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**Family Cost-Sharing for
Children with Special
Health Care Needs in
Employer-Based Managed
Care Plans 1999-2001**

Final Report

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EXECUTIVE SUMMARY

POLICY CONTEXT

An estimated 12.8 percent of children in the United States have a special health care need and approximately 65 percent of them are insured through private, employer-based health insurance plans (U.S. DHHS 2004). Typically, these plans cover the majority of the costs for certain medical services such as hospitalizations, outpatient, and specialty care, but cover a smaller portion of the costs for other health services, such as mental health care or speech therapy. Families usually share the costs of covered services through copayments and deductibles, but the extent of this cost-sharing depends on several factors, including the services the child uses and the benefits in the health plan the employee selects. Few studies have examined the extent of family cost-sharing for this vulnerable and high-cost group of children.

Better information on the extent to which families pay for health care provided to their children with special health care needs (CSHCN) would be useful for policymakers, physicians, researchers, program administrators and consumers, especially in light of the growing expectation that employees will share a greater proportion of health care costs than they now do. To develop this information, MCHB contracted with Mathematica Policy Research, Inc. (MPR) to conduct a study of children with special health care needs enrolled in commercial managed care plans in order to establish baseline data on the level of costs incurred by the families of these children. The MCHB can use this information to help monitor the nation's progress toward adequate, affordable insurance for children with special health care needs--an important national goal under the New Freedom Initiative.

DATA AND METHODS

The study addressed the following research questions:

- What were the average member costs per month¹ for CSHCN, and how did these costs change from 1999 to 2001?
- To what extent did average member costs per month vary by health status subgroups, employer size, and popular health plan options?
- What were the average member costs per month for CSHCN for specific services, and was there variation in member costs for specific services across age, gender, and health status subgroups? What proportion of the total costs for these services did member costs constitute?

¹Member costs per month are defined in this paper as the average costs members pay per month for copayments and deductibles.

To help answer these questions, MPR contracted with the Center for Health Care Policy and Evaluation (CHCPE) at UnitedHealth Group to develop a data set from three years (1999-2001) of administrative and claims data for children who were enrolled in two employer-sponsored UnitedHealth plans. The study population, which included any child under the age of 19 who was enrolled in the plan for at least six months (or three months for newborns), totaled 232,615 in 2001; 243,442 in 2000; and 218,388 in 1999. Using the Clinical Risk Group (CRG) classification system, we identified 10.6 percent of these children (23,124 individuals) as having a special health care need in 1999, 10.8 percent (26,327 children) in 2000, and 11.6 percent (26,949 children) in 2001.

KEY FINDINGS AND POLICY IMPLICATIONS

Our sample of children with special health care needs incurred \$99.4 million in health care costs in 2001. Of this amount, families paid \$10.3 million (10.4 percent). Over time, families paid increasingly more for their children's care. Average monthly member costs rose from \$24.60 in 1999 to \$34.00 in 2001, an increase of 38.2 percent. Other key findings include the following:

- Average monthly costs paid by parents of children with more complex conditions were higher, and increased more dramatically from 1999 to 2001, than the costs paid by parents of children with less complex conditions. In 2001, the average monthly member costs were \$103.23 for children who had catastrophic conditions, which is a 51 percent increase from their average costs in 1999. In comparison, average monthly costs for children who had a single minor chronic condition were \$24.59 in 2001, which was only a 35.3 percent increase from their average costs in 1999.
- Families paid the highest proportion of the total costs (30.8 percent) for mental health services, prescription drugs (25.5 percent), and primary care visits (17.4 percent).
- Certain factors, such as the option to go out of network or working for a smaller employer, increased the likelihood of incurring higher copayments and deductibles.

Although this study does not include costs paid by family members for insurance premiums or services not covered by their insurance plans, these findings provide a descriptive foundation for understanding the costs of copayments and deductibles incurred by families of children with special health care needs. Our research shows that the costs paid by families represent a small proportion of the total costs, but the actual dollar amounts paid for the copayments and deductibles are substantial for some families. Overall, our findings indicate that some families of children with special health care needs are at substantial risk for heavy financial burdens. These families may require extra support or assistance in managing these financial demands, especially because they may also be facing the emotional demands associated with caring for children with chronic or life-threatening health conditions.

As the health care environment continues to evolve, consumers will likely be asked to assume a greater financial responsibility for care, possibly through increased deductibles and

copayments. These changes are almost certain to intensify the financial burden on families of children with special health care needs.

