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Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



CHILDREN WITH SEVERE CHRONIC CONDITIONS ON MEDICAID

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EXECUTIVE SUMMARY

Many children with special health care needs depend on the health and supportive services provided by Medicaid. It is important that policymakers have a sound understanding of these children's patterns of health care use, especially given the shift to managed care. Previous studies of children on Medicaid with severe disability and/or chronic illness have focused on "SSI-related" children, or children with extremely high health care costs. This study provides further analysis of Medicaid expenditures for SSI children, and adds to the literature by applying diagnostic and utilization-based criteria to claims data to identify children with severe chronic illness. This methodology enables analysis of the service use patterns and expenditures for children with severe chronic conditions who are receiving Medicaid, but are not enrolled in SSI.

Three data sources were used in the analysis:

- Medicaid administrative records extracted from HCFA's "Tape-to-Tape" database provided data on Medicaid service utilization and expenditures. Tape-to-Tape files for calendar year 1992 from the states of California, Michigan and Georgia were used as the source of data, along with Tape-to-Tape files from the state of New York for calendar year 1991.
- The 1992 MarketScan data base, a proprietary database of integrated claims and population data of individuals enrolled in private insurance plans, was used to compare the prevalence of children with chronic conditions with private health insurance coverage to the prevalence of children with chronic conditions enrolled in Medicaid. The MarketScan database is constructed from the aggregate claims experience of employees and dependents of approximately 80 large employers representing the health insurance experience of approximately 7 million employees and dependents.
- For SSI children, data on the principal disabling condition (as identified by the disability determination process) was obtained from Social Security Administration records.

The principal findings of the study are:

- **There are many more children with severe chronic conditions receiving Medicaid coverage than simply those who become eligible for Medicaid through the SSI program.**

SSI children accounted for 1.7% to 4% of children on Medicaid in the four states. Diagnostic criteria identified an additional 1.4% to 2% of children on Medicaid with severe chronic conditions.

- **The prevalence of severe chronic conditions among children receiving Medicaid is much higher than the prevalence among privately insured children.**

Using the study criteria, the prevalence of severe chronic conditions among Medicaid-covered children was three to five times higher among Medicaid children across the four states than among privately insured children. Thus, managed care plans which enroll Medicaid children will encounter a much higher prevalence of chronic conditions than they have encountered in their commercial populations, even if SSI-related children are excluded.

- **Most SSI children did not meet the study criteria and most children meeting study criteria were not receiving SSI.**

SSI children tended to be older than the non-SSI children identified by the study criteria. In addition, while diagnoses on medical claims do well in identifying children with medical needs, they are much less successful in identifying children with functional disabilities. For example, the diagnosis of mental retardation may be significantly under-reported on medical claims, except for health care services which are specifically related to that condition. Consequently, in many cases it is difficult to identify the condition causing disability in SSI children solely by using medical claims data.

- **Medicaid expenditures for SSI children vary significantly by type of disability.**

Although SSI children have expenditures which are higher on average than those of AFDC children, the overall distributions have a similar shape. Thus, the health insurance risk profile of the SSI child population is markedly similar to that of the general population--a relatively small percentage of the population accounts for the majority of total health care costs. In addition, the relative Medicaid costs of SSI children with varying types of disabilities was remarkably consistent across the study states. The implication is that a single capitation payment for all SSI children will significantly overpay plans for SSI children with certain conditions and underpay plans for other conditions.

- **The average Medicaid expenditure for non-SSI children meeting the study diagnostic criteria was higher than the average for SSI children.**

This is not surprising since the study criteria tended to identify children with significant medical needs. However, the average expenditure for SSI children who also met the study diagnostic criteria was 2-3 times the average expenditure for children who met the study's diagnostic criteria but were not receiving SSI. Thus, within the group of children who met the same criteria, SSI children had the highest medical needs.

- **Inpatient hospital services account for most Medicaid expenditures for children with severe chronic conditions.**

Inpatient hospital expenditures accounted for about two-thirds to three-quarters of total expenditures for non-SSI children who met the diagnostic criteria. Such expenditures accounted for a somewhat lower proportion of total expenditures for SSI children. Data are also presented for the following services: ICF-MR and nursing facility, physician, occupational, physical, and speech therapy, skilled nursing and home health, prescribed drugs, other.

This study has implications for state Medicaid programs as they expand managed care initiatives to enroll more Medicaid-covered children, including children receiving SSI. First, Medicaid expenditures for children with severe chronic illness are predictably greater for children with specific types of conditions than for others. This suggests that states should use risk adjustment methods to account for *predictable* variation in Medicaid expenditures across diagnoses and conditions. Otherwise, to the extent that Medicaid managed care plans can influence enrollment of children with severe chronic illness, plans will have an incentive to selectively enroll children with predictably lower health care costs.

Further, while SSI children, on average, have higher medical and supportive service needs than non-SSI children, this study also demonstrates the relatively high incidence of severe chronic conditions among Medicaid children not receiving SSI. Managed care plans with experience in primarily serving children with private insurance will encounter a more challenging caseload of children with complex medical needs in their Medicaid contracts, even if SSI children are excluded from enrollment. States and plans need to work together to ensure that provider networks and care management practices in Medicaid plans are adequate to serve this caseload, and that payments to plans fairly reflect the risk profiles of these populations.

Claims data provide a useful data base for the development of risk adjustment models. However, for certain disabling conditions the diagnosis coding on claims is far from complete. This is to be expected since providers are reporting the medical conditions they treat, which do not necessarily represent the underlying condition causing disability. This distinction shows up quite clearly when one compares SSA and Medicaid coding for children with mental retardation. Diagnosis coding may become much more complete if risk adjustment provides an incentive to report additional diagnoses. The implication is that condition-specific capitation rates derived from existing Medicaid claims databases represent a starting point in implementing a risk adjustment system. However, once a risk adjustment system is implemented, it is also likely that the reporting of conditions, and therefore reported expenditures for various conditions, will change in turn, as plans and providers adapt to the financial incentives of risk adjustment.

