DOCTORS AND DOLLARS ARE NOT ENOUGH

A Report by the

CHILDREN'S DEFENSE FUND
of the Washington Research Project, Inc.
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How to Improve Health Services for Children and their Families

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The photographs in this book are for illustrative purposes. They are meant to imply no direct relationship between any particular child and the text.

Cover
The drawing on the cover was done by eight-year-old Thea Richardson, who lives in Boston.
This book is the third in a series of reports the Children’s Defense Fund (CDF) will issue over the next year on conditions of children which urgently require public awareness and action. The publications are part of CDF’s goal to provide long range and systematic advocacy on behalf of children. We address problems which we believe affect large numbers of children. Through a combination of research, public education, litigation, community organization and monitoring federal policies and programs, we try to identify how best to change the practices that result in the neglect or mistreatment of millions of children.

We believe that in a number of areas, children’s needs are so clear that we cannot allow them to go unmet, entirely or in part, for all children or for certain groups of children. These areas include the right of all children to an adequate education; to fair and humane treatment under our system of juvenile justice; to privacy from the abuses of school record keeping systems; to child care and other needed social services; and to primary health care services.

This book is devoted to how we can provide primary health care services to all children and their families. There is nothing more essential to a child’s growing up, to being able to take advantage of education or other social services, to becoming a productive, whole adult than good health. Deficits in nutrition, prenatal care, preventive services and regular check-ups and treatment of health problems can have irreparable consequences to children that will impair their capacity to partake of and contribute to this society for the rest of their lives. These consequences are unnecessary. The elements of good health care programs described throughout this book should become standard expectations for children’s health care services in this country. We are ready to work with interested individuals and groups of professionals and parents who share our concern for the health and physical well-being of our young.

Marian Wright Edelman,
Director
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Our appreciation above all to the people whose work makes up the fabric of these pages, the people on the front line of attempts to deliver effective and humane care to millions of mothers and children, who took precious time out to help us understand and describe what they were doing.

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Introduction

Nothing causes parents greater concern than their children's health. Nothing is as immediate or requires more attention, common sense and good judgment. Every parent experiences fear when a child's temperature rises to 104 degrees. No one has to explain how incapacitating it is to be sick or in pain—for a child or a parent—how difficult it is to function well, to find the energy to do schoolwork, housework, or to communicate with patience to family and friends. In almost every culture an elder is apt to chide or comfort a complaining youth: "It's not so bad ... as long as you have your health."

No social service should be more accessible than health care. And yet the care and treatment of illness are based on highly scientific, technical, often obscure research and knowledge that is incomprehensible to most lay persons. Doctors write prescriptions in Latin; they describe conditions and diseases in English few reasonably intelligent adults can understand. The literature of how to organize and reform health care services is laced with words and phrases whose meanings are known only to the few sophisticated health policy analysts who write and use them—usually with each other.

It is often impossible to engage parents and professionals in a dialogue about health care. Most people cannot understand what to do about problems like telephone answering services that don't answer, doctors who don't make house calls to tend to sick children, and fewer and fewer good, general doctors whom a family can get to know and depend on. Parents, who glorify doctors because of their special knowledge of life and death, find it almost impossible to participate in the health decisions that can radically affect their lives and the lives of their children.

We want this book to do two things: first, to explain in terms everyone can understand the current thinking on organizing health care for children. How will certain decisions, policies, funding patterns or methods of organizing health care affect children and their families? We believe it is crucial that parents know the issues in this area. It is also crucial that they find ways to let their health care professionals and their legislators know what they want and need. We believe that consumers of health care—parents and other interested citizens—if well informed, can make a difference in the way children's health services are designed and offered. We have tried to touch on the main arguments and to summarize research findings from the literature and the experience of programs on such important subjects as the financing of care, access to care, the organization of health services, manpower constraints and ties between the health system and other related concerns such as food, housing, jobs and education. The arguments and descriptions of research are not meant to be exhaustive, for there are hundreds of articles and many good books which focus on each of these aspects. We hope interested readers will pursue further discussions from sources in the footnotes in each chapter and from the bibliography at the end of the book.

