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Who Cares for Medicaid-Enrolled Children With Chronic Conditions?

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ABSTRACT. ***Objective.*** **To estimate generalist, pediatric subspecialist, and any subspecialist use by Medicaid-enrolled children with chronic conditions and to determine the correlates of use.**

Methods. **We analyzed Medicaid claims data collected from 1989 to 1992 from 4 states for 57 328 children and adolescents with 11 chronic conditions. We calculated annual rates of generalist, subspecialist, and pediatric subspecialist use. We used logistic regression to determine the association of demographics, urban residence, and case-mix (Adjusted Clinical Groups) with the use of relevant pediatric and any subspecialist care.**

Results. **Most children with chronic conditions had visits to generalists (range per condition: 78%–90% for children with Supplemental Security Income [SSI] and 85%–94% for children without SSI) during the year studied. Fewer children visited any relevant subspecialists (24%–59% for children with SSI and 13%–56% for children without SSI) or relevant pediatric subspecialists (10%–53% for children with SSI and 3%–37% for children without SSI). In general, children who were more likely to use pediatric subspecialists were younger, lived in urban areas, were white (only significant for non-SSI children), and had higher Adjusted Clinical Groups scores. Use of any subspecialists followed a similar pattern except that urban residence is statistically significant only for children with SSI and the youngest age group does not differ from the oldest age group for children without SSI.**

Conclusions. **Children who had chronic conditions and were enrolled in Medicaid received a majority of their care from generalist physicians. For most conditions, a majority of children did not receive any relevant subspecialty care during the year and many of these children did not receive care form providers with pediatric-specific training.** ***Pediatrics*** **2001;108:906–912;** ***children, chronic conditions, Medicaid, subspecialist, generalist, primary care, referral, Supplemental Security Income.***

ABBREVIATIONS. ADHD, attention-deficit/hyperactivity disorder; SSI, Supplemental Security Income; AIDS, acquired immunodeficiency syndrome; AMA, American Medical Association; ACG, Adjusted Clinical Groups; RR, relative risk; CI, confidence interval.

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Children with chronic conditions need both high-quality primary care and up-to-date subspecialty care for the optimal management of their chronic condition.[1] Substantial improvements in survival of these children, coupled with rapid advances in technologies to improve their care, indicate the importance of ensuring them a broad range of primary through tertiary care services. Nonetheless, ensuring optimal use of a full range of appropriate care for children with chronic conditions is problematic. Most childhood chronic conditions are sufficiently rare that any one pediatrician will have very few children with any one condition (asthma, attention-deficit/hyperactivity disorder [ADHD], and mental retardation are exceptions).[2,3] Changes in the recommendations for care of children with chronic conditions and the relative rarity of many conditions make pediatric subspecialist care important for children with chronic conditions because pediatric subspecialists are more likely to see an adequate volume of patients to maintain expertise and quality is associated with volume in some studies (see, eg, Tilford et al[4] and Phibbs et al[5]). How much care children with chronic conditions receive from subspecialists and especially pediatric subspecialists has received little attention.

Numerous studies have documented substantial variations in practice patterns in health care, especially hospital care for children,[6,7] and suggest that variations in primary care use influence hospital admission rates.[8] A Swedish study from the 1980s found an average of 1.2 primary care visits and 2.5 subspecialty care visits per year for chronically ill children compared with 1.0 and 0.5 for a non–chronically ill control group. This study related the use of specialized care to the severity of the child's condition.[9] Adolescents with cystic fibrosis and sickle cell disease reported subspecialists as the most common main physician (53% and 46%, respectively), and among those with a main physician, 83% reported seeing that provider in the past year.[10]

Patterns of referral suggest varied patterns of subspecialist use. One study of pediatricians documented referrals of 2.3% of visits, with otitis media, refraction errors, orthopedic signs/symptoms, and behavioral problems the most common reasons for referral.[11] Kansas family and general physicians refer 70% of children with ADHD for diagnosis or treatment.[12] Children with congenital heart conditions identified through a registry had earlier referrals if they lived in an urban area.[13] A study of Quebec child health providers showed referral variations by disease, with some subspecialist contact for 25% of patients with asthma, 99% of patients with congenital heart disease, and 79% of patients with diabetes.[14] These studies described only referral rates and provided no information on ongoing patterns of care by primary care and subspecialty physicians.