This report is one in a series of reports that uses claims and administrative data from 1999 to 2001 to describe patterns of use and cost of health services for children with special health care needs enrolled in commercial managed care plans. Other reports examine pharmaceutical costs for this group of children (Ireys et al. 2004) and patterns in the use and cost of services for children with special health care needs who also have emotional and behavioral disorders (Humensky et al. 2004). A prior report (Ireys et al. 2002) describes the development of the database used in these studies.

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I. INTRODUCTION

An estimated 12.8 percent of children in the United States have a special health care need, many of whom have complex, chronic health conditions and require access to a wide range of medical services, and approximately 65 percent of these children are insured through private, employer-based health insurance plans (U.S. DHHS 2004). Typically, these plans cover the majority of the costs for certain medical services such as hospitalizations, outpatient, and specialty care, but cover a smaller portion of the costs for other health services, such as mental health care or speech therapy. Families usually share the costs of covered services through copayments and deductibles, but the extent of this cost-sharing depends on several factors, including the services the child uses and the benefits in the health plan the employee selects.

Although it has been reported that health care for children with chronic illnesses is significantly more expensive than health care for the average child (Neff and Anderson 1995), few studies have examined family cost-sharing for this vulnerable and high-cost group of children. Better information on the extent to which families help pay for health care provided to their children with special health care needs (CSHCN) would be useful for policy makers and consumers, especially in light of the growing expectation for employees to share a greater proportion of health care costs (Trude 2003).

To develop this information, MCHB contracted with Mathematica Policy Research, Inc. (MPR) to conduct a study of children with special health care needs enrolled in commercial managed care plans in order to establish baseline data on the level of costs incurred by the families of these children. The MCHB can use this information to help monitor the nation's progress toward adequate, affordable insurance for children with special health care needs—an important national goal under the New Freedom Initiative. The study results also will be of

interest to consumers, researchers, and program administrators who are working to enhance comprehensive systems of care for these children. Specifically, the study addressed the following questions:

1. What were the average member costs per month for CSHCN, and how did these costs change from 1999 to 2001?
2. To what extent did the average member costs per month vary by health status subgroups, employer size, and popular health plan options?
3. What were the average member costs per month for CSHCN for specific services, and was there variation in member costs for specific services across age, gender, and health status subgroups? What proportion of the total costs for these services did member costs constitute?

To help answer these questions, MPR contracted with the Center for Health Care Policy and Evaluation (CHCPE) at UnitedHealth Group to develop a data set from three years (1999-2001) of administrative and claims data for children who were enrolled in two employer-sponsored UnitedHealth plans (Ireys et al. 2002). The study population included any child under the age of 19 who was enrolled in the plan for at least six months (or three months for newborns). We identified children with special health care needs using the Clinical Risk Group (CRG) classification system (Neff et al. 2001). Our methods—including a description of the database, study variables, and analytic approach—are described in Chapter II of this report. Chapter III presents the results, and Chapter IV outlines potential implications of the findings.

The report is one in a series in which MPR used the data set developed by CHCPE to describe patterns of health care use and costs for CSHCN. Other reports in the series examine mental health services for children with special health care needs who have emotional or behavioral problems (Humensky et al. 2004) and costs for prescription drugs (Ireys et al. 2004).

II. METHODS

A. DATA

The CHCPE database for this project was constructed from four UnitedHealth Group files:

1. *An enrollment file*, which contains demographic information—including gender and date of birth—on all health plan members and dependents, along with such other information as the member’s unique identifier, enrollment date, disenrollment date, and information about the product(s) in which the member is enrolled. The unique identifier is used to link the claims records of each member.
2. *A physician claims file*, which includes information submitted by physicians using the HCFA 1500 claim protocol, descriptions of all services performed for which they are reimbursed, the member’s unique identifier, a unique provider identifier (indicating specialty), up to four ICD-9-CM diagnosis codes, the place of service, billing information, and the insurance product under which the service falls.
3. *A facility claims file*, which contains information submitted by health care facilities (such as hospitals or nursing homes) using the UB92 claim protocol, including the following: the member’s unique identifier, unique facility identifier, facility type, revenue codes, services performed, up to nine ICD-9-CM diagnosis codes, the place of service, billing information, and the insurance product under which the service falls.
4. *A pharmacy claims file*, which contains information from claims submitted directly and electronically by retail pharmacies, including all outpatient prescription drugs that exceed the cost of the member’s copayment amount, the member’s unique identifier, pharmacy identifier, prescriber identifier, date dispensed, billing and payment information, copayment amount, and information specific to the drug prescribed (the National Drug Code, drug strength, quantity and days supply). Copayment amounts are determined by the member’s prescription drug benefit plan and whether the product dispensed is included in the list of preferred drugs. Non-preferred products require higher copayment amounts.

