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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. report	re: Motion for Judgement (9 pages)	n.d.	P6/b(6)
002. report	re: Medical Chronology (27 pages)	01/15/1999	P6/b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20471

FOLDER TITLE:
PBOR [Patients' Bill of Rights] [Folder 5]

2012-0463-S
rc810

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
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b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

Fax from Senator John H. Chafee

US Senator from Rhode Island
505 Dirksen Senate Office Building
Washington, D.C. 20510-3902
(202) 224-2921

456-5552

DATE: 7/9 11:10 am

To: Chris Jennings (Attn: Devorah)

From: Lisa Layman

Number of pages, including this cover sheet: ~~3~~ 4

Notes: URGENT!
Please deliver this fax to
Chris a.s.a.p.
Thanks, Lisa Layman

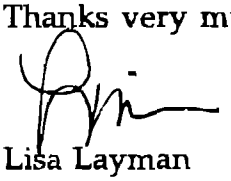
If there are transmission problems, please call the above named.

July 9, 1999

Chris,

I have not yet sent the attached mem to leg counsel. Most of the changes listed were suggested by Sara Rosenbaum this morning. Will you please distribute it to the folks who are reviewing the draft to see if they agree with her suggestions?

Thanks very much,



Lisa Layman
Office of Senator Chafee

MEMORANDUM

To: Bill Baird
From: Lisa Layman
Re: Modifications to BAI99.A07
Date: July 9, 1999

- P. 5 line 21 strike "and (3)"

  There is concern that sec 3(a)(1) is not adequate to save state external review processes that are at least as strong as that in the bill, following the decision in the Texas case. We would like to expand on this paragraph to clarify that title I shall not be contrued to prevent a state from establishing, implementing or continuing an external review system covering group and individual health plans.

  We believe with this clarification, we can then strike lines 10-17 on page 6.

- P.9 line 20 strike the word "legal"
  line 22 strike the word "legal"

- P.10 lines 1-2 strike the words "or representative"
  lines 1-3 move these lines to the end of sec 101(a)(1)(A)(i); (move to line 19 on page 10, after the words " State law),"

- P.12 line 1 strike the word "request"

- P.17 line 3, replace the period after "rendered" with a comma and add clause (iii) to be "or otherwise, either directly or indirectly, ties the compensation of the employees, agents, or contractors of the utilization review program to the level of savings achieved."

- P.19 line 2 replace the comma after the word "services" with a period, and strike everything following "services" through line 4.

- P.21 line 9 insert the word "the" after the word "with"
  line 11 strike the words "of the" after the word "time" and all of lines 12 and 13. Insert the words "the request is made." after the word "time" on line 11.

- P.22 lines 1-12. There is concern that this paragraph is confusing, in connection with paragraph (A). We want the plan to have to make the decision as to whether or not to expedite the review, and act on that,

within 72 hours -- with the caveat that if the treating health care professional says expedited review is necessary, the plan is bound by that and must expedite the review.

- P.22 strike lines 13-18
- P.23 strike lines 3-13
- P.35 line 20-22 strike "taking into account the medical record of the patient and" and insert "in light of the patient's medical record and taking into account any other"
- P.40 line 17 strike "made"
- P. 62 Amend section 122(b)(1)(A)(i) as follows:
  - line 10, change the word "may" to "shall"

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THE WALL STREET JOURNAL MAGAZINE OF PERSONAL BUSINESS

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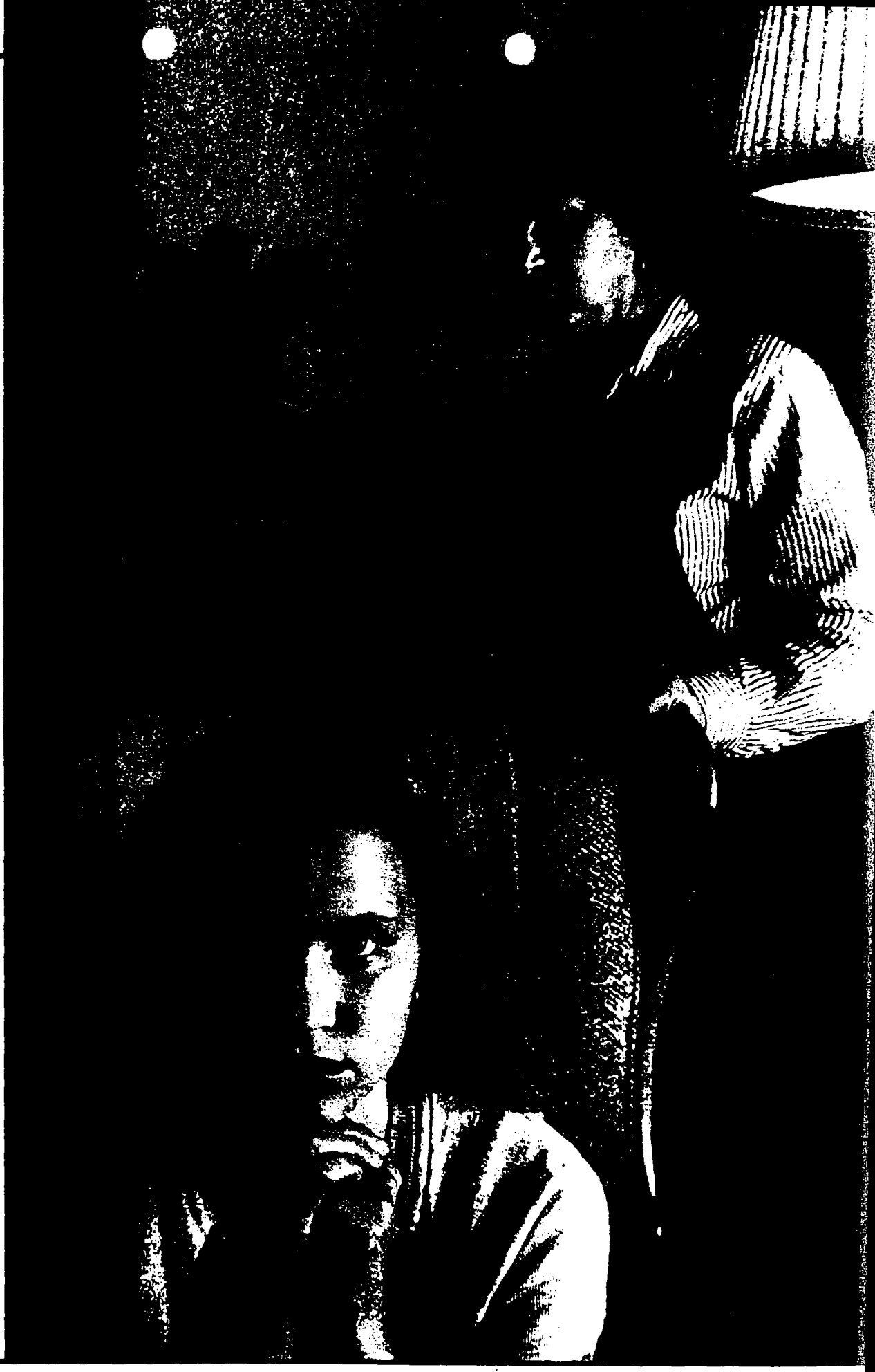
COLUMNS