We examined rates of use of subspecialists, pediatric subspecialists, and generalists for Medicaid-enrolled children with specific common and uncommon chronic conditions. We used data from 4 states during a period before extensive use of managed care for children with Medicaid because of Supplemental Security Income (SSI) program enrollment. Although no objective standard exists, we expected that most Medicaid-enrolled children with chronic conditions would have visits to both subspecialists and generalists at least yearly for evaluation and treatment. We further expected that children with more common conditions, such as asthma, ADHD, and mental retardation, would experience less subspecialist use, because general physicians will have substantial experience with these conditions. Children who live in urban areas may have easier access to pediatric subspecialists, who commonly locate in large urban teaching hospitals. Therefore, we also expected more pediatric subspecialist use among children who live in urban areas. We also expected more pediatric subspecialist use among younger children because of greater difficulties with diagnosing and caring for young children and among children with worse case mix because of a greater associated illness burden.

METHODS

We analyzed Medicaid eligibility, claims, and provider data from California, Georgia, Michigan, and Tennessee for the years 1989 to 1992 to determine patterns of generalist and relevant subspecialist use for children with selected chronic health conditions. We chose these 4 states because they represent a mix of urban and rural populations, have varied levels of program generosity, and could provide reasonably usable and comparable Medicaid files.

Sample Definition

The initial sample included all children who were ages 0 to 21 years and enrolled in the SSI program during any of these 4 years in these states and an age group-, gender-, and year-matched sample of children who were enrolled for a full year in Medicaid through any other source. This sample originally was drawn for another study that required including all children with SSI and a matched sample of non–SSI-enrolled children. SSI eligibility requires both proof of disability and low-income status. The SSI sample, therefore, has a high rate of children with chronic conditions. The non-SSI sample mainly includes children who are enrolled through the Aid to Families with Dependent Children program, as well as children of somewhat higher income who are eligible through the Medicaid expansions of the 1980s.

We limited the claims used for this sample to include only the last full calendar year of data for all children, to allow for observation of health care claims over time and to ensure use of the most recent data. (We also conducted analyses using the previous 2 years of claims data to determine whether this strategy might indicate substantially different patterns from those using a single year of claims.) We excluded children with capitated care and with private insurance, as care provided under these arrangements does not result in Medicaid claims. As such, we likely do not have full claims histories for these children. The eligibility file contains monthly indicators for whether the child had private insurance and whether the child had capitated care. From the resulting sample, we identified children with any of 11 chronic conditions: spina bifida, seizure disorder, hemophilia, congenital heart disease, asthma, sickle cell disease, juvenile arthritis, mental retardation, cerebral palsy, ADHD, and acquired immunodeficiency syndrome (AIDS). These conditions include both common (asthma, ADHD, mental retardation, cerebral palsy) and uncommon conditions and provide a representative sample of chronic illnesses in children.[3] Children with these conditions represent 26% of the original sample. We used both diagnostic codes (from inpatient and outpatient visits) and certain pharmacy claims (eg, methylphenidate use for ADHD or digitalis use for congenital heart diseases) to identify the 11 conditions. We originally sought to study diabetes; however, illogically high rates of identification in 1 state lead us to suspect a coding problem and to exclude this condition from analyses.

We developed algorithms to distinguish between conditions for which a single encounter likely identified a child (eg, sickle cell disease) and those for which the diagnostic code might be used to rule out the condition. In these latter situations, we required >1 encounter to identify the condition (see Table 1). We relied on any outpatient encounters in a variety of settings and for some conditions on inpatient encounters and pharmacy claims as well. Multiple claims to 1 provider for the same calendar date were considered 1 encounter. Some children may have had >1 of the study conditions (eg, a child with seizure disorder and mental retardation). In these cases, we included the child in analyses for both conditions, insofar as the study examined subspecialists relevant to each specific condition.

