no federal Medicaid rule or regulation defines or lists what specific supplies may or may not be provided. A June 16, 1997, memorandum from the Medicaid Director of the Office of Medical Services states: "states have the flexibility to adopt a reasonable definition of 'medical supplies, equipment and appliances.' Applying this standard, a state could reasonably define this term to exclude specific items that are not primarily and customarily used to serve a medical purpose, and that are customarily used for other purposes." We scored the seven equipment and supply items on the basis of Health Care Financing Administration (HCFA) officials' views on what is or is not generally covered.

[k]Data were included under the adaptive equipment category on the HSRI survey.

[l]Special diets or formulas are not covered, but devices such as adaptive straws, drinking glasses, and specialized utensils are considered to be assistive technology devices and are therefore covered.

[m]Medical implants are covered, but the surgery to implant a device is not covered.

Sources: Data on Medicaid waivers are from our analysis of American Public Human Services Association information published in 1998. (HCFA contracts with the association to collect data on Medicaid waivers.) Data are based on the 36 waivers under the section 1915(c) Home and Community-Based Waiver Program targeted exclusively to children with disabilities. Percentages for state title V programs are from our analysis of findings from a 1997 survey of state title V programs conducted by the University of Florida's Institute for Child Health Policy. We analyzed the survey's findings on the scope of services of 21 state title V programs. While not representative, these states are located in diverse geographic areas of the country and are the state of residence for 59 percent of the population of children on SSI. See Institute for Child Health Policy, University of Florida, Directory of State Title V CSHCN Programs' Eligibility Criteria and Scope of Services (Gainesville, Fla.: May 1997). Percentages for state family support programs are from John Agosta and Kerri Melda, Results of a National Survey of Family Support Programs for People With Disabilities and Their Families (Salem, Ore.: HSRI, 1995), p. 21. They represent 58 programs serving children (as well as adults in some cases) with developmental disabilities in 44 states. HSRI asked respondents whether the programs offered services in eight broad categories: service coordination and information and referral, medical expenses and health insurance, therapies, respite, recreation, home and vehicle modifications, adaptive equipment, and household expenses. According to HSRI, the respondents used their own discretion in determining how to place services in these categories.

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Related GAO Products

Supplemental Security Income: SSA Needs a Uniform Standard for Assessing Childhood Disability (GAO/HEHS-98-123, May 6, 1998).

Medicaid: Elevated Blood Lead Levels in Children (GAO/HEHS-98-78, Feb. 20, 1998).

Supplemental Security Income: Review of SSA Regulations Governing Children's Eligibility for the Program (GAO/HEHS-97-220R, Sept. 16, 1997).

Medicaid Managed Care: Challenge of Holding Plans Accountable Requires Greater State Effort (GAO/HEHS-97-86, May 16, 1997).

School Finance: State Efforts to Reduce Funding Gaps Between Poor and Wealthy Districts (GAO/HEHS-97-31, Feb. 5, 1997).

People With Disabilities: Federal Programs Could Work Together More Efficiently to Promote Employment (GAO/HEHS-96-126, Sept. 3, 1996).

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Medicaid: HealthPass: An Evaluation of a Managed Care Program for Certain Philadelphia Recipients (GAO/HRD-93-67, May 7, 1993).

Federally Funded Health Services: Information on Seven Programs Serving Low-Income Women and Children (GAO/HRD-92-73FS, May 28, 1992).

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