Barbara Lancaster says daughter Paige suffered from a brain tumor that her HMO doctor failed to detect until she finally forced him to do tests.

Is Your HMO Failing Your Kids?

Why is pediatrics the least scrutinized and perhaps the most suspect element of managed care?

BY WALECIA KONRAD

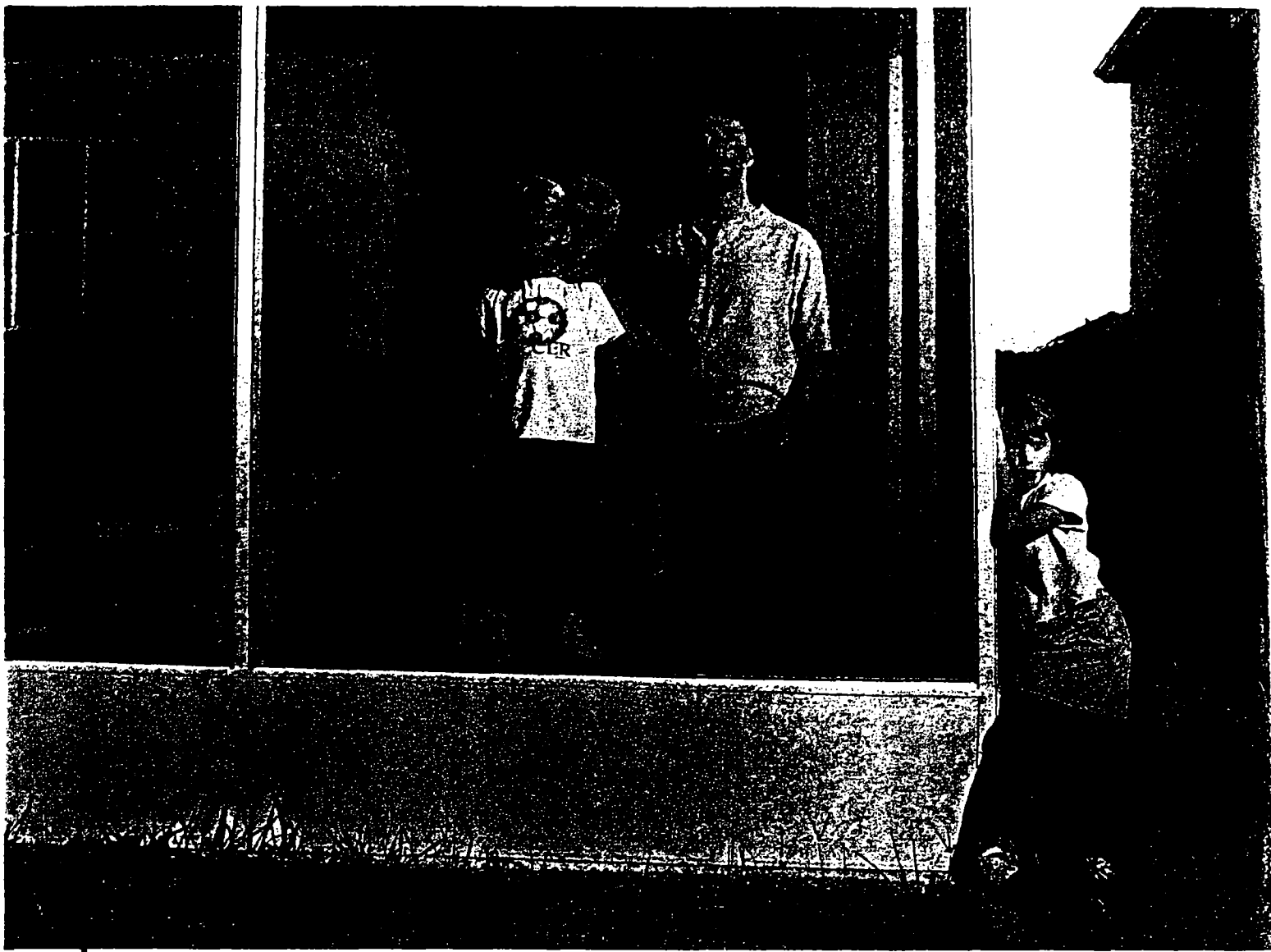
Additional reporting by Eric R. Tinson

It was a tense time. In November 1992 Katherine and Harry Christie's nine-year-old daughter, Carley, was experiencing severe stomach pains, fevers and vomiting. After a battery of tests—including a CAT scan and a biopsy—the Christies' doctor delivered the bad news: Carley had Wilms' tumor, a potentially fatal disease in which cancer cells are found in certain parts of the kidney.

Several months later, on a Friday in late January, surgery was performed. After four hours in the operating room, Dr. Stephen Shochat, a pediatric surgeon and well-known expert in Wilms' tumor, removed Carley's tumor. That weekend the Christies camped out with Carley in the intensive-care unit, helping their daughter recover from the surgery and trying to keep each other's spirits up.

On Sunday afternoon the telephone in the hospital room rang. Was it the doctor calling to check in? Was it perhaps the lab calling with the results of another

Photographs by **ROBERT LEWIS**



When the Tyrwers went back over their HMO contract, they learned that the vision therapy needed by Megan (right) was considered "not medically necessary."

series of tests? No. On the other end of the line was a man identifying himself as a "utilization review nurse" from the medical group contracted by TakeCare Health Plan in Concord, Calif., the Christies' health maintenance organization.