Second, we want to let people know that there
are some programs in some places in the country that are doing "the impossible"—that is, providing warm, sensitive, comprehensive, high quality health services to children and families at a cost that is reasonable and predictable. None of them is perfect, none is meeting all needs, and none is meant to be lifted in its entirety and placed in any one community. But the people who started and run them have valuable information and experience to offer those who want to change the way children in their community receive health care services.

Some Key Terms

Despite our efforts to write about health care in simple English, there are some special terms that are so commonly used in these discussions we found it difficult to exclude them entirely. For example, our focus throughout the book is on primary care. Primary care includes all those services which have traditionally been provided by general practitioners, pediatricians, internists, obstetricians and dentists—and which are provided in doctors' offices, health centers and clinics—to patients not in need of hospitalization or specialized care. Some of these services are now being increasingly and successfully provided by a wider variety of personnel, including nurse practitioners, child health and pediatric associates, mental health counselors, social workers, family health workers, nurse midwives and physicians' assistants. Most of these services are an individual's point of first contact with the health system and include such things as preventive services, acute care not requiring the services of a specialist, assessment of all health-related problems and management and coordination of resources necessary to deal with all those problems.

We concentrate on primary care for four reasons: (1) it includes the overwhelming majority of health services needed by children; (2) it is too often ignored because in discussions of health care it takes a back seat to topics like catastrophic illnesses and recent technological achievements of modern medical science; (3) it is the area where there are the most striking disparities in access to and quality of services received by the affluent and the poor; and (4) good primary care can alleviate suffering, prevent illness and help families improve their health and use medical services wisely. It therefore deserves top priority for those concerned with children's health care.

Another term we use often is comprehensive care. Comprehensive care is made up of all health and support services required to return an individual to a state of physical and mental well-being and to maintain that state. These services include (but are not limited to) preventive, acute and emergency medical care; dental care; rehabilitative services; social services; health education; and services which help people make use of health care, such as outreach, transportation and child care.¹

The terms medical care, health care and health services are often used interchangeably but, in fact, they have distinct meanings. Medical care refers to the traditional procedures that doctors or nurses do to patients to make them better. Health care includes medical care as well as a broader array of services, also rendered to individuals, such as counseling, help in coping with a variety of health-related problems and many kinds of health education. Health services include all kinds of health care and, in addition, those services that are provided to entire populations in a community, such as sanitation, fluoridation or help in obtaining the enforcement of safe housing codes.

Findings

As we reviewed the programs that have attempted over the past ten years to improve health care for children and families and as we thought about the qualities that made them work, it became clear that we as a society have yet to decide and must decide that all children are entitled to decent health care. Universal entitlement to basic, primary health services should be a funded fact. We must end the policies and trade-offs that assume some children are expendable and can go without the benefits of quality health care. As Chapter 1 demonstrates, the difference health care makes in the lives of children is real and significant. No one should have to go without it.

We also found that while providing money is

¹ For a more complete list of the services we believe should be included in comprehensive care, see Appendices A and B in this book.
necessary to improving services, it alone is not sufficient. There are numerous examples of more money added to our current patchwork of public and private sources of care that have neither improved the system nor, in the long run, benefited people very much. As Chapter 2 illustrates, spending money in ways which do not encourage changes in how care is organized and delivered will only add to the problems we have. Any proposal for financing health care must take into account the substantive recommendations made throughout Chapters 3 and 4 for it truly to improve children's health services.

Chapters 3 and 4 are the heart of this book. They define all the common sense and practical issues which many professionals and reformers see as insignificant compared to the "weightier" problems of health care, but which often are the turning points determining whether care is received at all and what kind of care it will be. For instance, how could the availability of food stamps possibly be of serious concern to a group of doctors? It is a matter unrelated to their technical training and beyond the scope of their professional responsibilities. Or is it? What if a parent whose child has iron deficiency anemia cannot afford to purchase the foods the doctor has recommended be a regular part of the child's diet? What if the parent is eligible for food stamps but does not know how or where to apply for them? Without money or stamps, the doctor's instructions may go unheeded and the child is likely to return for diagnosis of the same problem.