The Medicaid program plays a critical role in national health care policy in providing medical assistance and supportive services to children with severe disabilities and chronic illness.^{1,2} First, through its links with the Supplemental Security Income (SSI) program, Medicaid provides health insurance coverage to most children who receive disability benefits under SSI. In 1996, there were approximately 1 million children with disabilities receiving cash assistance under the SSI program.

Second, Medicaid is the primary source of health insurance coverage for children living below the poverty threshold, and previous studies have shown that children living in poverty have significantly higher rates of disability and chronic illness than children living in non-poor households.^{3,4}

Third, through a number of special eligibility provisions, Medicaid also provides health insurance benefits to many children with significant health care needs who otherwise would not qualify for Medicaid. This includes children who qualify for Medicaid under its "medically needy" provisions, children who receive home and community-based services under Section 1915(c) waiver programs, and children who are placed in out-of-home residential settings, such as nursing homes, foster care homes, and institutions for persons with developmental disabilities.

It is also important to note that the Medicaid benefit package provides access to a much broader array of covered services than either Medicare or commercial health insurance plans. Not only does Medicaid provide coverage for basic medical care such as inpatient hospital, physician, and prescription drugs (generally without copayment requirements), in most states Medicaid also provides access to an array of specialized therapeutic services for children with disabilities such as physical, speech and occupational therapies, as well as fairly deep coverage of skilled home care visits, home health aide services, personal care services, case management services, and other socially oriented supportive services under Medicaid home and community-based waiver programs. Thus, even for many children in lower-income households which have private insurance coverage for basic health care, Medicaid provides supplemental coverage for specialized therapies and community-based services that are not covered under private insurance plans.

A. MEDICAID MANAGED CARE AND CHILDREN WITH DISABILITIES

Presently, the Medicaid program is undergoing a dramatic transformation as States are increasingly relying on managed care tools as mechanisms for controlling Medicaid expenditures and requiring greater accountability from health care providers. In this transformation, Medicaid enrollees with predictable medical and supportive care needs are seen as vulnerable to the utilization management programs of managed care plans. Children with severe chronic illness covered under Medicaid will be seen as "financial losers" to managed care plans if premium payments to plans are not adjusted to reflect the financial risks of serving this population.^{5,6,7} Otherwise, plans will rationally implement a series of behaviors to: (a) avoid enrollment of children with disabilities into the plans; (b) encourage or force disenrollment of children who are enrolled; and/or (c) reduce access to covered services in order to limit financial risk.

Nonetheless, based upon the perceived "success" of Medicaid managed care for AFDC-related populations, states are now moving aggressively to develop managed care programs for their SSI-related populations, including disabled children.⁸ While managed care models may hold promise for promoting more appropriate utilization of covered benefits, better coordination of medical care, and more rationale integration of acute care and supportive services, both states and managed care plans need better information on the characteristics of children with disabilities enrolled in Medicaid. Better information on the risk profiles of children with disabilities on Medicaid is essential for negotiating fairer transactions between purchasers (states) and sellers (plans) of health insurance coverage for this population.

B. PURPOSE OF STUDY

Given the critical role of Medicaid in providing health and supportive services to children with severe chronic illness, and the radical policy transformations that are occurring in the Medicaid program with the shift to managed care, it is important that policymakers have a sound understanding of the characteristics of children with special health care needs on Medicaid and their patterns of health care use. Previous studies of children with severe disability and/or chronic illness on Medicaid have generally either focused exclusively on "SSI-related" children, or children with extremely high health care costs.^{1,9-13} This study adds to the literature by using *diagnostic and utilization-based criteria* to identify an analytical population of children with severe chronic illness, in addition to SSI eligibility status, and also by comparing utilization patterns of SSI-related children and non-SSI children with severe chronic illnesses. Thus, this study takes a much broader approach to looking at children with special health care needs on Medicaid than previous studies, and the implications of this broader perspective on Medicaid's shift to managed care purchasing strategies.

The primary research questions addressed in the study were as follows:

- How many children with severe chronic conditions are enrolled in Medicaid, including both SSI children and children not receiving SSI benefits?
- How does Medicaid's coverage of children with severe chronic conditions vary across states?
- How do the characteristics of SSI children compare to the characteristics of children with chronic conditions on Medicaid not receiving SSI?
- How do the health care utilization and expenditure patterns of SSI children compare with the utilization and expenditure patterns of children with severe chronic conditions not receiving SSI?
- How do health care utilization and expenditure patterns of children with chronic conditions on Medicaid (both SSI and non-SSI children) vary by type of impairment?

C. DATA SOURCES

The primary data source used in the study were Medicaid administrative records extracted from state Medicaid Management Information Systems (MMIS). Under a separate contract supported by the Office of Research and Demonstrations at the Health Care Financing Administration (HCFA), raw MMIS files in selected states have been reconstructed into a research database after an extensive editing, code mapping, and reformatting process that resulted in uniform, person-based, enrollment and claims records suitable for research. This dataset is commonly referred to as the Medicaid "Tape-to-Tape" database. In the current study, Tape-to-Tape files for calendar year 1992 from the states of California, Michigan and Georgia were used as the source of data, along with Tape-to-Tape files from the state of New York for calendar year 1991.

Two additional data sources were also used in the study. First, the 1992 MarketScan data base, a proprietary database of integrated claims and population data of individuals enrolled in private insurance plans, was used to compare the prevalence of children with chronic conditions with private health insurance coverage to the prevalence of children with chronic conditions enrolled in Medicaid. The MarketScan database is constructed from the aggregate claims experience of employees and dependents of approximately 80 large employers, both private and public (e.g., state governments). The 1992 MarketScan represents the health insurance experience of approximately 7 million employees and dependents with employer-sponsored health insurance coverage.

