Changing Patterns of Conditions Among Children Receiving Supplemental Security Income Disability Benefits

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Objective: To determine the relative growth of types of chronic health conditions among children and adolescents receiving Supplemental Security Income (SSI) benefits before and after major SSI program changes, including changes in definitions of childhood disability and outreach to identify eligible children.

Design: Retrospective analysis of Medicaid claims from California, Georgia, Michigan, and Tennessee.

Participants: All children (aged ≤21 years) newly enrolled in SSI programs in these states from July 1989 (n=21,222) to June 1992 (n=38,789).

Methods: Medicaid data indicate eligibility status and diagnoses for services rendered. For children newly enrolled before (time 1, July 1989 to June 1990), during (time 2, July 1990 to June 1991), and after (time 3, July 1991 to June 1992) the program changes, we used claims for the first 6 months of enrollment to determine rates of chronic conditions in general and rates of asthma, attention-deficit/hyperactivity disorder (ADHD), and mental retardation specifically. We also followed up time 1 enrollees during the study period to determine the likelihood of a chronic condition claim at any time.

Main Outcome Measure: Presence of claims for chronic conditions.

Results: New SSI enrollees almost doubled during the study period. Increasing numbers of new enrollees had chronic condition claims in their first 6 months (from 29% to 36%); 58% of time 1 enrollees had such claims during any study month. Rates of chronic physical conditions other than asthma increased 14% (time 1 to time 3); asthma rates increased 73%. Rates of mental health conditions other than mental retardation and ADHD increased 63%; rates of mental retardation decreased 29%, while rates of ADHD increased almost 3-fold.

Conclusions: The number of children with chronic conditions receiving SSI benefits experienced rapid growth from 1989 to 1992. Growth was particularly marked for children with diagnoses of asthma and ADHD.


Editor's Notes: This article nicely demonstrates the results of a program designed to encourage children’s access to needed services. I’d like to see the results of a study like this in some managed-cost organization.

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MATERIALS AND METHODS

We used Medicaid enrollment files and claims data for 4 years (1989-1992) for 4 states (California, Georgia, Michigan, and Tennessee) to estimate changes in rates of key diagnoses from before to after the major changes in program policy. These years included the key program policy changes noted above, and the data therefore allow examination of their associations with the clinical conditions that newly eligible children had. We defined 3 time periods during the 4 study years: July 1989 to June 1990 (time 1, prior to the changes in policy); July 1990 to June 1991 (time 2, during program changes); and July 1991 to June 1992 (time 3, after the policy changes). We included claims data up to December 1992 so as to have a 6-month window following first SSI enrollment to identify any claims for a chronic condition.

State Medicaid data came from the tape-to-tape project sponsored by the Health Care Financing Administration (HCFA) for California, Georgia, Michigan, and Tennessee and were supplied by the main HCFA contractor (MedStat Group, Santa Barbara, Calif). Available Medicaid files include all paid claims (for physician services, hospital and outpatient department care, long-term care, and prescription drugs), as well as enrollment data that indicate the child’s basis for eligibility each month and thus indicate whether a child recently obtained SSI eligibility. Other data elements included the child’s age, sex, and race/ethnicity (categorized as white, black, other, and unspecified). The study sample included all SSI recipients, aged 0 to 21 years, who enrolled from July 1989 to June 1992 in the 4 states, regardless of the length of their enrollment. Unlike children receiving Medicaid through other forms of eligibility, most children with SSI eligibility typically have long periods of continuous Medicaid enrollment. We used Medicaid eligibility categories of “blind” or “disabled” to define SSI-eligible Medicaid recipients.

We used a broad general classification of childhood conditions as chronic, based on a categorization of International Classification of Diseases, Ninth Revision (ICD-9) codes (available from the authors) used in previous studies, and then separated these conditions into primary physical, mental health, or mental retardation groups. We also developed algorithms to identify children with 2 specific diagnoses of interest (asthma and ADHD) in the Medicaid data files. For both of these conditions, a single claim may be ambiguous, such as when a physician uses a label without confirming that the child has the disease. Thus, for these conditions we required at least 2 outpatient claims or 1 hospitalization. The more common severe physical conditions included asthma, leukemia, spina bifida, diabetes, arthritis, hemophilia, congenital heart disease, and sickle cell disease. We expected a much higher rate of growth for asthma (as a condition with many less disabling cases) than for the other physical conditions studied.