Where is the line between good medicine— including prevention, early diagnosis and efficient treatment—and helping to provide for a child's nutrition? We are not suggesting that doctors themselves should add to their duties all the support services necessary to enable families to receive effective health care. Doctors should, however, formally recognize that such services are a vital part of health care and help to create settings in which such services are an integral part.

Finally, we have seen again and again how important it is to involve parents in assuring quality health care. Parents are crucial to monitoring their children's health, noticing when something is wrong, getting children to medical care and carrying out the doctor's or other health professional's recommendations for treatment. Parents are equally indispensable to monitoring their community's health care resources. Where are improvements most needed? Is there information about children's needs that should be included in program planning? Can resources be rearranged to reflect the community's priorities? Chapter 5 of this book discusses some of the obstacles citizens are likely to face when seeking change and the principles of quality health care which we discuss throughout the book. We hope it will help parents and other interested citizens to be effective advocates for their children's health care.

We have used the term "quality" in this introduction very generally, and we know it is an exceedingly complicated and elusive thing to measure in reality. Health care is not an unmixed blessing. Not all doctors have the same level of competence; not all procedures may be necessary or beneficial. But the complexity of these issues makes it more, not less, important that parents become active participants in the decisions and programs affecting the health of their children.

Today, there are increasing opportunities for citizens to influence the design of health services at the local level. Many federally-funded health programs have advisory committees which must include consumers. (For a summary of major federal health programs for mothers and children, see Appendix C.) In addition, the National Health Planning and Resources Development Act of 1974 has established planning agencies at the state and multi-county levels which are responsible to boards composed of a majority of consumers. And there are more and more independent groups responding to the need for consumer advocates to assess and monitor the quality of health services and to work with professionals and policy-makers toward specific changes.

We urge those who are interested in taking action to use this book as a resource for ideas and for contacts. Compare the health programs serving children in your community with the principles of good health care delivery discussed throughout Chapters 3 and 4 and summarized in Chapter 5 and

determine which of the programs addresses the particular problems in your community.\

We publish this book at a time when resources are scarce, cutbacks in human services are common and cynicism about social programs is prevalent. But unlike so many other areas of social policy for children, we know what to do to improve children's health services. The programs described throughout this book demonstrate what works. It is tragic for these very services to be cut back or cut off by federal, state or local action or inaction. The experiences of the last decade have provided the necessary foundation for constructive change. Now is the time to build on it.

3 Programs found in the literature about health care are listed in the footnotes; programs CDF staff contacted personally are listed in Appendix E.
Wilson Diver is by far the smallest, thinnest and most frail looking of the nine Diver children. At age twelve, he looks younger than his eleven-year-old sister Theresa and his ten-year-old brother Curtiss. On meeting Wilson for the first time, everyone believes he is either on his way to a hospital or has just come out of one. It doesn’t help young Wilson’s condition any that he and his family are among the poorest families in Massachusetts.

It was very clear to his mother, Mrs. Claudia Diver, that her seventh baby even at birth was not as strong as the other ones. He had a fine disposition; he learned to walk when everybody thinks it’s normal to begin walking, and talk when talking’s supposed to begin, but he was, somehow, an unwell child. The first sign of illness came when he was about two, when for weeks at a time he would lie in his bed whimpering, having trouble breathing and running abnormally high temperatures. As he grew up these bouts of bronchitis, asthmatic bronchitis as they later were diagnosed, came more frequently—eight, nine times a year. Like all children, Wilson would show the beginning signs of a cold. He would cough a bit, sneeze, and find his nose running. At night, the coughing became unbearable. He might cough without respite for two minutes, until finally his chest would sag and deep rings lined his eyes. By flaring his nostrils and opening his mouth, he barely got sufficient air into his lungs. The cold weather naturally made his life miserable, particularly at night when there was no heat in the Diver apartment. There was no way to keep him warm or provide him any relief. His mother would prop him up in bed and hold him while she and several of his sleepy brothers and sisters would just stare at him, expecting him surely to die at any minute. No one could believe how sick Wilson could get in such a short time. One day he would be fine, the next morning he would show symptoms of a cold, and by that night he would look to be on the brink of death.