A second additional data set used in the study was administrative records on children receiving SSI benefits obtained from the Social Security Administration. For this component of the study, Tape-to-Tape enrollment records of children who were identified as disabled were linked with SSI administrative records by the Social Security Administration. Successful linkages were completed for three of the four states selected for the study--California, Georgia and New York. Linked files were not constructed for Medicaid children with disabilities in Michigan due to the absence of appropriate linking variables. The primary data of interest from SSA administrative records was the "primary disabling condition" of children who had applied for and been determined eligible for SSI cash benefits.

D. METHODOLOGY FOR IDENTIFYING CHILDREN WITH CHRONIC CONDITIONS

The study required a methodology for identifying children with severe chronic conditions from Medicaid administrative records (eligibility and claims records) contained in the Tape-to-Tape database. For children receiving SSI benefits, this was a straightforward process, since SSI children are a unique eligibility group in Medicaid enrollment records and are classified as such on administrative files. For this study, all children who were ever classified as "SSI cash" children (children in families receiving cash benefits) at any time during the study year (1992 in Georgia, California, and Michigan and 1991 in New York) were included in the study, as well as "SSI-non cash" children, who are children who meet the disability criteria for the SSI program but who are not eligible for cash assistance, usually because their families do not meet program financial criteria. We refer to these two groups together as "SSI-related" children. In all four states, the vast majority of SSI children were children receiving SSI cash benefits.

For other children enrolled in Medicaid who were not classified as SSI-related, a methodology was developed to identify children who had a high probability of having a severe and chronic condition.¹⁴ First, a pediatric specialist with expertise in the care of children with severe disabilities identified a set of diagnosis codes that had high correlation with severe chronic conditions. In addition, a combination of diagnosis codes, procedure codes, utilization criteria and cost criteria were used to identify a set of additional disabled children in the dataset. For example, a combination of diagnosis codes and utilization criteria were used to identify children with asthma and epilepsy that were likely to have a disability related to their diagnosis. While the great majority of children with asthma and epilepsy do not have a serious condition, there is a subset of children with severe forms of these conditions who are functionally impaired by their illness. Thus, for these two conditions, a combination of diagnosis and utilization criteria were used to define disability. In order to be included in the analytical population, such children were required to have a diagnosis of asthma or epilepsy plus two or more hospitalizations during the study year, or three or more emergency room visits with a primary diagnosis of asthma or epilepsy.

In addition, some children were included in the analytical population solely because they had high utilization which may indicate a severe condition. By contrast to adult disability, child disability is characterized by a very large number of diagnoses, most of which are extremely rare. Although the list of "severe" diagnoses in our study includes 350 of the most common ones, there are many more diagnoses which occur quite rarely. The utilization criteria were developed, in part, to avoid missing children with such rare conditions.

Separate criteria were used to identify children with a high likelihood of physical disability and children with mental disabilities. The criteria used in our methodological approach to identifying severe chronic conditions from Medicaid claims data are

presented in Exhibit 1 and Exhibit 2. It is important to acknowledge that while we believe that the criteria used in this methodological approach are likely to be highly correlated with severe and chronic disability for non-SSI children, that there was no way to independently verify the validity of this approach. An example of a such a verification process might be an abstraction of medical records data, or to conduct a survey of a sample of children identified through these criteria, but such verification procedures were not feasible in the course of this study.

EXHIBIT 1. Physical Disability Criteria	
<u>Diagnostic Criteria</u>	Has at least one of approximately 350 diagnosis codes for severe and chronic conditions. Omits asthma and epilepsy because these conditions, controlled for severity, are picked up by other screens. Uses both primary and secondary diagnoses. The composition of these diagnosis codes is provided in Appendix A.
<u>Combined Diagnosis and Utilization Criteria</u>	<p>Has a primary diagnosis of asthma in combination with 2 or more hospitalizations, or 3+ emergency room visits with a primary diagnosis of asthma</p> <p>Has a primary diagnosis of epilepsy in combination with 1 or more hospitalizations, or has 3+ emergency room visits with a primary diagnosis of epilepsy</p>
<u>Utilization Criteria</u>	<p>Has 3 or more hospital admissions with a non-psychiatric primary diagnosis</p> <p>Has 20 or more days of inpatient hospital care with a non-psychiatric primary diagnosis</p> <p>Has total out patient payment of \$5,000 or more for non-psychiatric primary diagnoses</p> <p>Has total payment of \$20,000 or more for non-psychiatric primary diagnoses</p>

EXHIBIT 2. Mental Health Disability Criteria	
<u>Diagnostic Criteria</u>	Has at least one of 10 "severe" mental health diagnosis codes for severe and chronic conditions (Appendix B), or has a diagnosis code indicating moderate, severe, or profound mental retardation
<u>Combined Diagnosis and Utilization Criteria</u>	<p>Has 30 days or more of inpatient hospital care with any of the primary psychiatric diagnoses listed in Appendix B, including both the "severe" and "long" lists</p> <p>Has outpatient payments of \$5,000 or more for any of the primary psychiatric diagnoses listed in Appendix B, including both the "severe" and "long" lists</p>

E. RESULTS

There are many more children with severe chronic conditions receiving Medicaid coverage than simply those who become eligible for Medicaid through the SSI program.

Table 1 shows the number of children with disabilities identified in the Tape-to-Tape data set using our methodological approach. The table presents the number of SSI-related children, and then the number of *additional* children identified through diagnostic and utilization criteria. An important finding is that in all states, it is apparent that the total number of children with severe chronic conditions receiving Medicaid is much larger than just the number of children who qualify for SSI benefits. Non-SSI disabled children receiving Medicaid comprised 50% of the analytical population in California, 46% of the analytical population in Michigan, 41% of the analytical population children in New York, and 33% of the analytical population in Georgia. Thus, it is clear that Medicaid's coverage of children with severe disabilities extends significantly beyond its coverage of children receiving SSI disability benefits.