Staff in the CHCPE identified two plans, one from a midwestern state and the other from a southern state, which together are large enough to yield a combined membership of about 1 million individuals. We expected that this pool of members would allow us to identify a substantial number of children with special health care needs. These plans are open-access, independent practice associations (IPAs) and include enrollees from small, medium, and large

employers. Although exact benefit packages and copayment and deductible arrangements vary by employer, both plans cover common medical services including inpatient, outpatient, specialty care, mental health services, physical, speech, and occupational therapies, and prescription drugs.

CHCPE staff used the member's unique identifier across all four files to build each child's record, which contained information on demographic characteristics (age, gender, ZIP code, and county code), primary and secondary ICD-9 codes, CPT-4 and ICD-9 procedure codes, encounter data (including date of service, provider specialty, and site codes), and payment data for visits or services received covered by the health plan. The process of creating the database included quality-control checks to ensure that no records were missed and that all records for each child were appropriately linked.

B. DEFINITIONS

1. Study Population

The study population was defined as plan members who were under 19 years of age at the end of each study year, had been enrolled in the plan for at least six months (three months for newborns), and were insured under a comprehensive benefit package that included coverage for prescription drugs and mental health services. The number of children who met these criteria totaled 218,388 in 1999; 243,442 in 2000; and 232,615 in 2001.

We reported costs for the following age groupings: 0 to 5, 6 to 12, and 13 to 18. These age groupings were created to reflect broad developmental stages (infants and toddlers, school-aged children, and adolescents). We did not separate infants from toddlers because we were concerned about potentially small cell sizes. However, examining infants as a separate group would be an important step for future research in order to understand service use and costs related to neonatal conditions and associated stays in neonatal intensive care units.

The Clinical Risk Group (CRG) classification system was used to define children with special health care needs. This system assigns individuals to one of nine health status categories on the basis of their most significant diagnosis or diagnoses and service history (see Table II.1). Children with special health care needs were defined as such if they were assigned to health status category of three or higher. Because only a very small number of children were assigned to the “significant chronic pair” and “chronic triplet” groups, our analysis combined the two into one group called “pairs and triplets.” Except for the at-risk component, the CRG system allowed us to select a sample of children that resembles the population of CSHCN, defined by MCHB as “children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al. 1998).

Using the CRG classification system, we found that:

- 10.6 percent of children (23,124 individuals) had a special health care need in 1999
- 10.8 percent of children (26,327 individuals) had a special health care need in 2000
- 11.6 percent of children (26,949 individuals) had a special health care need in 2001

In general, approximately 20 percent of the CSHCN study population were young children; 40 percent were between the ages of 6 to 12; and 40 percent were adolescent. Additionally, boys accounted for a slightly higher proportion of the CSHCN population (about 56 percent) than did girls (about 44 percent) in all three study years. Further details regarding the study population appear in Humensky et al. (2004) and Ireys et al. (2004).

TABLE II.1
HEALTH STATUS CATEGORIES IN THE CRG SYSTEM

Category	Description
1. Healthy	Individuals who do not use services
2. Significant Acute	Individuals with conditions that place an individual at risk for developing a chronic condition
3. Single Minor Chronic	Individuals with conditions that can generally be managed throughout an individual's life with few complications
4. Multiple Minor Chronic	Individuals with minor chronic conditions in two or more body systems
5. Single Dominant or Moderate Chronic	Individuals with serious medical conditions that often result in progressive deterioration of health and that contribute to debility, death, and a future need for medical services (single dominant) or individuals with conditions that are not progressive, are highly variable, and that can contribute to debility, death and a future need for medical services (moderate chronic)
6. Significant Chronic Pair	Individuals with dominant or moderate chronic conditions in two organ systems
7. Chronic Triplet	Individuals with dominant or moderate chronic conditions in three or more organ systems
8. Dominant, Metastatic, or Complicated Malignancies	Individuals with malignancies that have a difficult progression (for example, brain tumors) or that are fundamentally systemic (for example, leukemia)
9. Catastrophic Conditions	Individuals with conditions that are expected to be lifelong, that are often progressive, and that require extensive services

NOTE: Adapted from Neff et al. 2002.