We used claims for the first 6 months of SSI enrollment to determine whether the child had a chronic condition. For the group enrolled during time 1, we also followed their claims throughout the study period to determine the likelihood in later months of a chronic condition claim. In all cases, our approach to defining chronic condition is conservative, insofar as a child might have a chronic health condition for which treatment was sought but the claim might be labeled with another diagnosis or purpose for visit. In addition, children with chronic conditions might not have a claim or visit for that condition in the 6 months following enrollment.

We first determined numbers and demographic characteristics of total new enrollees by state during each period. We then determined numbers of new enrollees with chronic conditions in each period and rates for physical, mental health, and mental retardation categories and for asthma and ADHD. We determined significant differences in rates between time 1 and time 3 by the χ² test. For children and adolescents who enrolled during time 1, we also determined the numbers of those with chronic conditions when including claims from all months following enrollment, to estimate more likely rates of conditions among SSI recipients than found when limiting follow-up to only 6 months. We finally calculated changes in relative proportions of each diagnosis or diagnostic group over time.

years: (1) the publication of new guidelines by the Social Security Administration for determining mental health disability in children in 1990, which added new eligible diagnoses (including attention-deficit/hyperactivity disorder [ADHD]) and thereby increased the access of children with mental health conditions to SSI; (2) the 1990 Supreme Court Zebley decision, which led to a new regulation (published in 1991) for determining disability among children with multiple conditions and for assessing how health conditions affect the functioning of children; and (3) a major effort by the Social Security Administration to identify potential child recipients in the late 1980s and the early 1990s, partially under congressional mandate.

These policy changes, especially the new Zebley regulation and the broadened mental health listings, were expected to change the types of condition and the severity of physical and developmental problems affecting new enrollees compared with previous ones. In general terms, the Zebley decision allowed children with multiple conditions, none of which alone met usual severity criteria, to become eligible for benefits. The decision also required the development of methods of assessing functioning of children, going beyond simple assessment of physiological severity. This requirement led the administration to develop the Individualized Functional Assessment approach. Although developed with the intent of assessing children with multiple conditions, far higher percentages of children with mental health conditions (65%) and mental retardation (33%) than of children with physical conditions (7%) gained eligibility through this new individualized approach. In addition, the administration developed new categories of presumptive eligibility, including newborns who were extremely premature or had very low birthweight. Thus, in comparison with children enrolled in the period before these policy changes, we expected later enrollees to include larger numbers of children with less disabling conditions and for there to be particular growth among children with mental health impairments. We also expected that the expanded use of presumptive eligibility due to levels of prematurity would lead to a lower mean age of new recipients.

In this study, we used Medicaid claims data to estimate clinical characteristics of new SSI enrollees before and
after these major policy changes. We expected substantially less growth among serious chronic physical conditions (such as leukemia, cystic fibrosis, or spina bifida), expecting that most children with these conditions would have been eligible even before the major policy changes. On the other hand, we expected that children with less disabling physical conditions (such as asthma) and with mental health conditions other than mental retardation would become more prevalent among SSI enrollees during this time.

RESULTS

All states experienced a major growth in numbers of enrollees from time 1 to time 3, varying from 52% to 151%, with growth for the 4 states together being 83% (Table 1). As expected, very young children experienced higher rates of growth than did older children, accounting for 7% of new enrollees in time 1 and 18% in time 3 (Table 2). Male predominance among new enrollees (about 60%) remained essentially unchanged during the study period. Rates of African American children among new enrollees grew from 22% to 29% during the study period, with commensurate declines in rates of white children (from 50% to 41%).