Coverage for Carley's surgery was denied. Because Dr. Shochat was not on the HMO's approved list of surgeons and the Christies had not gotten written preapproval to use an out-of-network doctor, TakeCare was no longer responsible for payment. The Christies would have to foot the $40,000 bill themselves.

Shock at getting the call turned to anger over its message. Relief over Carley's surgery was replaced by a stunning disbelief that the HMO, which had earlier thwarted the Christies in their attempt to get the care they felt they needed for Carley, was now saying it was not going to pay for surgery that might have saved their daughter's life.

This is the kind of thing that isn't supposed to happen. Yes, HMOs have gotten a bad rap for supposedly squeezing the bottom line at the expense of patient care, for putting patients through hoops before approving their medical procedures, for turning health care into an unfeeling, strictly commercial enterprise.

But most of the criticisms are generally aimed at the way HMOs treat adults, particularly adults with chronic illnesses or life-threatening ailments—heart disease, breast cancer, prostate cancer—that require special care and expensive, long-term treatments. Children are supposed to be the one group that is being well served by the HMO revolution; families, the natural constituents for these health organizations. Join an HMO and the endless routine visits to the pediatrician's office, late-night emergency-room visits for the inevitable fevers and falls and, just in case you need it, access to highly trained doctors if anything goes seriously wrong are all taken care of with low premiums and even lower copayments. After all, HMOs were designed on the premise of *preventative* care. Exact-

ly the kind of care children, with their routine vaccinations and checkups, need.

It hasn't quite worked out that way.

A close look at the evaluation data available to the public and interviews with dozens of parents, pediatricians, consumer advocates and HMO administrators show that, conceptually sound as this theory may be, in practice, children's health is the least scrutinized and perhaps most suspect aspect of this country's dramatic transition to managed health care. This phenomenon becomes even more pronounced with chronically ill children—a small percentage of the population at large and a population often overlooked by HMOs and other managed-care plans. "Children's health is the poor stepchild in the HMO business," says David Lansky, president of the nonprofit Foundation for Accountability, which independently develops tools for evaluating HMOs.

How can that be? Consider the following:

Adult health issues in managed care have been the subject of countless studies, including such tomes as *A Consumer Guide to Coronary Artery Bypass Graft Surgery*, put out by the Pennsylvania Health Care Cost Containment Council, or the *New England Journal of Medicine's Health Policy Report: Managed Care and Mental Health*. But ask about studies on children and HMOs, and most researchers draw a blank. After giving it some thought, they'll point to a 1989, 12-year, $80 million RAND Corp. experiment. HMO proponents like to highlight the part of the study that says children enrolled in an HMO received preventative care at a 40 percent higher rate than their counterparts who received fee-for-service care. But a closer look indicates that the extensive study is anything but conclusive. "The results of this experiment neither strongly support nor indict fee-for-service or prepaid care [HMOs] for children," says the first page of the report.

More recent research efforts are just as lacking. The National Committee for Quality Assurance, the independent organization that accredits HMOs, collects information on 71 data points to analyze and evaluate HMO performance. But only 12 of those points—just 16 percent—have anything to do with children. And of those, three deal with prenatal or obstetrical care and two deal with adolescents. By comparison, no such dearth of information exists on adult treatments. Looking for the latest numbers on beta blockers? The NCQA will tell you that an average of 62 percent of heart-attack victims receive this drug from their HMO to ward off a second attack. Interested in similar data on treatments for chicken pox or ear infections? Sorry. Not available.

More frustrating is the reluctance on the part of participating plans to disclose information on what few childhood measures exist. (Making data public is not a requirement for accreditation.) Only 99 plans out of the 329 in NCQA's database, for instance, release information on how many children have a yearly checkup during years three through six. Moreover, only 88 plans provide data on how many infants come in for three or more checkups during their first 15 months. Contrast that with the wealth of routine data these plans provide you on their adult care. More than 200 plans reported on breast cancer screening, for example, while 322 disclosed their cervical-cancer screening rates.

Even among plans that disclose everything in the NCQA survey, the information is far from reliable, a reflection of the fact that only 50 plans agreed to have their data audited. In addition, the NCQA measures change from year to year, making it hard to draw long-range conclusions.

Even consumer groups and government agencies come up short when the subject turns to HMO pediatric care. Organizations such as the Center for the Study of Services, Families USA and the Agency for Health Care Policy and Research have never looked specifically at pediatrics. And various coalitions have sprung up throughout the country to evaluate HMOs, including the Pacific Business Group on Health and the Massachusetts Health Care Purchaser Group, but they have yet to address the topic beyond routine immunizations and the number of office visits kids receive. "There has been a lot done on children and a lot done on managed care," says Amy Taylor, an economist with the Agency for Health Care Policy and Research. "But to my knowledge there just hasn't been a more comprehensive combined look."

'Kids who are low-income, who are qualified for state aid, are receiving better care than those in HMOs,' says a California researcher.

HMO industry officials acknowledge that more data could certainly be collected but deny that the lack of information indicates that children don't get the treatment they need. "There is by far more research on managed care's track record with respect to adults," says Karen Ignagni, president of the American Association of Health Plans, an industry group representing more than 1,000 managed-care plans. "But that doesn't mean we don't get the same good outcomes with children. It just means we have to do more research on kids."

Meanwhile, a cottage industry of consultants, from big firms such as Towers Perrin to specialists such as Scheur Management Group, outside Boston, have jumped into the field by putting together HMO "report cards" for their corporate clients. To get a passing grade, however, plans don't have to do much for children except give them their shots. These surveys rarely ask such basics as how many kids are enrolled in a plan, how many pediatric specialists are on board and whether or not it's affiliated with a children's hospital. Instead, they seek to find out how many adults between the ages of 20 and 44 have seen a health care provider in the past three years, or how many adult diabetics are receiving regular eye exams. The con-

One Family's Frustrations

If ever there were a poster family for the drawbacks of the HMO system, then the Phillipses of Matthews, N.C., would surely qualify. No catastrophic illnesses here. No debilitating diseases. Just the daily, numbing, unrelenting frustration of trying to get simple questions answered and routine medical treatments approved.

How long does Pam Phillips say she typically had to wait on the phone before being able set up an appointment for her 12-year-old daughter, Megan, or her seven-year-old son, Parker? Thirty minutes or more. "You cut a part out of your day just to make an appointment," recalls Phillips.