2. Costs

Costs were defined as payments for services rendered in the selected calendar year (even if the payment itself was in a subsequent year). Total costs included (1) plan costs (payments made to providers by the health plan) and (2) member costs (copayments and deductibles paid by the member for services covered by the health plan). Member costs as a percent of the total costs of services were calculated by dividing the amount members paid by total amount paid for the service. Premium costs and costs for services and treatments not covered by the health plan were excluded. Therefore, the member costs reported in this paper are only one component of the total costs borne by families for services provided to their children with special health care needs.

3. Service Use

The CHCPE database provides substantial detail on the procedure, provider, and site, allowing us to classify all services into well-defined categories. The use of lab tests, x-rays, or durable medical equipment (DME) were defined on the basis of one claim, per member, per day. Site codes, provider codes, and current procedural terminology (CPT) codes from facility and provider claims data were used to assign services to the following categories: inpatient, outpatient, specialist, primary care physician, mental health, emergency room, home health, and other nonphysician providers. Provider codes were used to classify therapy services as occupational therapy, physical therapy, or speech therapy. Prescription drug costs were determined from claims submitted directly and electronically by retail pharmacies. Inpatient costs include all services provided during a hospital stay (e.g., prescription drugs, medical equipment, lab tests, x-rays, and therapies) with the exception of physician services.

4. Plan Options and Employer Size

Our study also assessed member costs by type of plan and employer size. Ninety-nine percent of the study population used one of two UnitedHealth Group plan options: Choice or Choice Plus. Children enrolled in Choice must use providers in the UnitedHealth Group network. Children enrolled in Choice Plus can use out-of-network care, but higher copayments and deductibles are required. The other one percent of the study population was enrolled in either the Select or Select Plus options. Under these options, members were assigned to a primary care provider who served as a case manager.

Employers who offered these UnitedHealth insurance plans to their employees were separated into four groups. Small employers were defined as those having less than 25 employees. Medium employers were defined as those with 26 to 50 employees, and medium-large employers were defined as those with 51 and 250 employees. Any employer with more than 250 employees was defined as large. According to these definitions, approximately two-thirds of the study population had insurance that was provided by a family member working for a small employer.

C. ANALYTIC METHODS

Study findings are based on descriptive analyses. Total costs were calculated by combining the total amounts paid to providers by the plans and the members. Average monthly member costs were calculated by (1) combining the total amounts of copays and deductibles (2) and dividing this amount by the number of member months (i.e., the number of children times the number of months each child was enrolled). Average member costs per month were calculated for each year by age, gender, plan type, employer size, and health status group.

III. RESULTS

A. TOTAL AND MEMBER COSTS, 1999-2001

Our sample of children with special health care needs incurred \$99.4 million in health care costs in 2001. Of this amount, families paid \$10.3 million (10.4 percent). Over time, families paid increasingly more for their children's care. Average monthly member costs rose from \$24.60 in 1999 to \$34.00 in 2001, an increase of 38.2 percent (Table III.1).

Average monthly member costs varied widely by age and health status. Compared to the other age groups, the youngest group (0-5 years) incurred the highest average monthly member costs in each year. For example, member costs per month for the youngest group were \$39.98 in 2001, compared with \$30.23 and \$34.44 for the school-aged children and adolescents, respectively. The higher costs for the youngest group probably result from infants staying in neonatal intensive care units. Future research should examine infants as a separate group.

Although the absolute value of the member costs for the youngest group was high, these costs represented a smaller proportion of total costs compared with the other age groups. For example, member costs were 6.4 percent of total costs in 2001 in the youngest group. In contrast, member costs were 13.5 percent and 12.4 percent of total costs for the school-aged children and adolescents, respectively.

Monthly costs paid by parents of children with multiple or complex conditions were higher, and increased more from 1999 to 2001, than the costs paid by parents of children with minor or single conditions. In 2001, the average monthly member costs were \$103.23 for children who had catastrophic conditions, which is a 51 percent increase from their average costs in 1999. In comparison, average monthly costs for children who had a single minor chronic condition were \$24.59 in 2001, which was only a 35.3 percent increase from their average costs in 1999.