Wilson was examined once by a young medical student in the large hospital six miles from the Diver house. The doctor said that he heard nothing in Wilson’s chest to indicate a problem. “Some kids,” he told Mrs. Diver, “are just susceptible to pulmonary and bronchial complications when they get sick.” He did give them some medicine to try the next time Wilson got sick. The medicine seemed to help, at least it gave Wilson some relief in breathing. Strangely though, it also seemed to stimulate him so that he was unable to sleep at night. Mrs. Diver had to decide which was more important, relief in breathing or sleep.

By his twelfth year, Wilson Diver was accustomed to his periodic illnesses. He did his best to avoid catching colds, but he simply was more susceptible to them than anyone he knew. No matter how warmly he dressed or wisely he ate, the infections got to him. Claudia Diver kept promising she would move the family to a warmer climate, for she had relatives in Birmingham, but the shortage of money never allowed for this. And where could she find a job as good as the one she had now in the small factory so near to her home? “Wilson has...
survived this long," she said, "and he's getting bigger and stronger. He'll survive the rest of the way. He has to."

In February, two months almost to the day before Wilson’s thirteenth birthday, he got sick again. All the usual signs were present: the unstoppable coughing at night, the runny nose and eyes, the pains in the sinus areas behind his cheeks and forehead, and the chest aching from strain and fatigue. But this time the infection seemed to hang on longer than before, indeed several days longer, and a new symptom appeared. Early one morning, after he had managed to get back to sleep for a few hours, Wilson became nauseated and began to vomit violently. Even when he had rid his stomach of all its contents, a muscular reflex continued, and he gagged until he felt he would expel his lungs. A bit of blood appeared in the vomit.

Awakened by the sounds of Wilson wretching and crying, Wilson’s older brother, McCay, found him in the bathroom and promptly awoke everyone. At six o’clock in the morning they decided that, difficult as it would be, they had to take Wilson to the hospital. A portion of the hospital trip was described by Wilson himself several months later.

"First we called the police, you know, and they said they couldn’t send nobody around to our house unless we could prove it was an emergency. McCay said I should get on the phone and cough for ‘em. He wasn’t joking neither. But they would not come out. So we went down to the corner and waited for the bus and, man, it was so cold out there we might as well have frozen altogether. Everybody was standing around me, trying to keep me warm, you know. Must have had ten coats and jackets on me. And I kept up this gagging and choking I was doing too. So maybe after half hour, the bus comes, and we get on.

"Then we had to transfer to another bus, and finally we got there. We were real early too, and this waiting room they got there was crowded with people, it was like we were going to a bus station or something. Every chair was filled up. An old man gave his seat to my mother, but McCay and me, we sat on the floor. And the place was cold too, man, and there wasn’t anything to eat. They had a real nice water fountain, I remember.

"Now here’s the truth: we must have got there by eight o’clock, and we didn’t talk to no one, no one, man, until eleven, or maybe even later. And then it was this woman who took our names and stuff like that, you know. She wasn’t even a nurse! She was just taking our names. And the place is getting more crowded every minute. You should have seen the people coming in there too. Broken legs and bleeding. Then they brought this one guy in on a table with wheels and they said he died. The man died there after the doctors saw him.

"So then, like at twelve, the woman calls our name and we go up to this little desk, and she tells my mother that we don’t have the right kind of insurance to get medical help. My mother needed to prove where she worked or something, I don’t remember, but anyway, McCay has to go home and get something that proves she can come to the hospital. And ‘cause we don’t have a telephone we couldn’t call up at home, and anyway no one was home ‘cause they were all at school.