	California 1992	New York 1991	Georgia 1992	Michigan 1992
Number of SSI-Related Children	59,577	47,501	23,485	22,869
Non-SSI Children Identified Through Diagnoses	48,621	22,626	8,422	15,951
Non-SSI Children Identified Solely Through Utilization Criteria	10,399	10,546	3,307	3,859
Total Children with Severe Chronic Conditions	118,597	80,673	35,214	42,679
Percent SSI	50%	59%	67%	54%
Percent Non-SSI through Diagnoses	41%	28%	24%	37%
Percent Non-SSI Solely Through Utilization	9%	13%	9%	9%
Total Children on Medicaid	3,459,265	1,474,300	585,148	785,477
Percent of Children on Medicaid with Severe Chronic Conditions	3.4%	5.5%	6.0%	5.4%

Table 1 also presents the number of children with severe chronic conditions as a percentage of the total number of children enrolled on Medicaid in each of the four study states. Children with severe chronic conditions accounted for 3.4% of all Medicaid-enrolled in California, 5.4% of all Medicaid children in Michigan, 5.5% of all children in New York, and 6.0% of all children in Georgia. There was an inverse relationship between the percentage of all children on Medicaid with severe chronic conditions, and the percentage of additional non-SSI children identified as disabled through diagnosis and utilization criteria. For example, California had the highest percentage of children

identified through diagnosis and utilization criteria of the four study states, but the lowest percentage of children with severe chronic conditions overall.

We believe this relationship is primarily a function of state Medicaid eligibility policy. Of the four states, California had the most generous Medicaid eligibility policies, and thus the largest number of children enrolled in the Medicaid program. California's more generous eligibility policies brought a higher number of non-SSI children with severe chronic conditions into the program than in the other three states, but overall, a lower percentage of all non-SSI children who enrolled in Medicaid had severe chronic conditions. Georgia, on the other hand, had the most restrictive eligibility policies of the four states at the time, and this restricted access to Medicaid coverage for non-SSI disabled children.¹⁵ However, because Georgia's Medicaid policies were the most restrictive, the percentage of all children covered by Medicaid in Georgia with severe disabilities was the highest.

The prevalence of severe chronic conditions among children receiving Medicaid is much higher than the prevalence among privately insured children.

We applied our methodological approach for identifying children with severe chronic conditions in the Medicaid data set to our data set of privately insured children, excluding SSI status.¹⁶ In this analysis, the prevalence of severe chronic conditions among Medicaid-covered children was three to five times higher among Medicaid children across the four states than among privately insured children. Thus, managed care plans which enroll Medicaid children will encounter a much higher prevalence of chronic conditions than they have encountered in their commercial populations, even if SSI-related children are excluded.¹⁷

Most SSI children did not meet the study diagnosis and utilization criteria and most children meeting study criteria were not receiving SSI.

There was less overlap between children who were identified through clinical criteria and those who were receiving SSI benefits than expected. Table 2 presents data on the number of children who were both receiving SSI benefits and who met the clinical and utilization criteria established for this study. The percentage of SSI children who also met the study criteria ranged from 22.4% in Georgia to 31.2% in New York. Thus, on average, only about one in four children receiving SSI benefits also met the diagnosis and/or utilization criteria established for study.

The converse was also true. The percentage of all children who met the disability criteria and who were also receiving SSI benefits ranged from 22.4% in California to 31.0% in Georgia. Thus, only about one in four children who met the clinical and utilization criteria established for the study were also receiving SSI.

TABLE 2. Number of Children with Severe Chronic Conditions Enrolled in Medicaid by SSI Status				
	California 1992	New York 1991	Georgia 1992	Michigan 1992
SSI--Met Study Criteria	17,052	14,828	5,271	6,064
SSI--Did Not Meet Criteria	42,525	32,673	18,214	16,805
Total SSI Children	59,577	47,501	23,485	22,869
Non-SSI--Met Criteria	59,020	33,172	11,729	19,810
Percent of SSI Children Meeting Study Criteria	28.6%	31.2%	22.4%	26.5%
Percent of Children Meeting Criteria on SSI	22.4%	30.9%	31.0%	23.4%
Total Analytic Population	118,597	80,673	35,214	42,679
Total Medicaid Child Population	3,459,265	1,474,300	585,148	785,477

There are several reasons why there is not more overlap between SSI children and children who were identified through the study criteria. First, eligibility for SSI benefits is determined by *functional*, as well as, medical criteria.^{18,19} The SSA disability determination process relies on reports from physicians and others on the child's medical condition and ability to function. In contrast, the criteria used in this study for identifying children with severe and chronic conditions rely solely on medical diagnoses and utilization data. Although we attempted to identify chronic conditions which often result in functional disability, we did not have any method for determining whether such disability actually occurred.

For example, a large percentage of children receiving SSI benefits are children with mental retardation.^{20,21,22} While the diagnoses of moderate, severe, and profound mental retardation were included in the study criteria as indicative of a severe chronic condition, we did not include a diagnosis of mild mental retardation, or simply a diagnosis of mental retardation without differentiation. Thus, the study criteria most likely do not include children with milder levels of mental retardation who are receiving SSI benefits, as well as SSI children with more severe levels of mental retardation that are not coded as such on Medicaid claims. In addition, in many of the health care encounters for children with mental retardation, it is unlikely that there will be any diagnosis code for mental retardation on the claim, unless the service is specifically related to that condition, e.g., ICFMR or therapy.