Variables

Physician Specialty Status

We determined the physician's subspecialty status for each encounter. The Medicaid files identify the provider for each visit and indicate the self-identified subspecialty status for each physician. These Medicaid designations, however, do not indicate board status or distinguish between pediatric and other subspecialists. To obtain additional information on subspecialty, we used the 1992 American Medical Association (AMA) provider database (obtained from KM Lists, Inc, Berlin, NJ). We included only providers in the AMA database who were licensed in at least 1 of the study states. We merged the Medicaid provider file with the AMA provider database using a probabilistic merge based on name and residence in each of the 4 study states. The AMA provider file contains both subspecialty board status (including pediatric subspecialties) and the physician's self-identified specialty. We considered a match acceptable when it agreed on at least 50% of the name characters and 80% of the city characters or at least 90% of the name characters.

This method determined specific providers for approximately 65% of Medicaid physician claims. For these visits, we classified the subspecialty visits as provided by pediatric or other subspecialists based on AMA board- or self-identified or boarded designations. We included only those subspecialists who were relevant to the condition (see Table 1). We were not able to identify developmental pediatricians; therefore, the rates of subspecialist use, especially for conditions associated with developmental delay, do not include these visits. Providers with a pediatric subspecialty designation were coded as pediatric; all other subspecialist designations were considered "other."

For physicians who were not identified by the AMA merge, we used the Medicaid self-designation (which does not distinguish pediatric from other subspecialists). Claims from a health center or a hospital outpatient department without a specified physician listed were considered as "other" subspecialist visits when they had a "subspecialist" procedure code and when the diagnosis was for the chronic condition or generalist visits for a generalist procedure code. "Subspecialist" procedure codes were identified on a condition-by-condition basis and included procedures that are relevant to that condition and that are likely to be conducted by subspecialists (determined by 1 of the co-authors [J.M.P.]). Approximately 9% of claims were eligible for subspecialty identification with this method. When the hospital was a children's hospital, we considered subspecialist visits as pediatric.

TABLE 1. Inclusion Criteria, *ICD-9* Codes, and Relevant Subspecialists for Study Conditions

Condition	Inclusion Criteria	*ICD-9* Codes	Subspecialists Included
Asthma	Two or more outpatient claims, or 1 or more inpatient claims	493.xx	Allergy/immunology, pulmonary medicine
Mental retardation	Two or more outpatient claims	317–319.99	Neurology, psychiatry
ADHD	Two or more outpatient claims *or* 1 outpatient claim *and* 1 drug claim for ritalin, tricyclics, dextroamphetamine, or clonidine or 1 drug claim for pemoline	314.xx	Psychiatry, neurology
Spina bifida	One or more inpatient or outpatient claims	741.xx	Neurosurgery, orthopedics, urology, neurology, general surgery
Seizure disorder	One or more inpatient or outpatient claims	345.xx	Psychiatry, neurology
Hemophilia	One or more inpatient or outpatient claims or any receipt of clotting factors	286.0–286.19	Hematology, orthopedics
Congenital heart disease	One or more outpatient or inpatient claim *or* 1 drug claim for digitalis or antiarrhythmic	745.xx–747.49	Cardiology, cardiovascular surgeon
Sickle cell disease	Two or more outpatient or 1 or more inpatient claims	282.6–282.69	Hematology, orthopedics, pulmonary medicine, infectious disease, neurology, critical care
Juvenile arthritis	Two or more outpatient claims or 1 or more inpatient claims	714.xx	Infectious disease, allergy/immunology, rheumatology, orthopedics
Cerebral palsy	Two or more outpatient claims	343.xx	Neurology, psychiatry, orthopedics, rehabilitative medicine
AIDS	Two or more outpatient claims *or* 1 or more inpatient claim *or* 1 outpatient claim *and* drug claim for Bactrim	042.xx	Hematology, infectious disease, allergy/immunology, pulmonary medicine

ICD-9 indicates *International Classification of Diseases, Ninth Revision.*
* xx indicates that all *ICD-9* codes in the 3-digit category are included.