In terms of member costs as a percent of the total costs paid for services, however, families of children with more complex conditions paid smaller proportions of the total costs than families of children with less complex conditions. In 2001, 3.6 percent of total costs were paid by families of children in the catastrophic group, compared to 15.5 percent of total costs paid by families of children in the single minor group. The families of children with complex conditions probably paid a smaller proportion of the total costs because their children used services that had proportionally low copayments and deductibles or because their children's deductibles were met, and once this occurred, cost-sharing was not required.

TABLE III.1

AVERAGE MONTHLY MEMBER COSTS (IN DOLLARS) AND MEMBER COSTS AS A PERCENT OF TOTAL COSTS BY AGE, GENDER, AND HEALTH STATUS GROUPS, 1999-2001

	1999			2000			2001		
	Number of Members	Member Cost Per Month	Percent of Total Cost	Number of Members	Member Cost Per Month	Percent of Total Cost	Number of Members	Member Cost Per Month	Percent of Total Cost
All CSHCN	23,124	\$24.60	8.7	26,327	\$28.19	9.3	26,949	\$34.00	10.4
Age Group									
0-5	4,981	\$29.00	5.2	5,466	\$ 33.03	5.4	5,726	\$39.98	6.4
6-12	8,746	\$22.10	11.9	10,099	\$ 25.17	12.6	9,937	\$30.23	13.5
13-18	9,397	\$24.73	10.6	10,762	\$ 28.69	11.4	11,286	\$34.44	12.4
Gender									
Female	10,127	\$24.84	8.8	11,420	\$28.34	9.6	11,882	\$33.79	10.3
Male	12,997	\$24.42	8.6	14,907	\$28.08	9.1	15,067	\$34.18	10.4
Health Status Groups									
Single Minor	10,040	\$18.17	14.3	11,555	\$20.23	13.9	11,683	\$24.59	15.5
Multiple Minor	440	\$30.22	12.3	551	\$31.16	11.1	612	\$39.67	10.7
Sing. Dom./Mod.	11,193	\$25.90	10.6	12,542	\$29.95	12.2	12,837	\$35.88	12.4
Pairs and Triplets	1,071	\$54.81	4.4	1,215	\$62.42	5.03	1,343	\$73.52	5.9
Malignancies	101	\$58.83	2.0	128	\$81.38	2.77	117	\$82.06	2.6
Catastrophic	279	\$ 68.30	2.4	336	\$89.10	2.57	357	\$103.23	3.6

SOURCE: UnitedHealth Group

Table III.2 shows average monthly member costs by type of health plan (Choice or Choice Plus) and employer size. As expected, children enrolled in the Choice Plus plan averaged higher member costs and were responsible for a larger proportion of the total costs per month.

Member costs differed markedly by employer size (Table III.2). Compared with members who worked for large employers, those who worked for smaller employers had higher average monthly costs, were responsible for larger proportions of the total cost, and experienced increases in the percent of the total costs for which they were responsible (Table III.2). For example, members working in small firms in 2001 paid more than three times the average monthly cost paid by members working in large firms (\$38.42 versus \$12.73). Additionally, between 1999 and 2001, the percent of the costs that they incurred increased from 10.1 percent to 11.8 percent; in contrast, the percent of total costs paid by members of large employers decreased from 4.1 to 3.8 percent. This difference is especially notable because the number of children with special health care needs covered by small firm health plans increased by 25 percent (from 15,080 to 18,775), and those covered by large firm health plan dropped by almost 16 percent. (from 1,464 to 1,236). Future studies should examine the distribution of health status groups across employer sizes to determine member costs for parents of children with multiple or complex chronic conditions who are employed in small firms. Although their population may be small, these families are likely to be at high risk for very large member payments.

TABLE III.2

AVERAGE MONTHLY MEMBER COSTS AND MEMBER COSTS AS A PERCENT OF TOTAL COSTS
BY HEALTH PLAN TYPE AND EMPLOYER SIZE, 1999-2001

	1999			2000			2001		
	Number of Members	Member Cost Per Month	Percent of Total Cost	Number of Members	Member Cost Per Month	Percent of Total Cost	Number of Members	Member Costs Per Month	Percent of Total Cost
All CHSCN	23,124	\$24.60	8.7	26,327	\$28.19	9.3	26,949	\$34.00	10.4
Plan Type									
Choice	10,461	\$21.31	7.2	10,904	\$24.31	8.4	10,487	\$28.60	8.8
Choice-Plus	12,504	\$27.40	9.3	15,183	\$31.10	9.9	16,136	\$37.61	11.4
Employer Size									
Small	15,080	\$28.16	10.1	17,829	\$31.84	10.4	18,775	\$38.42	11.8
Medium	2,907	\$20.40	7.4	3,078	\$22.56	7.8	2,987	\$27.64	7.8
Medium-Large	3,514	\$18.55	6.4	3,663	\$21.62	7.6	3,625	\$24.35	7.7
Large	1,464	\$12.14	4.1	1,517	\$14.85	4.4	1,236	\$12.73	3.8

SOURCE: UnitedHealth Group

NOTE: This table includes only children who were in Choice or Choice Plus plans.