The problems with the Phillipses' HMO, Cigna HealthCare, really began to emerge in 1994, when Parker was diagnosed with asthma, an ailment shared by 4.7 million children. Common though it may be, it was still a new experience for Phillips, and she found herself peppering her HMO pediatrician with questions. When should she give Parker his cromolyn (a nasal medication) or his Prelone (a steroid)? What is a peak-flow meter, and what should she do if it indicates Parker's nearing a crisis?

After repeated problems with their HMO, the Phillipses finally decided that they had had enough.

According to Phillips, it felt as if she were talking to a brick wall. "[The doctor] would say, 'This wasn't mentioned. You didn't bring him in for this. I have approximately two minutes per patient, and I have been in here long enough.'" Phillips says she tried to explain that she felt overwhelmed by Parker's treatment. But the doctor merely replied that perhaps Pam should pick another doctor in the group who wasn't so booked up, and then, she says, he reiterated that point in a letter that he sent some weeks later.

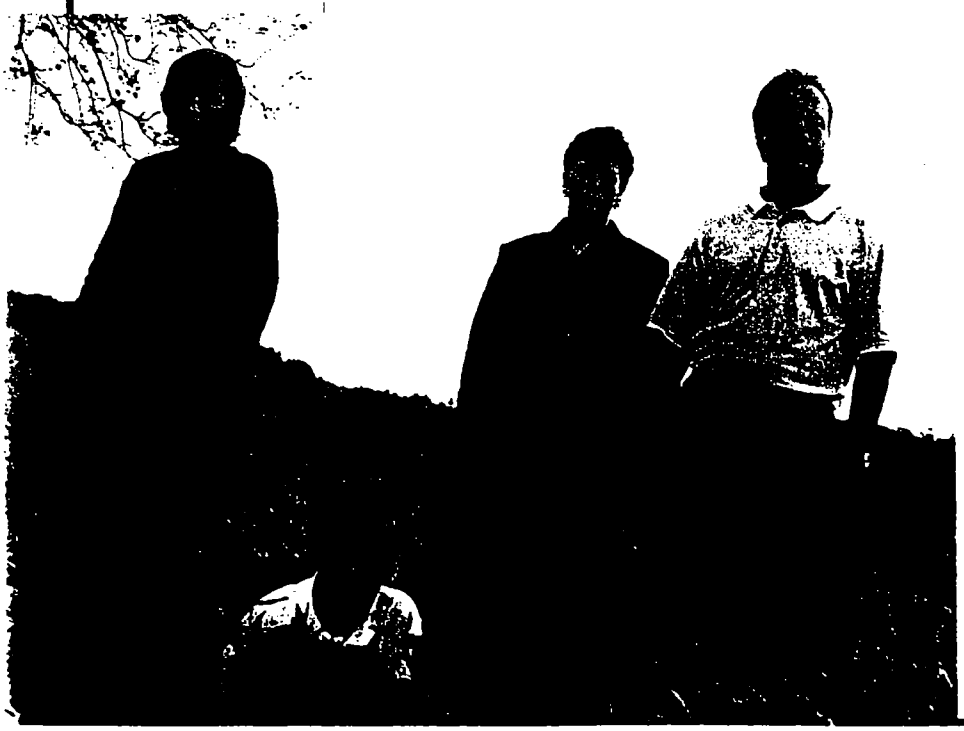
Bumped by one doctor but still with Cigna, Phillips then began to run into more problems, this time with Megan, who was experiencing a series of increasingly sharp headaches and bouts of vomiting in late 1994 and early 1995. Phillips suspected a link with the chronic stomach problems her daughter had experienced since infancy. However, her requests for a referral to a gastroenterologist were initially brushed off. Instead, Megan was put through a gauntlet of eye and head examinations to rule out the possibility of a brain tumor before her doctor agreed to the GE referral. Once he saw her, Megan's gastroenterologist diagnosed the problem as a severely impacted colon. Megan was easily treated, and everyone was relieved that the examinations had turned up nothing. But Phillips walked away frustrated that her first request, one that would have caught the problem earlier, went unheeded.

Things got so bad that, in April 1995, when Parker fell from a tree house, Phillips found her first reaction—to get her son to an emergency room immediately—was quickly eclipsed by a concern that Cigna would refuse payment unless she got prior approval. So she found herself hustling a groggy Parker into the car, then frantically dialing her cell phone with one hand, steering the car with the other, before finally getting through to a Cigna administrator who gave the okay. An extreme reaction? Perhaps. But Phillips says she felt so beaten down by the system at that point that even a visit to the ER filled her with dread about a possible fight over the medical bill.

The family has since switched plans.

Dr. William Popik, the national medical director for Cigna HealthCare, acknowledges that the Phillipses had a legitimate complaint with the delays they experienced, explaining that the waiting time for appointments was a problem when he took over two years ago. But, he adds, many of those problems have since been addressed. Says Popik: "Within the last year we've begun rolling out a 24-hour health care information line. Members have an 800 number and can call 24 hours a day, seven days a week, anywhere in the country, and get medical advice."

Popik says he cannot directly address Phillips's concerns about her first doctor (the family has declined to disclose the physician's name) but adds that he would not have condoned someone's suggesting that they had patients on a time clock. He does, however, say that he sympathizes, in part, with doctors, who must field all kinds of demands. "You think that you can do something in 15 minutes," says Popik. "And that's what you're planning on doing, and then at the end of 15 minutes somebody asks you something that, if done well, would take another 15 or 30 minutes—you can't do it." ***—Eric R. Tinson***



sultants themselves apparently see no problem in this lack of focus on children. "Kids don't always need someone who specializes in pediatrics," says Arlen Collins, senior medical consultant at Scheur Management and himself a pediatrician. "Parents just think they do." (Not all experts agree: "A tracheotomy on a two-year-old is a completely different procedure than a tracheotomy on an adult, I can assure you," says Dr. Vincent Riccardi, a pediatrician and head of American Medical Consumers, a for-profit group that helps patients deal with managed-care plans.)

"Kids are ignored for simple economic reasons," explains David Lansky. Children younger than 18 make up only about 20 to 25 percent of the general population. And the majority of them are basically healthy. Unlike heart-attack patients or the elderly, who account for huge chunks of national spending on health care, only 5 percent of all children account for about 90 percent of all pediatric health care expenditures. Those that do fall ill tend to do so with rare and difficult-to-treat conditions such as cystic fibrosis, congenital heart problems or spina bifida. These are the kinds of illnesses that require a battery of expensive specialists administering continuing care throughout a child's life—in other words, the kind of cases that are anathema to managed care's cost-conscious mandate.