Pediatricians, internists, and family/general practitioners in the AMA or unmatched Medicaid provider files were counted as generalists when they were not classified as subspecialists. We combined claims to relevant pediatric and other subspecialists to get a count of any subspecialty visits. We counted claims (duplicate claims to 1 provider on 1 date were counted as 1 visit) to yield person counts of the number of visits to pediatric subspecialists, any subspecialists, and generalists.

Demographic Data

We used Medicaid eligibility files to obtain demographic information. We categorized age into 3 groups (<6 years old, 6–12 years, and 13–21 years). We categorized race into white and nonwhite (these data have limited race/ethnicity data). We classified children as living in urban or rural areas by merging the zip code information in the eligibility files to 1990 Census data, which indicate the percentage of a zip code that is urban (Area Resource File, Office of Research and Planning, Bureau of Health Professions, Health Resources and Services Administration, Department of Health and Human Services). We considered any zip code with >50% of its population living in an urban area as urban; we also created a variable indicating whether the zip code was missing.

Health-Related Predictors

We classified children as having SSI enrollment on the basis of the monthly Medicaid enrollment codes, considering a child with an SSI enrollment code in any month as SSI-enrolled. We computed an Adjusted Clinical Groups (ACG) category for all children.[15] The ACG are a series of health status categories that are defined by morbidity, age, and gender, based on the premise that the level of resources necessary for delivering appropriate health care to a population is correlated with the "illness burden" of that population.[16] We then assigned a score to each ACG category. The score is the mean expenditure for all children in 1992 with that ACG category in the child's state divided by the mean expenditure for that state in 1992. Thus, a higher score indicates a higher average expenditure for children in that ACG group. We grouped the scores into 5 groups. We also created indicator variables for each of the conditions.

Statistical Analyses

We first examined percentage distributions of demographic characteristics (age, gender, urban/rural), SSI status, and state by condition. We then determined, by condition and SSI status, the percentage of children who visited each provider type (pediatric subspecialists, any subspecialists, and generalists) and, for users only, the mean number of visits. Finally, we calculated logistic regressions by SSI status to determine the associations of pediatric subspecialist use and any subspecialist use with demographic characteristics, SSI enrollment, and ACG score, controlling for having missing urban information, specific condition, and state. We calculated risk ratios using Zhang and Kai's[17] formula because the incidence of visits to subspecialists generally was higher than 10%.

RESULTS

Table 2 shows the demographic and Medicaid characteristics by condition. Our strategy identified 57 328 children; numbers of children with a given condition varied from 321 children with AIDS to 16 302 children with asthma (some children had >1 condition). For all conditions other than arthritis, males predominated, especially (as expected) for hemophilia and ADHD, each with <20% female. Almost all children with sickle cell disease were nonwhite, and approximately two thirds of those with asthma, hemophilia, and AIDS were nonwhite. Most children with each study condition (except asthma) received Medicaid as a result of SSI program enrollment. The low percentage of children who had asthma and SSI likely is due to the wide range in the severity of asthma.

Table 3 shows the utilization of any relevant subspecialists, relevant pediatric subspecialists, and generalists by condition for children with SSI enrollment. Among children with SSI, visits to any subspecialist were most common among children with congenital heart disease, spina bifida, and seizure disorder (59%, 58%, and 56%, respectively). Children with relatively common conditions (asthma, ADHD, and mental retardation) had lower levels

TABLE 2. Demographic and Medicaid Characteristics for Children With Chronic Conditions (Percentage Distributions by Condition)