TABLE 3. Age Distribution of SSI and Non-SSI Children, by State (percent)								
Age	California		Georgia		Michigan		New York	
	SSI	Non-SSI	SSI	Non-SSI	SSI	Non-SSI	SSI	Non-SSI
0 - 5 years	19.9	45.7	18.4	65.1	15.5	52.7	18.2	53.0
6 - 10 years	23.5	16.2	25.5	11.3	24.3	13.6	23.7	14.7
11 - 15 years	23.2	16.9	27.2	10.4	27.0	15.2	25.8	15.0
16 - 20 years	33.4	21.2	29.8	13.2	33.1	18.6	32.3	17.4
Total	8029.9	100.0	8178.4	100.0	8455.5	100.0	8198.2	100.2

Second, children who met the study criteria were, on average, considerably younger than children receiving SSI benefits, as shown in Table 3. Whereas children under the age of six comprised only about 20 percent of SSI children on Medicaid, children in this age group comprised from 46% (California) to 65% (Georgia) of non-SSI children with severe chronic conditions across the four states. Thus, it is clear that the diagnosis and utilization criteria developed for the study identified many young children with severe conditions that are not receiving SSI benefits. Since it may take a good deal of time before parents of children with severe chronic conditions learn about the SSI program, and because the application process for SSI benefits may take a considerable amount of time before the application is completed and approved, we believe it is reasonable to assume that many of the very young children identified through the study criteria may have eventually become recipients of SSI cash assistance, if they survived their childhood condition.

Third, it is also possible that the disability criteria established specifically for this study, while having the objective of identifying children with a severe and chronic disability, nonetheless identified a high number of children whose conditions are more acute than chronic. This could be particularly true of the utilization criteria established for the study. While we were aware of collinearity problems related to using utilization criteria as a method for defining disability, we wanted to examine the relationship between the non-utilization based disability criteria and the population of children with high Medicaid costs. It is entirely possible in applying utilization criteria to define our analytical population, that we identified children with high health care use related to acute medical conditions, such as injuries or premature birth, that do not necessarily result in extended or life long disability.

TABLE 4. Number and Percent of Children Meeting Study Criteria by Type of Criteria

	California 1992	Georgia 1992	New York 1991	Michigan 1992
Meet Criteria Using Diagnosis Codes	57,442 (75.5%)	11,589 (68.2%)	27,768 (57.9%)	19,110 (73.9%)
Meet Criteria Using Diagnosis Codes and Utilization	6,628 (8.8%)	1,292 (7.6%)	6,434 (13.4%)	2,266 (8.8%)
Meet Criteria Using Utilization Criteria	11,962 (15.9%)	4,119 (24.2%)	13,978 (28.7%)	4,498 (17.4%)
Total Meeting Criteria	76,073 (100.0%)	17,000 (100.0%)	48,000 (100.0%)	25,874 (100.0%)
Column numbers and percentages do not sum to totals due to children meeting multiple criteria.				

Most children meeting the study criteria did so on the basis of diagnosis, not utilization.

Given the above discussion, Table 4 presents data on the number and percent of children who met the criteria established for this study, by type of criteria.²³ The table shows that most of the children who met the study criteria did so on the basis of diagnosis alone, not on the basis of combined diagnosis and utilization criteria, or on

utilization criteria alone. The percentage of children who met the diagnostic criteria for inclusion in the study ranged from a low of 58% in New York to a high of 76% in California. Conversely, the percentage who met one or more of the utilization criteria established for inclusion in the analytical population ranged from a low of 29% in California to a high of 49% in New York.²⁴ Thus, while overall, most of the children who met the criteria established for the study did so on the basis of diagnosis, there were also significant differences across states.

Children meeting the study criteria had higher Medicaid expenditures than SSI children.

Overall, children who met the study criteria had significantly higher Medicaid expenditures during the study year than children who were receiving SSI benefits, as shown in Table 5. However, there was a consistent pattern across all four states: SSI children who also met the criteria (about 16% of all children in the study) had the highest Medicaid expenditures, non-SSI children who met the criteria (about 45%) had the next highest expenditures, while SSI children who did not meet the study criteria (40% of all children in our analytical population) had the lowest expenditures.

TABLE 5. Mean Medicaid Expenditures for Children with Severe Chronic Conditions by Disability Category

	Non-SSI Children				SSI Children Meeting Study Criteria				Other SSI Children	Non-SSI
	Diag.	Diag. & Util. Criteria	Util. Criteria	Non-SSI (All)	Diag.	Diag. & Util.	Util. Criteria	SSI Meeting Criteria (All)		
CA 1992	\$6,887	\$8,422	\$36,038	\$11,520	\$13,541	\$20,653	\$43,403	\$17,265	\$1,030	\$9,316
GA 1992	\$5,656	\$7,813	\$16,404	\$8,120	\$13,593	\$16,722	\$31,215	\$15,649	\$1,303	\$6,157
NY 1991	\$8,625	\$21,917	\$30,817	\$16,219	\$24,297	\$47,080	\$52,997	\$32,477	\$1,334	\$14,434
MI 1992	\$6,100	\$20,314	\$22,460	\$9,479	\$11,491	\$27,180	\$25,214	\$13,267	\$1,149	\$7,179

Children receiving SSI benefits who did not meet either the diagnostic or utilization criteria established for the study (about 75% of all SSI children) had relatively low average Medicaid expenditures, in the range of only \$1,000-\$1,300 per year. As previously discussed, a large percentage of children receiving SSI benefits are children with a primary disabling condition of mental retardation, and while this disability may hinder a child's ability to participate in many activities of daily life, many children with mental retardation do not have basic health care needs that differ dramatically from the basic health care needs of non-disabled children. Therefore, while all SSI children have a functional disability which impedes their ability to participate in normal daily activities, the health insurance risk profile of the SSI child population is markedly similar to that of the general population--a relatively small percentage of the population accounts for the majority of total health care costs.