The percentages of new enrollees with claims for chronic conditions indicate that most children with such claims had them for chronic physical conditions (Table 3). This table uses claims only in the 6 months following SSI enrollment and thus represents a conservative estimate of the prevalence of these conditions, insofar as the child might not have a claim that soon after enrollment. By this approach, 28.8% of time 1 new enrollees had any chronic condition claim, as did 29.5% of time 2 enrollees and 36.1% of time 3 enrollees. Children enrolled during time 3 had higher rates of asthma and ADHD than did children enrolled during time 1, although the relative rates of these conditions indicate that about 25% to 30% of new enrollees in times 1 and 3 had a claim for a chronic physical condition, while the rates of claims for children with mental health conditions of all kinds increased from about 12.8% in time 1 to 20.1% in time 3. Table 4 describes the rates of these same conditions when time 1 enrollees are followed up for the full period of their enrollment, thus increasing the opportunity to generate a claim for a chronic condition. Here, almost 60% of the new enrollees had at least 1 claim for a chronic condition.
As indicated in Table 5, all physical conditions other than asthma contributed a smaller proportion of new enrollees in the later period than in the earlier period in all states, with the exception of California. Across the 4 states, there was a 14% increase in rates from the time prior to the policy changes to after them. Given the dramatic growth in general program enrollment during this time, these rates document increased total numbers of children with these relatively more disabling chronic physical conditions receiving benefits in the later period than in the earlier one, as shown in Table 3. Asthma rates, however, followed a different pattern, with rates across the study states 73% higher in the later period than in the earlier one. Although some of this increase may reflect changes in community prevalence of severe asthma, the high rates of growth suggest that the new rules made more children with this condition eligible. The number of children with other chronic physical conditions had, therefore, a lower rate of growth than the number of those with asthma.

Among children with mental health conditions, the rate changes also varied across the states, although in aggregate there was a 63% growth in the rates of mental health conditions other than mental retardation and ADHD. As one of the more common mental health diagnoses, ADHD experienced a much higher rate of growth, with almost 3 times the prevalence in later enrollees than in the first period. Mental retardation, in contrast, had proportionately less growth in rates than other study conditions, experiencing only a 29% decline in rates during the study period.

### Table 5. Changes in Proportions of Chronic Condition Groups Among New Enrollees (Time 3 Rates Divided by Time 1 Rates)

<table>
<thead>
<tr>
<th>State</th>
<th>Chronic Physical Conditions</th>
<th>Mental Health Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Other Than Asthma</td>
<td>Asthma</td>
</tr>
<tr>
<td>Georgia</td>
<td>0.76</td>
<td>1.41</td>
</tr>
<tr>
<td>Michigan</td>
<td>0.86</td>
<td>1.84</td>
</tr>
<tr>
<td>Tennessee</td>
<td>0.87</td>
<td>1.21</td>
</tr>
<tr>
<td>California</td>
<td>1.38</td>
<td>2.07</td>
</tr>
<tr>
<td>All study states</td>
<td>1.14</td>
<td>1.73</td>
</tr>
</tbody>
</table>

*ADHD indicates attention-deficit/hyperactivity disorder.

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Beginning around 1990, the SSI program experienced a rapid growth of child and adolescent beneficiaries. Although our results indicate major growth in numbers of all conditions, we found much higher rates of growth among children with asthma or mental health conditions other than mental retardation. Within this latter category, children with ADHD had particularly high rates of growth, although they still constituted only 6% of new enrollees in the post-transition period. Some growth among more disabling physical conditions, which were presumably eligible under the old rules prior to the new listings and the Zebley decision, likely reflected increasing public awareness of the eligibility of children and adolescents for the SSI program and increasing outreach to hospitals and other sites where children and their families receive services. The substantially higher rates of growth among children with asthma likely followed the more liberal definitions of disability and opportunities for children with less-disabling chronic conditions or disabilities to gain access to the program. The particularly high rates of growth among mental health conditions, including ADHD, followed the changing rules, including the addition of ADHD to the mental health listings, the broadening of the mental health listings, and the development of the Individualized Functional Assessment. Although we found differences across the states in rates of growth of ADHD, all states experienced at least a doubling of rates during the study period.

These data have important limitations. All of the information regarding the health conditions among these children newly receiving SSI benefits comes from medical claims data. Because the primary purpose of claims data is to assure provider reimbursement, expenditure data for Medicaid claims are considered relatively reliable. Diagnosis codes, however, reflect bias because providers tend to code conditions and procedures that are likely to be reimbursed. Thus, the diagnoses on claims may not accurately reflect the conditions that children have. Furthermore, a child with a chronic condition may not have had a visit for the specific condition during the 6 months of claims observation. Our data relating to children newly enrolled in time 1 provide information regarding rates of chronic condition based on cumulative claims for a longer period of time, although one cannot conclude that all children newly enrolled in SSI during these years would have similar patterns of conditions. Finally, we have no information from visits or procedures by sources of treatment not reimbursed by Medicaid. Although Medicaid offers relatively comprehensive coverage, some children covered by SSI have other insurance that may reimburse other providers for services for these conditions. We have presented most of our data aggregated across the 4 states (Table 2 through Table 4). Although 1 state might be driving the effects here, state-specific analyses provide similar findings, and the data in Table 5 indicate generally stable trends across the states with the exception of mental retardation.