	Asthma	Mental Retardation	ADHD	Spina Bifida	Seizure Disorder	Hemophilia	Congenital Heart Disease	Sickle Cell Disease	Juvenile Arthritis	Cerebral Palsy	AIDS
n	16 302	9 169	8 364	2 592	10 973	380	6 143	2 133	686	10 679	321
Age											
0–5	30.6	11.5	8.1	29.0	19.8	18.2	43.4	21.3	7.7	24.5	44.2
6–12	33.3	25.6	66.7	33.2	29.5	38.4	27.6	31.5	25.4	37.8	21.8
13–21	36.1	62.9	25.2	37.8	50.7	43.4	29.0	47.2	66.9	37.6	34.0
Gender (female)	36.3	42.0	18.2	50.0	43.9	12.1	48.2	46.3	60.5	45.1	48.6
White	35.3	51.0	55.9	49.0	49.0	38.2	42.3	5.8	48.3	49.0	31.5
Urban	85.6	88.3	74.6	80.5	82.3	85.7	93.2	86.4	83.5	84.9	94.8
State											
CA	50.9	61.3	30.1	54.7	53.3	55.8	58.0	30.8	57.9	57.4	53.6
GA	19.5	14.7	31.8	15.7	16.4	17.6	18.0	35.2	14.1	12.2	24.6
MI	16.5	18.7	23.3	11.9	16.4	18.7	12.9	19.4	15.3	15.8	16.2
TN	13.1	5.3	14.8	17.7	13.9	7.9	11.0	14.6	12.7	14.6	5.6
SSI enrollment	48.4	97.8	71.8	97.9	91.9	90.8	86.2	91.0	71.7	99.0	91.3

Medicaid enrollees (age 0–21 years), 1989–1992, from California, Georgia, Michigan, and Tennessee; last full year of data on each enrollee.

TABLE 3. Visits to Any Relevant Subspecialists, Any Relevant Pediatric Subspecialists, and Generalists by Condition for Children With SSI

Condition	Any Subspecialist		Pediatric Subspecialist		Generalist		*n*
	% Who Visited	Mean	% Who Visited	Mean	% Who Visited	Mean	
Asthma	24	16.4	10	3.8	90	9.6	7886
Mental retardation	37	17.4	11	2.5	78	6.4	8963
ADHD	37	13.6	15	3.4	87	6.3	6003
Spina bifida	58	20.3	17	2.1	81	7.9	2538
Seizure disorder	56	14.1	25	2.4	87	7.4	10 082
Hemophilia	44	15.9	30	5.0	84	9.0	345
Congenital heart disease	59	11.4	53	2.6	90	8.8	5296
Sickle cell disease	36	6.9	27	4.0	86	7.4	1940
Juvenile arthritis	48	14.4	18	4.5	84	8.7	492
Cerebral palsy	45	17.8	18	2.2	83	6.7	10 574
AIDS	44	28.8	20	3.7	86	11.3	293

Medicaid enrollees (age 0–21 years), 1989–1992, from California, Georgia, Michigan, and Tennessee; last full year of data on each enrollee.

of subspecialist visits. For the children who had SSI and saw a relevant subspecialist, the mean number of visits for those with visits ranged from 6.9 for children with congenital heart disease to 28.8 for children with AIDS.

Visits to relevant pediatric subspecialists were most common among children with congenital heart disease (53%), followed by hemophilia, sickle cell disease, and seizure disorder (30%, 27%, and 25%, respectively). Children with asthma, mental retardation, and ADHD were the least likely to visit a relevant pediatric subspecialist (10%, 11%, and 15%, respectively). The mean number of annual visits to relevant pediatric subspecialists ranges from 2.1 to 5.0 visits for those with visits. When we examined rates of use for children with 2 full years of data (not shown) to increase the likelihood of identifying a claim for relevant subspecialty care, the percentage who saw any relevant subspecialist and any relevant pediatric subspecialist increased only by 5 to 10 and 3 to 7 percentage points, respectively.

Study children had a much higher likelihood of a generalist visit than a visit to a relevant subspecialist. For all conditions, at least 75% of the children had at least 1 generalist visit during the study year. The mean number of visits to generalists for those with any visits ranged from 6 to 11. Our classification method considers a provider who is both a general pediatrician and a cardiologist as a cardiologist. This problem of dual roles more likely affects internal medicine practice than pediatrics[18] but could lead to underreporting of generalist visits in this study. Counting visits to providers who are classified as both subspecialists and generalists as generalists and including 2 years of claims data (for those with 2 years of enrollment) would raise the percentages of children who had a generalist visit to >80% for all conditions.