In a rare look at how HMOs treat seriously ill children, Elizabeth Jameson, a senior analyst at the Institute for Health Policy Studies at the University of California at San Francisco School of Medicine, a leading health-policy group, extensively surveyed 59 pediatricians, social workers and nurses who treat large numbers of children with three serious childhood disorders: sickle-cell anemia, spina bifida and craniofacial abnormalities. Jameson looked exclusively at HMOs that hold outside contracts with doctors, as opposed to "closed end" plans, which require all doctors to be on staff.

The forthcoming study, says Jameson, points to one overwhelming conclusion: Children in these managed-care plans are far less likely to gain access to care consistent with recognized clinical guidelines than are children insured by Medi-Cal and California Children's Service, two state public health plans for low-income families. "The results of my study are incredibly dramatic," says Jameson. "Kids who are low-income, who are qualified for state aid, are receiving better care than those in HMOs."

Kids with sickle-cell anemia, for instance, often avoid problems related to chronic lung disease by undergoing a series of pulmonary tests. But these tests are routinely denied by managed-care plans, according to Jameson's survey results, despite their preventative nature and the fact that these procedures fall under accepted medical guidelines for treating sickle-cell-anemia patients. Meanwhile, children with public insurance in California routinely receive these tests.

While Jameson's study deals exclusively with treatment of chronically ill children, in general there are three specific ways in which HMOs work that tend to undermine their potential to give even healthy children the level of pediatric care your family expects.

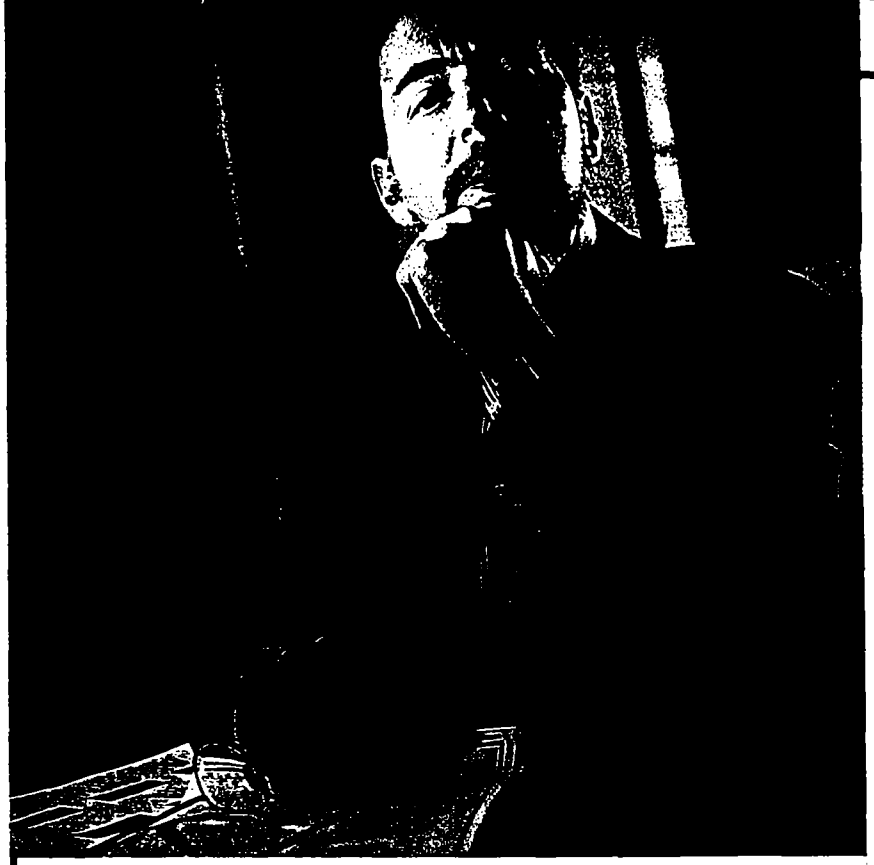
First is the HMOs' constant restraint in allowing primary-care physicians to conduct costly tests and recommend specialists. This, of course, is a problem with adults too. But the situation is more acute with kids, because their ailments are often a mystery to doctors untrained in pediatrics or family care. "What sets children apart as patients," says Jameson, "is that they must be diagnosed and treated in the context of their rapid and continuous growth and development."

Consider 16-year-old Paige Lancaster from Stafford, Va. She started having severe headaches back when she was 11 years old. Paige was covered by her father's insurance with Kaiser Permanente of the Mid-Atlantic States. For more than a year Paige's mother, Barbara Lancaster, would take her daughter every few months to her Kaiser pediatrician, Dr. Corder Campbell, pleading with him to help find out what was causing Paige's headaches, nausea and bloodshot eyes. But the doctor insisted that this was normal for some preteen girls and prescribed adult dosages of migraine medicine. Lancaster, concerned with her daughter's complaints of pain, short-term memory loss and dramatically slipping grades, continued to lobby her doctor. "Should she see someone else? Have some tests?" she asked him. Each time, Lancaster says, he dismissed the problem as migraines.

By the time Paige was a freshman in high school, she was routinely vomiting from the headaches. Her learning problems were so extreme Paige was placed in a special program at school. Her teachers, wanting to rule out any physical reasons for Paige's difficulties, kept asking Paige's mom what tests had been done. The school psychologist even wrote a letter to Campbell requesting an MRI and an EEG. According to Lancaster, Campbell's response was less than enthusiastic. "I'd like to report them for practicing medicine without a license," Lancaster remembers him saying. When he did finally order the tests, the MRI showed Paige had a cyst that emanated from a tumor covering 40 percent of her brain. It took two surgeries and severe radiation to get rid of most of it. And although she is recovering, Paige and her mom are still not sure to what extent Paige may be suffering permanent damage. "It just keeps hitting me in the face that Paige didn't have to

'Of course you want the most qualified doctors when it comes to your loved ones. But the *most* qualified isn't always what you'll get. That's what goes along with lower costs.'

The Christies' HMO was fined $500,000 because of the way it handled Carley's treatment.



"Children's health is the poor stepchild in the HMO business," says David Lansky.

go through the pain, the surgeries, the frustration with school, the humiliation and the fact that the rest of her life may not be the quality it could have been," says Barbara Lancaster, who has filed a lawsuit against Kaiser.