B. MEMBER COSTS FOR SPECIFIC SERVICES, 2001

The actual dollar amounts and the proportion of the total costs paid by members varied widely by type of service (Table III.3). Overall, in 2001, parents of children with special health care needs paid an average of \$11 per month for prescriptions and \$0.10 for home health services.²

²These average monthly member costs are based on total dollars paid for a particular service averaged across the entire sample of children with special health care needs. It is also possible to calculate costs only for members who used a particular service. For example, average monthly home health costs could be calculated only for those who used home health services. We did not pursue this approach because overall average monthly member costs provide a more standard figure that can be compared across studies and plans. However, future studies could calculate costs of selected services for those who use the service to provide further insight into the extent of costs experienced by families of children with special needs.

TABLE III.3

AVERAGE MONTHLY MEMBER COSTS (IN DOLLARS)
FOR SELECTED SERVICES, BY AGE, GENDER, AND HEALTH STATUS, 2001

	Members	Total	PCP	Specialist	Mental Health	Out-patient Phys-cians	Drugs	Other Out-patient	ER	OT/PT /ST	Lab	X-ray	DME	Home Health	In-patient
All CHSCN	26,949	34.00	5.06	2.85	3.17	2.31	11.30	0.57	1.89	0.44	0.88	1.61	1.20	0.10	2.62
Age Group															
0-5	5,726	39.98	9.07	3.41	0.53	4.02	9.32	0.34	2.82	0.82	1.07	1.74	2.23	0.23	4.39
6-12	9,937	30.23	4.45	2.46	3.28	1.70	11.88	0.46	1.46	0.25	0.69	1.23	0.89	0.06	1.41
13-18	11,286	34.44	3.67	2.93	4.33	2.03	11.74	0.79	1.83	0.42	0.95	1.87	0.99	0.06	2.83
Gender															
Female	11,882	33.79	5.13	3.10	2.94	2.22	10.66	0.69	1.84	0.45	1.04	1.73	1.24	0.08	2.68
Male	15,067	34.18	5.01	2.65	3.35	2.38	11.81	0.48	1.94	0.44	0.75	1.51	1.17	0.11	2.58
Health Status Groups															
Single Minor	11,683	24.59	4.40	2.39	2.89	1.66	8.20	0.61	1.38	0.31	0.58	1.26	0.19	0.02	0.70
Multiple Minor	612	39.67	5.64	4.79	3.52	3.57	12.72	0.84	2.11	0.62	1.10	2.25	0.45	0.04	2.03
Sing. Dom./Mod.	12,837	35.88	5.24	2.78	3.28	2.20	12.68	0.50	2.11	0.36	0.93	1.56	1.03	0.07	3.14
Pairs and Triplets	1,343	73.52	7.94	5.55	5.08	5.64	21.31	0.94	3.98	1.25	2.36	3.69	4.11	0.58	11.09
Malignancies	117	82.06	9.98	5.68	1.12	9.86	20.88	0.21	1.86	0.06	3.35	8.13	1.30	0.00	19.63
Catastrophic	357	103.23	6.94	6.13	0.98	10.53	20.86	0.48	2.96	4.34	1.89	3.72	31.51	1.83	11.06

SOURCE: UnitedHealth Group

NOTE: PCP is Primary Care Provider; ER is Emergency Room; DME is Durable Medical Equipment; OT/PT/ST is Occupational Therapy, Physical Therapy and Speech Therapy.

Children in the youngest age group (0-5 years) averaged the highest monthly member costs for several services, including primary care (\$9.07), specialty care (\$3.41), emergency room (\$2.82), DME (\$2.23), inpatient care (\$4.39) and outpatient services (\$4.02). In contrast, school-age children and teenagers averaged higher monthly member costs for mental health services (\$3.28 and \$4.33 for children and adolescents, respectively) and prescription drugs (\$11.88 and \$11.74, respectively).