We show in Table 4 parallel results for children without SSI. Rates of visits to any relevant subspecialist and to relevant pediatric subspecialists are, for the most part, lower for children without SSI compared with children with SSI. Exceptions are mental retardation for any relevant subspecialist visit, hemophilia for relevant pediatric subspecialist visits, and cerebral palsy for both kinds of visits. Children who are not enrolled in SSI and who have congenital heart disease, seizure disorder, and cerebral palsy are high users of any relevant subspecialist (56%, 52%, and 52%, respectively). Low users are children with asthma, sickle cell disease, and AIDS (13%, 19%, and 18%, respectively). Use of relevant pediatric subspecialists was most common among children with congenital heart disease, cerebral palsy, and hemophilia (47%, 22%, and 37%, respectively). As was the case with children who were enrolled in SSI, rates of visits to generalists were high for children without SSI; all conditions had rates at least at 85%.

TABLE 4. Visits to Any Relevant Subspecialists, Any Relevant Pediatric Subspecialists, and Generalists by Condition for Children Without SSI

Condition	Any Subspecialist		Pediatric Subspecialist		Generalist		*n*
	% Who Visited	Mean	% Who Visited	Mean	% Who Visited	Mean	
Asthma	13	6.3	3	6.0	90	7.0	8416
Mental retardation	45	12.9	10	2.7	85	5.1	206
ADHD	34	11.6	9	4.3	90	5.9	2361
Spina bifida	39	8.7	6	7.3	89	8.7	54
Seizure disorder	52	7.6	19	2.8	88	6.7	891
Hemophilia	37	9.8	37	6.0	94	7.2	35
Congenital heart disease	56	4.6	47	1.8	91	6.0	847
Sickle cell disease	19	3.6	11	3.4	90	5.9	193
Juvenile arthritis	29	11.1	5	3.3	93	6.8	194
Cerebral palsy	52	7.7	22	2.5	90	6.6	105
AIDS	18	10.4	7	9.5	93	6.5	28

Medicaid enrollees (age 0–21 years), 1989–1992, from California, Georgia, Michigan, and Tennessee; last full year of data on each enrollee.

Table 5 shows relative risks computed from the results of 4 logistic regressions. The first 4 columns show the results for children with SSI, and the second and third columns show the results for children without SSI. In both cases, the results for relevant pediatric subspecialists precede the results for any relevant subspecialist use. Some general patterns emerge. In general, children who are younger than 13 years have a higher likelihood of seeing a relevant subspecialist (pediatric or any) than children who are age 13 and older, with the exception of non–SSI-enrolled children age 0 to 5 for any subspecialist use. Urban residence is associated with a higher likelihood of seeing a relevant pediatric subspecialist (relative risk [RR]: 1.17; 95% confidence interval [CI] 1.10–1.25); among children who were enrolled in SSI and among children who were not enrolled in SSI, it predicts seeing a pediatric subspecialist (RR: 1.47; 95% CI: 1.18–1.81) and any relevant subspecialist (RR: 1.22; 95% CI: 1.09–1.35). The groupings of the ACG score show that as the case mix gets worse, the likelihood of seeing any relevant subspecialist or a relevant pediatric subspecialist increases for both the SSI and non-SSI populations.

White race predicts any relevant subspecialist use (RR: 1.05; (5% CI: 1.03–1.08) among those enrolled in SSI and relevant pediatric subspecialist use (RR: 1.18; 95% CI: 1.03–1.36) and any relevant subspecialist (RR: 1.28; 95% CI: 1.20–1.37) for children without SSI. Female gender is associated with more pediatric subspecialist use among children with without SSI (RR: 1.26; 95% CI: 1.09–1.45).