Lancaster sought the advice of Michael Miller, a local attorney. As he looked closer at the case, Miller consulted with Dr. Bruce Bertoff, an ear, nose and throat surgeon who is also an attorney in Miller's office. "Based on conversations I've had with other doctors," says Bertoff, "Kaiser will traditionally hold back five to 10 percent of the physicians' income and put it in a pool and pay it at the end of the year, depending on how close the physicians come to certain economic targets." One of the best ways primary-care physicians can keep costs down, argues Bertoff, is to avoid expensive tests and specialist referrals. This incentive program, Miller and Bertoff charge, is what kept Paige's primary physician from administering an MRI and referring her to a pediatric neurologist.

Neither Campbell nor his lawyer, Anthony Tringa, would comment on the Lancaster incident, and referred all calls to the HMO, which disputes the charges. "I'm very confident that our compensation system will not be an issue in the Lancaster case," says Dr. Larry Oates, Kaiser's associate medical director. He says that incentives are only a small part of a Kaiser physician's salary-based compensation, and that for the past four years the HMO has tied incentive programs for all physicians to broad goals such as quality of care and member satisfaction. Financial goals that deal with issues such as hospital stays or specialist referrals are applied to Kaiser's physician group as a whole. "We haven't driven that down to the individual physician level," says Oates, "because we are concerned about the impact on patient care."

Even when an ailment is finally diagnosed, chances are kids may be less likely than adults to get proper treatment. Why? Because most HMOs can recommend only plan-based specialists. And as Katherine and Harry Christie learned with their daughter, Carley, that's no guarantee that the doctor is the best, or even well regarded, in his field.

The parents had learned, for example, that the National Cancer Institute recommends that pediatric surgeons with direct experience in Wilms' tumor perform the operation. But when the Christies met that week with the HMO oncologist who would be treating Carley, they found out her surgeon was neither a pediatric specialist nor an expert in Wilms' tumor. It was even more disconcerting when the Christies found out that Dr. Stephen Shochat, a pediatric surgeon with plenty of experience treating this rare cancer, practiced in the children's branch of the same hospital as their assigned doctor and was even

The Best HMOs for Kids

To find the HMOs with the best track records in treating children, we searched the database of the National Committee on Quality Assurance, the organization that accredits HMOs, for plans that voluntarily reported data in all of the following five areas of pediatric care. Out of that small pool (only 17) we chose seven plans that scored in the top half in each category.

	PERCENTAGE OF CHILDREN IN THE PLAN WHO RECEIVE THE FOLLOWING CARE				
PLAN	CHILDHOOD IMMUNIZATIONS	3 OR MORE WELL-CHILD VISITS IN THE FIRST 15 MOS.	1 OR MORE WELL-CHILD VISITS IN YEARS 3–6	ADOLESCENT WELL-CHILD VISITS	ADOLESCENT IMMUNIZATION
COLUMBIA MEDICAL PLAN (MD.)	91.0	98.0	79.0	42.3	87.6
FALLON COMMUNITY HEALTH (MASS.)	92.5	95.5	78.3	46.7	84.7
HEALTH CARE PLAN (N.Y.)	90.0	98.3	74.7	37.7	64.7
HEALTH NEW ENGLAND (MASS.)	75.5	97.9	72.4	35.6	83.0
HEALTHGUARD OF LANCASTER (PA.)	61.3	100.0	67.4	44.5	60.6
NYLCARE HEALTH PLANS (MD.)	82.2	95.1	88.1	48.4	59.9
WELBORN HEALTH PLANS (IND.)	76.3	99.4	71.6	40.0	85.6

DATA: NCQA; SMARTMONEY

How to Choose the Right HMO

The good news about HMOs: If you're stuck in a poor plan these days, chances are you can get into a better one. Employers who once restricted you to just one HMO may now offer an alternative or two. In fact, it's not uncommon for a family with two working spouses to have as many as four different plans from which to choose.

The bad news: The complexities of analyzing the differences among the various options and figuring out which is best for your family may make you long for the days of "take it or leave it."

Here's a quick primer on what to expect when you're trying to pick the right managed-care plan, and how to make the most of your managed-care plan options.

Deciphering the Code

Don't think you're necessarily going to be offered an HMO with its own staff of doctors on call. Increasingly, you'll be asked to choose among an IPA, a PPO and a POS. Huh?

Here's what it all means. An IPA, or independent practice association, is a network of doctors, hospitals and labs that are paid a set fee by the HMO and that, in turn, have some leeway in how treatments are handled and costs contained. A PPO, or preferred-provider organization, is what some insurance companies have devised as their own entry into the HMO market. These groups contract with specific doctors and hospitals at a discounted rate. A newer option, a sort of hybrid of managed care and a traditional indemnity plan, is a POS (point-of-service) plan. This allows you to see a doctor outside the HMO—but at the cost of higher deductibles and copayments.

Wait, there's more. Another trend is for doctors and/or hospitals to band together, create their own managed-care operation and then sell this service directly to self-insured employers. This option—which, fortunately, does not have its own acronym yet—has led to the creation of a handful of pediatric HMOs.

So which plan is best for you and your family? Most parents may find that a POS plan, with its greater flexibility, is the way to go. But there's a catch here. A good POS plan depends on the HMO's offering top-rate physicians and access to high-quality routine and emergency health care. If it doesn't, parents will find themselves consistently going off plan and paying higher rates. If you're deciding between a mediocre HMO with the POS option and a top-ranking HMO with a network of well-qualified pediatric specialists, you may be better off in the latter.

Which leads to our next point . . .

Evaluating Your HMO

Access to care is the key issue in determining which plan is best for you. Unfortunately, you won't find the answer in a plan's marketing materials or your company's employee handbook. Far more revealing is the complete list of doctors affiliated with each plan. (Get a copy from your benefits department.) If you're lucky, your current physician and pediatrician may already be part of the HMO. (It's not unusual for doctors to sign up with as many as 25 or 30 plans.) If yours is not among them, it's time for a little research.

Call a customer-service representative at each of the plans you're considering and ask the following questions.

How many pediatric specialists are part of the network? Experts say, at a minimum, you should have access to a pediatric orthopedist, neurologist, cardiologist, gastroenterologist and ear, nose and throat doctor. If your health plan doesn't have the pediatric specialists you need, your primary-care physician may balk at referring you to a more costly doctor outside the plan.