The Social Security Administration maintains limited clinical or diagnostic information to help describe changing patterns of conditions among SSI enrollees. Social Security Administration files include only the primary diagnosis by which the child became eligible and at times a second diagnosis. The diagnosis used for determining eligibility is typically the one that leads to a determination most quickly, even in cases where that condition may not be the one most central to the child’s health. These data, based on total numbers enrolled at any time rather than new enroll-
es only, also indicate major growth in the relative prevalence of mental health conditions other than mental retardation among child and adolescent recipients in the past several years. In 1989, Social Security Administration data indicated that 6% of child and adolescent SSI enrollees had mental health conditions other than mental retardation. By 1993, those numbers had increased to approximately 22% of enrollees. At this time, about 42% of child and adolescent recipients had a Social Security Administration diagnosis of mental retardation; 36% had physical disabilities. The Medicaid data presented here provide results similar to those from the Social Security Administration.

During the study period, Social Security Administration rules for determining childhood disability changed, mainly through the development of methods to assess children’s functioning and through the expansion of the mental health conditions eligible for benefits. During this same period, Medicaid rules generally remained stable. Thus, Social Security Administration data (based on these changing methods of determination) could overstate changes in clinical status, whereas the Medicaid data may provide more valid estimates of clinical utilization, at least in certain categories. Insofar as mental retardation often does not lead to a specific medical claim with that diagnosis, however, this category may be particularly underrepresented in Medicaid data. Furthermore, Medicaid limits on mental health benefits and on reimbursement of non–mental health providers for these services may decrease the likelihood of identifying these conditions in Medicaid claims files. Thus, our findings (in comparison with Social Security Administration data) suggest different relative prevalences of physical conditions to mental health conditions in the population of children newly enrolled. The Medicaid data indicate that 44.7% have chronic physical conditions, only 6.9% have mental retardation, and 17.7% have other mental health conditions, as indicated in Table 4.

During the past few years, the rapid growth in the child and adolescent SSI program has caused controversy regarding the purpose of the program and the types of children who have gained access to its benefits. More specifically, Congress has raised questions regarding which children should receive cash benefits as a result of disability. The notion has been that the program might be limited to children and adolescents whose families can demonstrate a need for cash as a result of their child’s disabling condition. These concerns led to several activities, including a congressionally mandated National Commission on Childhood Disability to review public investments in childhood disability programs and changes in welfare reform legislation (the Personal Responsibility and Work Opportunity Act of 1996), which for the first time provided a specific definition of childhood disability and markedly tightened the eligibility criteria for program benefits. These new criteria specifically require reassessment of the eligibility of children who had received benefits as a result of the Individualized Functional Assessment, with particular targeting toward children with mental health conditions.

Our research findings indicate that some clinical populations, especially children with asthma and with mental health conditions other than mental retardation, experienced particularly speedy growth in rates among new enrollees (likely greater than that in the general population) in comparison with children with other chronic physical conditions and mental retardation. Providing cash benefits to these children with less-disabling conditions underlies much of the congressional and media concern about the program. Our data provide no information as to whether cash benefits would be particularly helpful to these families or whether the cash needs of these families are comparable to those of families whose children have other disabilities. Nonetheless, a key question has been the purpose for the provision of direct financial subsidy and whether all children with different chronic health conditions should be treated similarly or differently in the provision of these public benefits. While other public institutions (such as schools) have responsibilities for helping to manage certain conditions (such as ADHD or learning disabilities), should these conditions be included in a cash benefit program? Although our study provides no information regarding the utility of benefits to families, it does indicate that changes in policy in the early 1990s led to much greater increases in certain categories of chronic health conditions, as would be expected given the types of changes in the definitions of disability at that time. Nonetheless, despite these changes, at the end of the study period, the majority of child and adolescent SSI enrollees had diagnoses of severe mental retardation or physical disability.

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REFERENCES