TABLE 6. Distribution of Medicaid Expenditures by Study Criteria for Children in California, 1992								
Service Category	Non-SSI Children			SSI Children Meeting Study Criteria			Other SSI	All Children
	Diag. Alone	Diag. & Util.	Util. Alone	Diag. Alone	Diag. & Util.	Util. Alone		
Hospital	73%	54%	88%	45%	52%	36%	24%	67%
ICF-MR and Nursing Facility	1%	0%	1%	20%	7%	50%	1%	9%
Physician	11%	9%	6%	6%	7%	2%	17%	8%
Occupational, Physical and Speech Therapy	0%	0%	0%	0%	0%	0%	1%	0%
Skilled Nursing and Home Health	0%	0%	1%	3%	0%	3%	0%	1%
Prescribed Drugs	3%	4%	1%	6%	5%	2%	15%	3%
Other	11%	33%	5%	20%	29%	7%	43%	12%
Total	100%	100%	100%	100%	100%	100%	100%	100%

There were significant differences across states in average Medicaid expenditures for the analytical population. Average Medicaid costs for all study children in New York were over twice the average costs of children with disabilities in Michigan and Georgia, and about 50% higher than average expenditures per child in California.²⁵ These differences in average expenditures are partly attributable to the fact that New York had the highest percentage of SSI children who also met the study disability criteria and also the highest percentage of children who specifically met the "high-cost" utilization criteria. New York also had the highest average expenditures among non-SSI children who met the study criteria.²⁶

Inpatient hospital costs account for most Medicaid expenditures for children with severe chronic conditions.

Tables 6 through 9 present data on the distribution of Medicaid expenditures for the analytical population by type of service and SSI status. Inpatient hospital services accounted for the majority of Medicaid expenditures for all children in the study, although this ranged from a low of 53% in Georgia to a high of 67% in California. Inpatient hospital expenditures accounted for a higher percentage of expenditures for non-SSI children than for SSI children. Since inpatient hospital use was a significant component in the utilization criteria developed for the study, it is no surprise that SSI children who did not meet the study criteria had lower use of inpatient hospital services. "Other" medical services accounted for a large share of Medicaid costs for SSI children who did not meet the study criteria, such as lab and x-ray services, durable medical equipment, transportation services, personal care services, and home and community-based waiver services.

TABLE 7. Distribution of Medicaid Expenditures by Study Criteria for Children in Georgia, 1992								
Service Category	Non-SSI Children			SSI Children Meeting Study Criteria			Other SSI	All Children
	Diag. Alone	Diag. & Util.	Util. Alone	Diag. Alone	Diag. & Util.	Util. Alone		
Hospital	61%	69%	65%	47%	58%	39%	28%	53%
ICF-MR and Nursing Facility	0%	0%	0%	16%	3%	30%	0%	8%
Physician	21%	12%	19%	11%	9%	9%	23%	16%
Occupational, Physical and Speech Therapy	0%	0%	0%	1%	0%	1%	1%	1%
Skilled Nursing and Home Health	0%	0%	0%	2%	0%	4%	0%	1%
Prescribed Drugs	3%	5%	1%	5%	6%	2%	15%	5%
Other	14%	14%	13%	16%	15%	14%	33%	16%
Total	100%	100%	100%	100%	100%	100%	100%	100%

Michigan and Georgia, which had the lowest average expenditures overall for all children with severe chronic conditions, spent less for both inpatient hospital and institutional long term care services, and more for physician and other noninstitutional services. New York spent significantly more on ICF-MR and nursing home services for study children than the other states, while in Michigan, expenditures for institutional care were remarkably low. In all states, expenditures for therapy-related services represented a very small percentage of total spending.²⁷ Caution should be exercised in drawing conclusions from these tables, however, since these distributions are confounded by total Medicaid spending rates as well as the distribution of children across the three major study groups.

TABLE 8. Distribution of Medicaid Expenditures by Study Criteria for Children in New York, 1991								
Service Category	Non-SSI Children			SSI Children Meeting Study Criteria			Other SSI	All Children
	Diag. Alone	Diag. & Util.	Util. Alone	Diag. Alone	Diag. & Util.	Util. Alone		
Hospital	74%	77%	84%	43%	83%	36%	30%	63%
ICF-MR and Nursing Facility	1%	0%	2%	26%	2%	37%	1%	13%
Physician	4%	6%	2%	2%	2%	1%	11%	3%
Occupational, Physical and Speech Therapy	1%	0%	1%	3%	0%	1%	2%	1%
Skilled Nursing and Home Health	3%	0%	1%	11%	1%	8%	1%	5%
Prescribed Drugs	2%	1%	1%	2%	1%	1%	12%	2%
Other	15%	16%	9%	14%	11%	17%	43%	14%
Total	100%	100%	100%	100%	100%	100%	100%	100%

Expenditures for SSI children vary significantly by type of impairment.

As previously discussed, we also linked Medicaid administrative data on SSI children with Social Security records in three of the four study states. We did this because the SSI administrative records provide an independent source for determining the primary disabling condition of children in our analytical population, that is not dependent upon the coding of Medicaid claims by providers.

TABLE 9. Distribution of Medicaid Expenditures by Study Criteria for Children in Michigan, 1992

Service Category	Non-SSI Children			SSI Children Meeting Study Criteria			Other SSI	All Children
	Diag. Alone	Diag. & Util.	Util. Alone	Diag. Alone	Diag. & Util.	Util. Alone		
Hospital	66%	80%	78%	34%	72%	41%	16%	60%
ICF-MR and Nursing Facility	0%	0%	0%	8%	0%	7%	0%	2%
Physician	10%	5%	7%	7%	6%	7%	19%	8%
Occupational, Physical and Speech Therapy	1%	0%	0%	2%	0%	2%	7%	1%
Skilled Nursing and Home Health	2%	1%	1%	13%	1%	14%	5%	5%
Prescribed Drugs	5%	1%	1%	8%	2%	4%	13%	4%
Other	16%	13%	12%	29%	19%	26%	39%	19%
Total	100%	100%	100%	100%	100%	100%	100%	100%

Table 10 presents the distribution of SSI children in California, New York and Georgia by the "principal disabling condition" as recorded during the SSA disability determination process. Unfortunately, for approximately one third of all SSI children, the principal disabling condition was recorded as "unknown" on the SSA administrative files available for this project. However, for the remainder of the population, the distribution of disabling conditions was relatively similar across the three states, with mental retardation being the most prevalent condition among SSI children.