Which hospitals and emergency rooms are you contracted with? It is essential that your HMO be affiliated with a local children's hospital that offers pediatric emergency-room care. Beware an answer that leaves room for loopholes. "In an effort to market to more parents, HMOs have been saying they're affiliated with children's hospitals that aren't really children's hospitals," says Peters Willson, vice president for public policy at the National Association of Children's Hospitals. So ask for the specific name of the children's hospital and call that hospital directly; to make sure that it does, indeed, specialize in pediatric care. Also ask your potential primary-care physician if he or she routinely makes referrals to that specific facility. "Just because a hospital is affiliated with an HMO doesn't mean that is the hospital your doctor will send you to," says Willson.

How are emergency-room visits covered? There are two policies managed-care companies use to determine whether they'll pay an ER fee. Diagnostic coverage means the HMO will pay the bill only if you got prior approval or if, after the fact, the plan determines the situation was truly an emergency. In other words, you'll be stuck with the bill for the bruised knee that you thought was broken. Preferable is the "prudent layperson" policy, which is as simple as it sounds: If an average person thinks it's an emergency, it's covered. That's what you want. *—W.K.*

The complexities of deciding among the various HMO options available to you may well make you long for the days of 'take it or leave it.'

contracted with the same HMO. Unfortunately for the Christies, however, Shochat was a member of a different independent practice association, or IPA, than the one the Christies had signed up with when they joined TakeCare.

"What's going on?" Harry Christie asked Carley's primary-care doctor. He says her only response was to defend the adult urologist assigned to the case. He's one of the specialists in the medical group they chose under contract with their HMO, he says she explained. Dr. Shochat simply wasn't on that list.

Don't expect to get services you're not paying for, says one HMO official: 'It's like going to McDonald's and ordering a cheeseburger. If you want lettuce and tomato, order the Big Mac.'

No way, thought Christie. "I can't risk my daughter's life by placing her in the care of someone not qualified." So Christie told the primary-care physician he was going to make an appointment with Dr. Shochat. "You have to get us a referral," he told Carley's doctor.

When the HMO refused to pay, the Christies appealed several times, then ultimately took the case to arbitration. The committee ruled that TakeCare had to pay the bill. The Christies also filed a complaint with the California Department of Corporations, the state agency that oversees HMOs. The department fined TakeCare $500,000 three years after Carley's surgery, the largest fine ever imposed on a California managed-care organization.

TakeCare, after a series of HMO mergers, is now part of PacifiCare, which won't comment on the case. But Mark Reagan, an attorney with Foley Lardner Weissburg & Aronson, who represented TakeCare in the case, stands by the plan's initial endorsement of the adult urologist. "There is evidence out there that you don't have to know Wilms' tumor to treat it," says Reagan, "but you do need experience in removing kidneys. The TakeCare doctor assigned to the case was an expert in these surgeries." But was he the most qualified? "Of course you want the most qualified doctors when it comes to your loved ones," says Reagan. "But the *most* qualified isn't always what you'll get. That's what goes along with lower costs."

Another factor that leads HMOs to falter in their treatment of children is this: Most of their policies are based largely on adult care, which may not be appropriate for children. In Jameson's study, for example, one of the pediatricians surveyed referred a lupus patient to an adult urologist within his plan for a kidney biopsy. The adult urologist performed an open-back biopsy on the child. But this type of biopsy is inappropriate for children—a pediatric urologist would have performed a less invasive procedure. The open-back wound resulted in serious complications from the anesthetic required for the procedure. Jameson also found numerous examples of spina bifida patients who were denied a wheelchair or set of braces. HMO policies often provide for these devices only once or twice during a patient's lifetime. That may be fine for adults, but it doesn't take into account children's constant need for new devices as they grow.

Denise Tyriver knows what it's like to deal with plans that don't pay enough attention to child development. The Orlando mother of two switched her family to an HMO just this past June, when her husband's employer started offering the option. Tyriver's seven-year-old daughter, Megan, has an autism-related disorder, and her constant care has meant plenty of medical bills. The HMO looked like the perfect, less expensive option.

Like a lot of children with this condition, Megan has trouble focusing her eyes. An optometrist using special exercises may be able to help train her vision. But the doctor group affiliated with the Tyrivers' HMO, Florida Hospital Healthcare System, turned down the request. Why? The HMO, American Medical Healthcare, will not cover what are called "developmental treatments."

Stunned by the refusal, Denise Tyriver pulled out her plan's certificate of group coverage and studied it carefully. She found out her health plan did not, indeed, cover treatments such as "learning-disabled testing . . . speech therapy for other than acute traumatic injury or physical functional defect incurred while covered under this certificate; vision therapy, including eye exercises . . ." Says Tyriver: "There it was in black and white. I couldn't believe I hadn't paid attention before."

"Most plans don't cover developmental programs," explains Dr. Edward Cabrera, chief executive of American Medical Healthcare, "because it falls in the vague category of 'not medically necessary.' It may help the individual, but

The GOING RATE

	Atlanta, Ga.	Boise, Idaho	Boston, Mass.	Denver, Colo.	San Diego, Calif.
Well-baby pediatric visit	$54.00	$85.00	$70.00	$72.00	$45.00
Initial eye exam	44.00	64.00	50.00	60.00	75.00
Dental checkup	91.00	84.00	103.00	92.00	100.00
Sealants for the first four molars	100.00	109.00	180.00	80.00	112.00
Set of braces	2,700.00	3,500.00	3,250.00	4,100.00	2,700.00
Inoculations and physical required before start of kindergarten	129.00	91.00	125.00	132.00	115.00
Asthma inhaler	10.99	13.07	14.00	13.29	12.39
Dermatologist visit for acne treatment	65.00	76.00	85.00	98.00	65.00
Nose job (for deviated septum, of course)	6,200.00	3,000.00	4,500.00	3,900.00	5,000.00
At-home drug test	59.95	39.99	59.95	59.99	60.00
Tattoo removal for your wayward teenager	650.00	500.00	484.00	500.00	350.00
Weekly visit to shrink (for kid)	85.00	70.00	90.00	100.00	100.00
Weekly visit to shrink (for parent)	85.00	85.00	100.00	100.00	100.00
Weekly visit to family therapy (for the whole gang)	85.00	70.00	90.00	100.00	100.00

it may not solve a medical problem. It's just not in her plan, so it's not something she bought. It's kind of like going to McDonald's and ordering a cheeseburger. If you want lettuce and tomato, you have to order the Big Mac." ("Plans constantly use this reasoning to deny care, saying a procedure or treatment isn't medically necessary," says Carol O'Brien, an attorney at the American Medical Association. Worse, she adds, some plans have been gravitating toward even more ambiguous language, stating that they will cover "only what the plan deems medically reimbursable.")