"So McCay goes and he comes back, this time with the police. He just went there and told him his problem and this cop gave him a ride all the way. Now it’s like one, one-thirty, and I ain’t seen no one. Finally they get all the stuff straightened out on the paper, oh, here’s what it was. They thought it would be better for my mother to say she was on welfare than to say she had a job. Somehow it worked out better for them if they did it like that. So they did. She didn’t care, she just wanted me to see the doctor, ‘cause I wasn’t getting any better. Finally, they call my name and I see this doctor. He tells me to take off my shirt and lie on a table, one of those tables like that other guy died on, only this one had a clean sheet. So I get on the table and I’m thinking the doctor looks real young. And it’s cold in this little hall they got me in too, ‘cause it’s not a room, it’s just a hall with a sheet hanging down from the ceiling to kind of hide me, you know. Then the doctor goes out and he don’t come back. And I’m lying there with my shirt off, freezing, so finally I get up and walk out and ask somebody can I put my shirt on and he says, ‘You can put your hat on for all I care. If you can walk and ask questions like that you ain’t sick enough to be in the emergency room!’ So I get disgusted and go back to my little sheet room in the hall, you know, but I get dressed.

"Now, while all this is going on, McCay goes
home 'cause he's so hungry he can't stand it no more. But he asked someone before he left how come no one's helping me, and the woman tells him it's her job to choose which people who come into the room look the sickest. And since I didn't look that sick to her she kept me waiting. So then I go out again and tell someone I'm really hungry. This time it's a doctor and he looks at this little piece of paper they had me carry with me and he says, 'You've been vomiting, so you better not eat yet.' And when I went back again to my sheet room I saw that the clock said five-thirty. And still nobody had come to see me.

"You ain't going to believe that nobody came until six-thirty. Then this other doctor comes, not the first one, but a different one, and he's looking so tired and he's talking to so many people he looks like he should see a doctor himself. So guess what he says to me?

" 'Take your shirt off Mr. Wilson.'"

"I say, 'My first name's Wilson.' He don't hear me. He's got that thing in his ears already and he's starting to listen to my chest and my back. Then he lays me down and pushes his hands so hard on my stomach I thought he was going to kill me 'stead of cure me. Then he asks if I'm hungry. I say I ought to be, haven't eaten since last night. So he gives me this great hard candy and he tells me where he buys it and pats my face. Nice guy.

" 'How you feel,' he says.

"I tell him I want to go home.

" 'You're going to be fine, Wilson my boy,' he says. 'You're going to be good as new. You just got to eat my special candy.'

"Man, did I feel good after that. 'Can I go, doc?' I ask him.

'Hold still a bit longer,' he says.

"All this time he's writing on a sheet of paper.

"You got a phone number?' he says.

"No."

"What's your address?'

"I tell him. 'Now can I go?'

'Hold still.'

"So now I have to wait some more. But when he leaves he promises me he'll come right back. Don't worry! Then he leaves and I hear him tell another man, 'There's a boy in there who is very sick. We got to find him a bed.' I didn't know what he meant at first. But then I figured they want me to go to the hospital 'cause I wasn't fine, and I started to cry. Real soft 'cause I didn't want no one to find me. But when nobody came back I put my shirt on for like the tenth time and went to get my mother, but she was gone. And the room wasn't crowded any more. Then I really got scared. But this new woman had a note saying my mother would come back and that I shouldn't worry. Shouldn't worry, why not? They wanted to put me in the hospital which meant I was sick, real sick, man. I'd been there all day and only one person saw me and he only was there a couple minutes. Course he gave me that candy which was my breakfast, lunch and dinner. They did give me that!

"So then I waited some more.