DISCUSSION

This study provides the first data regarding rates of relevant subspecialist use by Medicaid-insured children with a range of chronic conditions. These children with chronic health conditions use generalist care much more commonly than relevant subspecialist care. Although no clear guidelines or standards of care define appropriate numbers of relevant subspecialist visits for children with chronic conditions, most of these children had no identified relevant subspecialty visit in the study year. Among the conditions studied, only children who were enrolled in SSI and had spina bifida, seizure disorder, and congenital heart disease and children who were not enrolled in SSI and had seizure disorder, congenital

TABLE 5. RR and 95% CI for Any Relevant Subspecialist Use and Relevant Pediatric Subspecialist Use, Controlling for Age, Gender, Race, Urban Residence, and ACG Score Groupings*

	Children Enrolled in SSI ($n = 44\,347$)				Children Not Enrolled in SSI ($n = 12\,981$)			
	Pediatric Subspecialist Use		Any Subspecialist Use		Pediatric Subspecialist Use		Any Subspecialist Use	
	RR	95% CI	RR	95% CI	RR	95% CI	RR	95% CI
Age								
0–5	1.80‡	1.72–1.88	1.19‡	1.22–1.32	1.93‡	1.63–2.27	0.93	0.84–1.02
6–12	1.54‡	1.47–1.60	1.11‡	1.08–1.14	2.08‡	1.79–2.41	1.19‡	1.10–1.28
13–21	1.00		1.00		1.00		1.00	
Gender (female)	1.01	0.97–1.05	0.99	0.96–1.01	1.26‡	1.09–1.45	1.05	0.98–1.13
White	1.03	0.98–1.07	1.05‡	1.03–1.08	1.18†	1.03–1.36	1.28‡	1.20–1.37
Urban	1.17‡	1.10–1.25	1.02	0.98–1.06	1.47‡	1.18–1.81	1.22‡	1.09–1.35
ACG Score								
<0.3	0.66‡	0.60–0.72	0.80‡	0.76–0.83	0.77†	0.63–0.95	0.89†	0.80–0.98
0.3–0.59	1.00		1.00		1.00		1.00	
0.6–0.99	1.19‡	1.12–1.27	1.16‡	1.12–1.19	0.95	0.78–1.16	1.16‡	1.05–1.28
1.0–1.99	1.40‡	1.32–1.47	1.28‡	1.25–1.31	1.32‡	1.11–1.58	1.19‡	1.08–1.31
≥2	1.54‡	1.46–1.63	1.44‡	1.40–1.47	1.55‡	1.22–1.95	1.61‡	1.42–1.81

Medicaid enrollees (age 0–21 years), 1989–1992, from California, Georgia, Michigan, and Tennessee; last full year of data on each enrollee, all conditions combined.
* Regressions controlled for all variables above plus indicators for state, condition, and missing data on urban status.
† $P \leq .05$ and $> .01$.
‡ $P \leq .01$.

heart disease, and cerebral palsy had a >50% likelihood of any relevant subspecialty visit in 1 year. These rates do not include use of developmental pediatricians, and they likely would increase if we included developmental pediatricians. Children with the most common chronic conditions generally had lowest rates of subspecialist use, perhaps reflecting primary care providers' comfort and knowledge in the care of these children. The notable exception to this pattern was children with mental retardation, who had relatively high rates of use of any relevant subspecialist among children without SSI. In general, younger children were more likely to use any relevant subspecialists and relevant pediatric subspecialists, likely reflecting greater difficulties in assessing many of these conditions and their complications in younger children. In general, children who had chronic conditions and lived in urban areas had higher rates of relevant pediatric subspecialist use than children who lived in nonurban areas. This finding supports the hypothesis that supply influences utilization; there is greater availability of pediatric subspecialists and children's hospitals in urban areas. Similarly, case mix as measured by the ACG score was associated with greater subspecialist use (any relevant subspecialist and relevant pediatric subspecialist), suggesting that subspecialists are used more when the illness burden is greater.

The much higher use of generalist services (in comparison with subspecialty services) in this study suggests that most of these children have access to primary care (although our data provide no information on the content, scope, or quality of that care). Thus, concerns that these chronic conditions may shunt children into subspecialty settings to the detriment of their receipt of primary care seem unsupported by our data. Indeed, this study suggests that these children and their families use primary care providers for most of their health care needs, including those that arise from their chronic condition.