More importantly, Table 11 presents average Medicaid expenditures for different types of disabling conditions. While total average payments vary across the three states for similar conditions, reflecting overall differences in Medicaid spending patterns across states, the *relative* differences across different types of conditions within states are quite similar. For example, children with mental retardation and attention deficit disorder generally had the lowest average expenditures among SSI children (except in New York, where children with attention deficit disorder had higher expenditures). On the other hand, children with conditions related to the digestive system, neoplasms, infections, and injury and poisoning, had consistently higher average Medicaid expenditures across the three study states.

Primary Impairment	California 1992		New York 1991		Georgia 1992	
	#	%	#	%	#	%
Infections	198	0.4%	237	0.6%	59	0.3%
Neoplasms	1,108	2.0%	659	1.6%	280	1.4%
Endocrine and Metabolic	554	1.0%	443	1.1%	282	1.4%
Blood and Blood Forming Organs	617	1.1%	563	1.4%	470	2.3%
Attention Deficit Disorder	793	1.4%	282	0.7%	501	2.5%
Mental Retardation	14,303	25.6%	10,327	25.0%	6,520	32.1%
Other Mental Disorders	4,441	7.9%	3,920	9.5%	1,584	7.8%
Nervous System and Sense Organs	8,361	14.9%	4,767	11.5%	1,905	9.4%
Circulatory System	310	0.6%	339	0.8%	116	0.6%
Respiratory System	718	1.3%	889	2.1%	352	1.7%
Digestive System	139	0.2%	103	0.2%	54	0.3%
Musculoskeletal System	779	1.4%	484	1.2%	181	0.9%
Congenital Anomalies	2,784	5.0%	1,308	3.2%	737	3.6%
Conditions in Perinatal Period	181	0.3%	17	0.0%	9	0.0%
Injury and Poisoning	466	0.8%	308	0.7%	178	0.9%
Other	1,749	3.1%	859	2.1%	524	2.6%
Unknown	18,432	33.0%	15,873	38.4%	6,571	32.3%
Total SSI Children ²	55,933	100%	41,378	100%	20,323	100%

1. Principal Disabling Condition means the primary reason as determined by the Social Security disability determination process, why the child qualifies for disability benefits.

2. The total number of SSI children in this table is slightly less than the number of SSI children in previous tables primarily because prior tables include SSI-related children (i.e., SSI "non-disabled" children on Medicaid).

These data are of policy relevance in regard to the enrollment of SSI children in Medicaid managed care plans. As states move to enroll SSI children into managed care, one issue is whether plans will be able to proactively enroll recipients whose health care needs are *predictably* lower than the premium payment received from the state for a particular rate cell. Currently, in those states which are enrolling SSI children into capitated plans, plans generally receive the same premium payment for all SSI children, regardless of disability condition. However, the data presented in Table 11 suggest that Medicaid expenditures for SSI children with different types of conditions are predictably different from one another. With this knowledge, managed care plans could undertake a variety of marketing and enrollment activities to ensure that they enroll SSI children with predictably lower costs than the average for SSI children (e.g., children with mental retardation). For example, if California made premiums to plans that reflected the average annual costs of serving all SSI children in 1992 (\$6,671 annually), a managed care plan could make, on average, a 100% profit for every SSI child with mental retardation that it enrolled in excess of the expected distribution of children with mental retardation enrolled in the plan. Thus, these data suggest that state Medicaid programs should risk-adjust premium payments to capitated plans for SSI children by type of disabling condition.^{28,29,30,31,32}

TABLE 11. Mean Medicaid Expenditures by Principal Disabling Condition for SSI Disabled Children			
Primary Impairment	California 1992	Georgia 1992	New York 1991
Infections	\$13,063	\$13,914	\$25,123
Neoplasms	19,848	23,471	20,925
Endocrine and Metabolic	10,995	10,258	11,840
Blood and Blood Forming Organs	17,102	8,165	14,618
Attention Deficit Disorder	2,257	1,454	12,154
Mental Retardation	2,970	2,008	7,027
Other Mental Disorders	4,546	2,800	16,862
Nervous System and Sense Organs	6,559	4,410	11,846
Circulatory System	10,850	13,129	14,977
Respiratory System	9,587	9,008	8,763
Digestive System	30,533	13,758	17,554
Musculoskeletal System	8,053	4,802	8,193
Congenital Anomalies	9,113	11,232	12,732
Conditions in Perinatal Period	16,673	6,765	8,636
Injury and Poisoning	17,560	12,164	31,476
Other	9,845	8,527	10,441
Unknown	7,174	5,670	10,978
Total	\$6,671	\$4,987	\$11,138

Summary

Traditionally, the Medicaid program has been viewed as serving two distinct groups of children--SSI-related children who have severe disabilities and above average need for health and supportive services, and AFDC-related children who are not disabled, but nevertheless need preventive services and care for acute illnesses. In reality, the situation is much more complicated. There are, in fact, a large number of children on Medicaid who have severe chronic conditions, but who are not receiving SSI. These children consume large amounts of medical services, are much more expensive to Medicaid than are other AFDC children, and their care is often complicated to manage. On the other hand, children who have qualified for SSI often have diverse needs. Even though all SSI children have significant disabilities, their conditions may be very different from a medical perspective. For example, many SSI children with mental retardation are more likely to experience the same sorts of illnesses as non-disabled children, and consequently, they may have modest needs for medical care. However, SSI children who have cancer are likely to have intense medical needs.