"Then, like at about ten o'clock in the night, a nurse came in this room where they got the television to say a policeman's outside waiting to take me home. She says I should be in the hospital and they've been waiting for a bed to open up, whatever that means, but since they had no room they were sending me home. But before I left she had to take some blood from me which hurt me, man, like out of natural sight pain! You going to drink it? I asked her. She didn't laugh. 'Too late for that nonsense,' she said. 'I been here all day lady,' I told her. 'Me too,' she said. She was an angry old bitch. Anyway, the cop took me home and had to carry me into the house. Everybody was asleep except my mother and McCay. They had tried to get back to the hospital but the buses weren't running no more. That was the longest day of my life man. Started out with me vomiting up my lungs and ended with a policeman carrying me home. But I knew I had to go back to the hospital. I told my mother couldn't she find a better hospital. She said they were all the same, and anyway, this one now had my records. I was doomed, man. That's what I told McCay the next day. If I go back there I'm going to die, man. Hospital's going to kill me off, just by all the waiting. My mother told me not to talk that way, but McCay, he said, 'Wilson's right. What about that man we saw who died on the table like the one they put Wilson on?' My mother told him to shut up, but he was right. Only I didn't want nobody to talk about it like he did. He didn't have to go back there like I did."

Ten days following Wilson's examination, the hospital sent a letter to Mrs. Diver indicating that
the results of his blood test suggested that Wilso should enter the hospital for further tests. The hosp-
ital would notify the Divers when a bed was free
but that it would be helpful if they could return to
the hospital before that time for a chest x-ray. It
was almost three weeks before the x-ray was taken.

"This time," Wilson said, "I only waited three
hours, only I was all by myself. But it was all right
'cause it meant I didn't have to go to school all that
day. People were nice to me too. The woman re-
membered me from before. But one week later
they wrote to us saying they had a record of me
coming in for x-rays but no record of the x-rays. So
I had to go back again. And you got to remember
that each trip to the hospital takes about two hours,
if you don't have to wait too long for the buses.
Each time you get to wait outside in the cold, you
know, and you're getting so cold you don't know
whether to go on or go back. One time I went back
and told my mother I went. Then I had to cut
school another day so I could go. So they did the
same x-ray all over. I was noticing then how my
chest seemed to be getting smaller. For a while I
was thinking so much about going to the hospital
and worrying about it, I didn't even think about
being ill. Although I near vomited again like I did
that one time. But I couldn't shake my cold, you
know. It's like it was stuck to me, like I'd have it
forever. I don't know. Maybe I will."

Three and one half months after his first exami-
nation and the decision to put him the hospital,
Wilson Diver was admitted. He was placed in a
ward room with five other young people. New doc-
tors examined him this time; he never saw the same
doctor twice. A third chest x-ray was taken and all
sorts of medical tests were performed. On the third
afternoon of his hospitalization, Mrs. Claudia
Diver was called into the doctor's room on the sec-
ond floor for consultation. Her son was suffering
with pulmonary problems, she was told. The
x-rays had recorded a rather large spot on his right
lung which indicated tuberculosis. Moreover,
while the doctors were not certain, several tests
suggested the possibility of his also having
leukemia, although they hoped it was a mild, treat-
able form. He was also malnourished. As Claudia
Diver reports it, the doctor was about to re-
monstrate with her for the way she had failed to
give her son proper medical attention. Then, she
said, he had looked at her, and he stopped himself.
She did not have to explain Wilson's cir-
cumstances, or her circumstances.
What Difference Does Health Care Make in the Lives of Children?

We know a lot about child health, yet American children are nowhere near as healthy as they could be. Good health is not distributed equitably among the nation’s children.