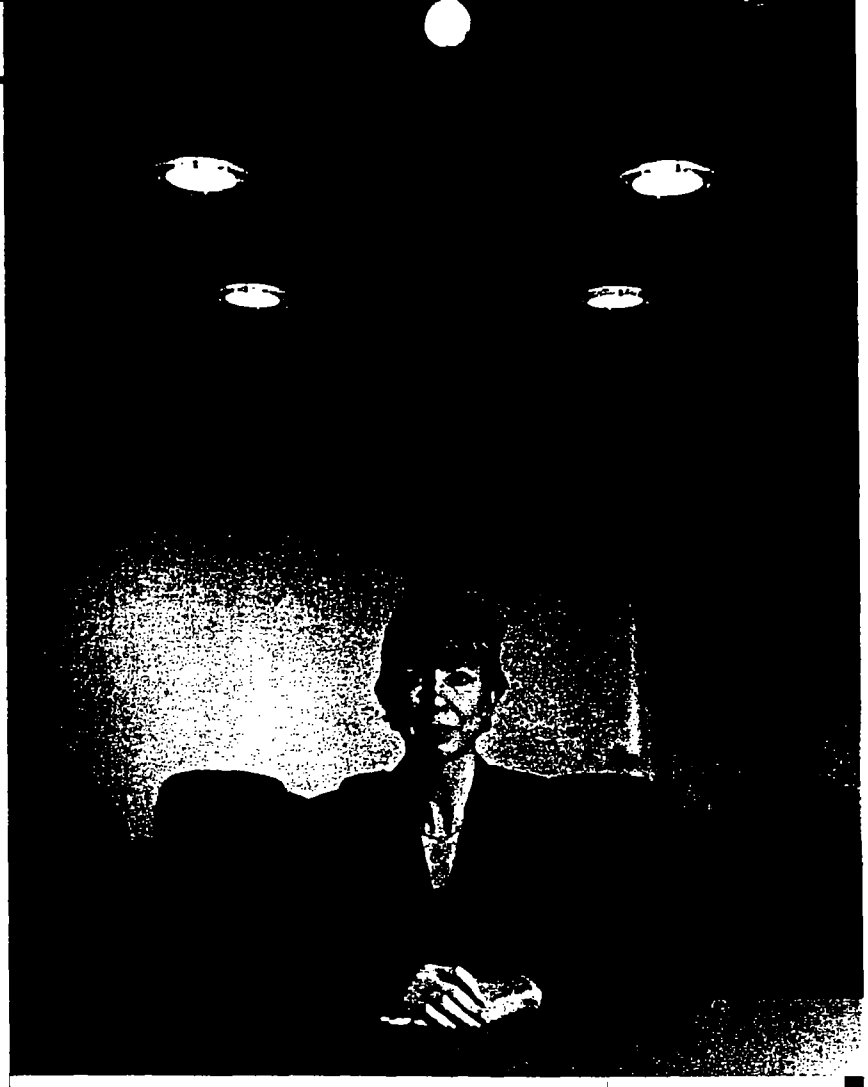
Fortunately, cases like the Tyrivers' are starting to put a long-overdue spotlight on the problems with pediatrics and managed care. The industry itself has come up with several encouraging initiatives, such as the pediatric Asthma Patient Management Program of U.S. Healthcare (now part of Aetna), under which kids with asthma—one of the most common pediatric ailments—experienced a 25 percent decrease in hospital admissions and a 60 percent decrease in emergency-room visits. Meanwhile, a subsidiary of United Healthcare has just announced its nationwide pediatric transplant network, which includes access to specialists from all over the country in pediatric heart, lung, liver, kidney and bone-marrow transplants.

The American Association of Health Plans has stepped up its efforts to track medical outcomes in pediatric care, says President Karen Ignagni. The association recently launched a research institute that will, among other things, look at children's special needs.

Perhaps most promising, the Foundation for Accountability, David Lansky's organization, is about a year into a two-year project that will pinpoint a group of consistent pediatric measurements that companies can use to evaluate how well managed care treats children. And he'll be working with the NCQA to implement these measures. Meanwhile, the NCQA is planning to release data on treatment of ear infections—a ubiquitous pediatric problem—next year. Also, federal and state governments have stepped up efforts to regulate managed-care companies. States have passed more than 200 laws on managed care this year, covering everything from grievance procedures to who can sue.

Recognizing that more regulation is probably unavoidable, Kaiser Permanente, HIP Health Insurance Plans and Group Health Cooperative of Puget Sound—three large nonprofit HMOs—have banded together with consumer organizations to come up with 18 enforceable guidelines for managed care, among them a full disclosure of how a health plan's compensation system is structured.

So what to do if your HMO denies payment for a treatment you think your child needs or the services of a doctor who's not covered in your plan? Should you just go ahead and do it anyway, and live with the fact that the money will come out of your own pocket?



That, apparently, is what many HMOs may well be counting on. Keep in mind that in order to keep costs down, medical directors of HMOs may sometimes automatically deny a certain number of procedures each month, says Linda Peeno, a former medical reviewer at Humana who is now a full-time advocate for health care reform. "They don't really pay attention to the specifics of each case," says Peeno. "And they figure most people won't fight."

But all HMOs are required to have a grievance or appeals process that allows customers to question the plan's denial of coverage. The appeals process is actually a plus of managed care. There's nothing like it at traditional fee-for-service insurers. And it can often work. HMOs have become more generous with appeals as a way to avoid malpractice suits. Some plans have reversal rates as high as 76 percent on denials.

"A lot of patients think that once a decision is made, it's in stone," says Cabrera at American Medical Healthcare, "but you can always appeal. With an appeal, we get a lot of new information about a case that we otherwise wouldn't know. I would encourage anyone who's been turned down to appeal." □

Karen Ignagni denies that the lack of data on children implies that HMOs are lacking when it comes to pediatric care.

we should

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Karen → congress

is answered

& continuity of

care