The purpose of this study was to use diagnosis and utilization data available through Medicaid administrative data to take a broader look at children with severe chronic conditions on Medicaid than had been done in previous studies of Medicaid disabled children. We believe there are two primary policy implications that emerge from the study findings. First is the obvious conclusion that there are many more children with severe chronic conditions receiving Medicaid than simply the population of children who are eligible for Medicaid because they receive SSI disability benefits. State Medicaid programs and health plans that are working together to provide medical care

to Medicaid children through managed care models need to be aware of the high prevalence of severe and chronic conditions among children who are *not* receiving SSI disability benefits and design programs that can appropriately meet the needs of these children.

The second major policy implication is that the *health* care needs of disabled children receiving SSI benefits are more diverse than many people probably realize. Indeed, the distribution of Medicaid costs for SSI children resembles more closely the distribution of health care costs for a population of non-disabled children than is realized, with a relatively low percentage of children accounting for a large percentage of total expenditures, and a large percentage of children with relatively low health care costs. However, unlike the health care expenditures of a non-disabled population of children, the health care expenditures of SSI children are much more predictable based upon their primary disabling condition. Thus, unless state Medicaid programs can design managed care enrollment policies which guarantee a random distribution of SSI children across all participating health plans, then states would be wise to risk adjust capitation payments to managed care plans using the primary disabling condition of a child as a risk adjuster. Otherwise managed care plans in states with non-random enrollment policies (e.g. states which allow families to choose among multiple plans) will rationally implement behaviors to disproportionately enroll lower-cost SSI children and avoid higher-cost children.

NOTES

1. Adler, Gerald and Rymer, Marilyn. "Children and Medicaid: The experience in four states." *Health Care Financing Review*. 9 (1): 1-20. 1987
2. Newacheck, Paul, Dana Hughes and Miriam Cisternas, "Children and Health Insurance: An Overview of Recent Trends." *Health Affairs*. (Spring): 245-254: 1995
3. 13.4% of AFDC children have a functional disability compared to 8.2% in the general population. Source: Disability Among the AFDC Population: Findings from the 1994 Disability Survey ASPE Research Note (forthcoming).
4. 8.5% of children with mothers on AFDC had a disability compared to 6.3% whose mothers were never on AFDC and 9.9% whose mothers were (but are not now) on AFDC. Source: "Disability Among Women on AFDC: An Issue Revisited." Proceedings of the American Statistical Association: Government Statistics Section. 1993.
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6. Fox, H., J. Wicks and P. Newacheck. "State Medicaid Health Maintenance Organization Policies and Special Needs Children." *Health Care Financing Review*. 15 (1): 25-37. 1993.
7. Neff, John. "Protecting Children with Chronic Illness in a Competitive Marketplace." *JAMA*. 262(23): 1866-1869. 1995.
8. However, under the provisions of the recently-enacted Balanced Budget Act of 1997, states are prevented from requiring enrollment of children with special health care needs into managed care plans without special waivers from the Health Care Financing Administration.
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13. Ku, Leighton. *Who is Paying the Big Bills? Very High Cost Pediatric Hospitalizations in California, 1987*. Lexington, MA: SysteMetrics/McGraw-Hill. 1990. [<http://aspe.hhs.gov/daltcp/reports/bigblles.htm>]
14. We wish to thank Dr. James Perrin of Massachusetts General Hospital for his assistance in helping us to define criteria for identifying severe and chronic physical disabilities among children. We also would like to thank Dr. Kevin Hennessey of ASPE in HHS for his assistance in developing the mental health criteria used in this study.
15. For example, Georgia was the only state of the four in the study which did not have a medically needy program in 1992. Georgia has since adopted a medically needy program and significantly expanded Medicaid coverage of children.
16. Thus, SSI children who also met the diagnosis or utilization criteria were included in this part of the analysis, while SSI children who did not meet these criteria were not included.
17. Fox, Harriette and Newacheck, Paul. "Private Health Insurance of Chronically Ill Children." *Pediatrics* 85(1): 50-57, 1990.
18. General Accounting Office. *Social Security: Rapid Rise in Children on Disability Rolls Follows New Regulation*. Washington, DC, September 1994.
19. General Accounting Office. *Social Security: New Functional Assessments for Children Raise Eligibility Questions*. Washington, DC, March 1995.
20. Data from the Social Security Administration indicate that about 40% of all children under the age of 22 receiving SSI cash benefits have a primary diagnosis of mental retardation. Source: Social Security Administration, *Social Security Bulletin, Annual Statistical Supplement, 1996*, Table 7.F, Page 318, SSA Publication No. 13-11700.
21. Kennedy, Lenna. "Children Receiving SSI Payments, December 1991." *Social Security Bulletin* 55(2):48-51, 1992.
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23. Thus, children receiving SSI benefits that did not meet the disability criteria are excluded from this table.

24. If children met both diagnostic and utilization criteria, they were counted in both categories.
25. SSI children who had no Medicaid claims at all during the study year were excluded from these averages. Thus, average Medicaid costs for SSI children who did not meet the disability criteria only includes children who used at least one Medicaid-covered service during the study year.
26. During the period 1991-1992 many states also provided significant funding for certain disabled children through other programs. For example, the California In-Home Supportive Services Program used Title V funds to supplement Medicaid. Such expenditures are not captured by the data base used in this project.
27. Although the percentage of all disabled children receiving therapies ranged from 4% in New York and Georgia to 14% in Michigan, the average expenditure for these services is very low when compared to the average amount for inpatient hospital services. Consequently, the share of total expenditures for therapies is quite low.
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