A child’s destiny in Sweet Water [Alabama], if he is black and poor or white and poor, is to be born to a mother who had received no prenatal care, to be born outside a hospital, in a rural cabin, attended either by a midwife (with various degrees of experience and training) or simply by a relative. Then the newborn infant gets no pediatric examination, no injections or ‘shots’ to prevent this or that disease, no vitamin supplements, no evaluation, no treatment of any kind. The heart is not heard, nor the lungs, abnormalities are not noticed, nor are attempts made at correction. Advice is not given, nor reassurance. Worst of all, accidents and injuries and illnesses are part of life, and either “take” the child or “spare” him or her. Fractures heal or they don’t, often without the benefit of splints or casts. Infections go away or they don’t. Burns and lacerations and cuts and sores and rashes either “clear up” or “stop themselves” or “leave the child” or they don’t, with obvious results: Worse and worse pain, more and more incapacity and disability—and always those complications, which themselves get no more care and attention and treatment than whatever kind of “pathology” caused the “sequelae” in the first place.¹

There are hard numbers to show that every year, inadequate and unequal provision of health care services to children and pregnant women in this country results in the unnecessary deaths of thousands of children. Many thousands more are disabled or suffer chronic conditions which, if untreated, rob them of years of their lives, impair their productivity, and cost the rest of us millions of dollars for remedial services and support. The statistics are a national scandal.

—The international statistics on infant deaths show that the infant mortality rate in the United States is worse than in 14 other countries.² And within the United States there are startling variations, ranging from 23 deaths in Mississippi to 12.2 deaths in Utah per 1,000 live births³ and from 26.2 for nonwhites, nationwide, to 15.2 for whites.⁴

—After infancy, contrasts in mortality figures remain. Among children aged 1 to 4, minority children die at a rate 70 percent higher than whites. And in the 5 to 9 age group, minority children die at a rate 40 percent higher than white children.⁵


Figures on how many American mothers die in childbirth show that three times as many nonwhite as white mothers die.  

Every year, thousands of children suffer from lead paint poisoning. In the course of a year, 300 to 400 children die from it and 6,000 more suffer irreversible brain damage.  

One indicator of malnutrition is a low hemoglobin level. Of all children ages 1 to 5, 30 to 40 percent are below standard. Low hemoglobin levels or other nutritional deficiencies are found twice as often among black Americans as among white Americans, affecting one out of every three black children.  

The Watts area of Los Angeles contained only 17 percent of the city’s population, but in category after category it harbored nearly 50 percent of the city’s ills. It had 48.5 percent of amoebic infections, 42 percent of food poisoning, 44.8 percent of whooping cough, 39 percent of epilepsy, 42.8 percent of rheumatic fever, 44.6 percent of dysentery, 46 percent of venereal disease, 36 percent of meningitis and 65 percent of reported tuberculosis reactors. The death rate in Watts was 22.3 percent higher than for the remainder of the city. The incidence of tuberculosis was four times higher in Watts than in the rest of Los Angeles County.  

Native American children die from heart disease, influenza, and pneumonia twice as frequently as other children. In a Chicano community in California, children display a whole range of vivid contrasts with national averages: four times as much amoebic dysentery, twice as much measles, mumps, and tuberculosis, and 1.4 times as much hepatitis.  

Pregnancy in young teenagers is on the rise. Both the number and rate of births to 14- to 16-year-old girls rose steadily between 1965 and 1973. Mothers under 15 years old are twice as likely as those between ages 20 to 34 to have babies of low birth weight — a condition disproportionately associated with infant deaths, birth defects, mental retardation, and a variety of other tragic outcomes.  

Like good health, good health care is also inequitably distributed among the nation’s children.  

Many children receive no care at all. Experts estimate that in 1971 at least ten million U.S. children under age 16 received no medical care whatsoever.  

According to a nationwide survey conducted in 1974, 22 percent of American children ages 6 to 16 had not seen a dentist in the past two years. Among children in families earning less than $7,000, 37 percent had not been to a dentist in the past two years and 21 percent had never been to a dentist.  


America’s Children, 1976, A Bicentennial Assessment, p. 34; Testimony of Jack Hood Vaughn, p. 2.  