We had expected to find higher rates of relevant subspecialty utilization for these children with complex chronic conditions, especially the less common conditions, although, admittedly, no clear standards for such use exist. Given the increasingly rapid growth of new technologies for many of these conditions, primary care physicians may face difficulties in keeping up with advances in the care for less common conditions and therefore may rely increasingly on subspecialty care for advice and consultation. Some of these conditions may not merit yearly or more frequent subspecialist visits (eg, asthma, cerebral palsy), and others may have periods of much stability (eg, congenital heart disease). For example, an older child with spina bifida may have no ongoing renal or new orthopedic problems and therefore have less need for regular subspecialty services. Nonetheless, other conditions for which frequent changes in status and technology occur (eg, hemophilia, AIDS) might indicate a need for subspecialist consultation. When we examined a sample with 2 full years of claims data, however, rates of subspecialty use rose only marginally. A limitation of the data is that informal consultations or telephone discussions between primary care providers and subspecialists do not lead to claims and were not identified in this study.

These findings cannot be generalized to children with private insurance or children who lack health insurance, both of whom may experience different rates of subspecialty use. The Medicaid population includes large numbers of children with moderate and severe chronic conditions. Children with Medicaid coverage may experience particular difficulty with access to subspecialty services, given limited resources and barriers to care from lack of transportation or cultural or language differences and the potential unwillingness of subspecialty providers to accept Medicaid patients.

The data presented here have several limitations that relate to the use of claims data to describe patterns of subspecialty use. First, the identification of chronic conditions reflects the diagnoses listed by physicians and recorded into the Medicaid database. Physicians may use an acute illness code when they see a child with a chronic condition, leading to underidentification of children. This problem, however, should have affected generalists more than subspecialists. Alternatively, we may identify children as having a condition that they do not actually have, because the child has erroneous codes or rule-out codes. We attempted to limit the impact of this type of error by using more stringent identification criteria when rule-out diagnoses were most likely. Because children with SSI must prove that they have a substantial disability to enroll in the program, these children should have at least 1 chronic condition or disability, although it may not be 1 of the 11 study conditions. Overidentification of children could help explain the low rates of visits to relevant subspecialists. Second, the identification of subspecialists as pediatric required a merge of Medicaid information to AMA subspecialty information. This strategy likely underidentifies subspecialists as pediatric. It also requires that the AMA correctly designate subspecialty status. Providers change their designation from specialists to generalists and the reverse at low rates,[19] likely improving accurate designation, yet providers may spend time practicing in areas other than their reported subspecialty.[20,21] Identification of a provider's subspecialty type is sensitive to whether all AMA subspecialty fields are used to identify subspecialists.[20] We used both the primary and secondary provider codes to capture all possible subspecialists. When we were not able to identify subspecialists (eg, developmental pediatricians), we underestimated rates of use. Third, the results presented here represent only children who are enrolled in Medicaid fee-for-service programs, because we excluded those with health maintenance organization or private insurance. Finally, children's hospitals and other organized pediatric services in general hospitals (usually academic health centers) provide a large amount of subspecialty care for children with chronic conditions. These institutions typically are found in cities with relatively few pediatric subspecialists in community settings (in distinction to adult subspecialists). These tertiary care institutions may have had inadequate systems in place for billing Medicaid for their services, and their services may be underrepresented in our data, thereby reducing the apparent use of subspecialty (and especially pediatric subspecialty services) by study children. In addition, for the cases for which we identified subspecialty status on the basis of procedure codes, we may have underidentified subspecialist visits.

These data provide a baseline of use of subspecialists before sizable use of managed care for Medicaid-enrolled children, for whom access to subspecialists and pediatric subspecialists may be more limited.[22] For this population, shifts to managed care and the associated requirements that children have a generalist primary care physician may not change care patterns as much as expected.

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Menard L. Comment. Alone together. *New Yorker Magazine*. July 2, 2001

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