Average monthly member costs for some services increased gradually as the complexity or severity of health status increased. In general, this was the case for primary care, specialty care, and (except for catastrophic conditions and malignancies) mental health services. For other services (e.g., inpatient and outpatient, and prescription drugs), average monthly member costs jumped dramatically for children in the catastrophic or malignancy groups. For still other services, costs were especially high in certain health status groups. For example, costs for DME and occupational, physical, and speech therapy were particularly high in the group of children with catastrophic conditions.

As shown in Table III.4, costs for prescription drugs were the most expensive to members in terms of the average member costs per month (\$11.30). Additionally, the members were responsible for over 25 percent of the total costs paid for prescription drugs. Because other services were not used by as many children, and the costs for these services were spread across the entire population, the average monthly costs may have been low, but the members who used them were still responsible for a large proportion of these services' costs. For example, average member costs for mental health services were \$3.17 per month, but members who used these services paid 30.8 percent of the total costs. Similarly, the average monthly member cost was only \$.44 per month for occupational, physical, and speech therapies, but members paid 22.0 percent of the total costs for these services.

TABLE III.4

AVERAGE MONTHLY MEMBER COSTS (IN DOLLARS)
AND MEMBER COSTS AS PERCENT OF TOTAL COSTS,
BY SELECTED SERVICES, 2001

	Average Costs per Month	Member Costs as a Percent of Total Costs
All CSHCN	34.00	10.4
Prescription Drugs	11.30	25.5
PCP	5.06	17.4
Mental Health	3.17	30.8
Specialist	2.85	8.3
Inpatient	2.62	2.9
Outpatient Physician	2.31	6.4
ER	1.89	10.7
X-ray	1.61	6.6
DME	1.20	17.1
Lab	0.88	4.9
Other Outpatient	0.57	14.3
OT/PT/ST	0.44	22.0
Home Health	0.10	0.9

SOURCE: UnitedHealth Group

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IV. SUMMARY AND IMPLICATIONS

A. KEY FINDINGS

The study documented in this report is one of the first studies to explore direct costs to families for services provided to children with special health care needs enrolled in commercial managed care plans. As mentioned, the costs we analyzed include copayments and deductibles, not premium costs or costs incurred for services not covered by the health plan. Several findings are noteworthy:

- In 2001, families of children with special health care needs paid 10.4 percent of the total cost, or \$10.3 million, of covered services.
- The proportion of total costs paid by families in 2001 increased 20 percent from 1999, when members paid 8.7 percent of total costs.
- Overall, members paid an average of \$34.00 per month in 2001, but the average for families of children with complex or severe conditions was much higher—\$103.23 per month, for example, for a child with a catastrophic condition.
- Families incurred the highest proportion of total costs for mental health services (30.8 percent), prescription drugs (25.5 percent), and primary care visits (17.4 percent).
- Certain factors, such the option to go out of network or working for a smaller employer, increased the likelihood of incurring higher copayments and deductibles.

B. IMPLICATIONS

Overall, our findings indicate that some families of children with special health care needs are at substantial risk for notable financial burdens. These families may require extra support or assistance in managing these financial demands, especially because they may also be facing the emotional demands associated with caring for children with chronic or life-threatening health conditions. To determine what kinds of assistance would be useful for which families, additional research is needed. Next steps could include the following:

- Examine average costs for members who use certain services to determine an average monthly member cost estimate for families whose children are likely to use these services over time
- Develop a comprehensive picture of family out-of-pocket costs by gathering information on costs paid by families for health services not covered by the plan
- Assess the need for additional assistance in covering costs for families who are paying large amounts in deductibles and copays over multiple years
- Develop and assess models through which families can have greater control over total service dollars as a potential means for tracking and managing cost increases

As the health care environment continues to evolve, consumers will likely be asked to assume more financial responsibility for care through higher deductibles and copayments (Trude and Grossman 2004). These changes are almost certain to increase the financial burden for families of children with special health care needs, and employers should be sensitive to this issue when determining the type of health care coverage they offer. Additionally, health plans may want to examine innovative methods of enhancing consumer choice in how monies are spent on services for children with chronic conditions as a strategy for constraining costs and maintaining quality of care. For the MCHB, it will be important to monitor these changes carefully in order to continue in its leadership role of promoting access to adequate, affordable health insurance for children with special health care needs.

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