—When U.S. children reach school age, they have an average of three decayed teeth; about half of all school-age children suffer from gum disease.¹⁹

—Immunizing children is clearly effective in preventing childhood diseases. Yet in 1974 nearly 5 million children ages one through four—or 37 percent—were not adequately immunized against polio. Forty percent were not vaccinated against rubella.²⁰

—in a 1972 study conducted by Meharry Medical College of 1,266 poor families in Nashville, Tennessee, physicians and dentists interviewed and examined family members to identify health needs. They found that:

(a) among families with already diagnosed medical problems, only 13 percent were receiving proper medical attention;
(b) 97 percent of the people in the study had health problems. For example, of every 100 persons, 51 needed a regular physical examination, 45 needed one or more immunizations, and 94 had inadequate diets;
(c) 95 percent of the persons examined by the dentist had unmet needs for dental services and more than 90 percent of diagnosed dental problems were receiving no care at all.²¹

These numbers quantify a great deal of needless pain and suffering. But the question remains: Would health care make a difference?

The answer is yes.

The elimination of poverty in this country would also make a difference in these statistics, and a very substantial one. But we should not let ourselves be put in a position of having to choose between improving employment opportunities and family income on the one hand or improving health services on the other. Suspending action in the field of health until changes occur in other infinitely more immovable fields like income redistribution is foolish. If we wait to provide equal health care for the poor until they are no longer too poor to pay for it, generations of children will suffer. The same can be said about housing, education and jobs. Action needs to be taken on all these issues, simultaneously, not one to the exclusion of the others.

Furthermore, trying to improve children's health solely by reducing poverty overlooks the unique contribution health care can make. It is not a token gesture. It can have real consequences for real people. The relationship between health care and children's health is perhaps most clearly demonstrated in studies of the effect of prenatal care on the outcome of pregnancy.

—Mothers who have had no prenatal care are three times more likely to give birth to infants with low birth weights,²² which is associated with almost half of all infant deaths,²³ and substantially increases the likelihood of birth defects.²⁴

—A landmark study of all births in New York City in 1968 showed that death rates of infants born to mothers in each of four categories of risk were lowest among infants whose mothers had adequate care, slightly higher if their mothers had intermediate care and the highest if the mothers had inadequate care. Mothers who began their prenatal care in the first eleven weeks of pregnancy and had at least nine visits had an infant mortality rate of 6.0 per 1,000, compared to a rate more than three times as high (19.0 per 1,000) for women who delayed their first visit until the twenty-eighth week or later and had fewer

than five visits. The researchers concluded that "generally, adequacy of care . . . is strongly and consistently associated with infant birth weight and survival, an association that is pronounced throughout the entire first year of life." 25

1,125 infants died in New York City in 1968, for reasons related primarily to inadequate prenatal care. 26 As Robert Coles observed in his foreword to the report of that study, these children "were not the victims of a profession's intellectual or scientific inadequacies. They were not boys and girls born too soon—because certain fatal diseases have yet to be understood and made responsive to medical treatment. They were boys and girls who, with their mothers, of course, needed only what millions of others received: adequate medical attention. Their deaths were, by and large, utterly avoidable." 27

There are other specific conditions where the effects of medical care can be isolated and measured. Experts agree that if strep throat were detected and treated adequately, rheumatic fever and chronic rheumatic heart disease would be almost nonexistent. 28 Yet in 1972, approximately 68,000 children under age 17 suffered from these two conditions. 29

Where organized health services have been made readily available to families, their impact is striking. In Baltimore, Maryland, where four comprehensive care programs were established in the most underserved areas of the city, the incidence of rheumatic fever was reduced by 60 percent among children in the census tracts eligible for any of the programs, while in the surrounding areas its incidence increased by 20 percent. 30

We have learned a great deal about the effects on children's health when communities take specific steps to organize and provide comprehensive health care services to families. 31

—Comparing infant mortality rates by income and race in nineteen cities, the spread among cities ranged from 22.3 in Pittsburgh to 2.8 in Denver. Denver had not only the lowest differentials between white and nonwhite and between low-income and other areas, it also had the lowest absolute rate in its low-income areas for both whites and nonwhites of the nineteen cities surveyed. 32 Denver has probably come closer than any city in the country to making comprehensive health services available to all its residents through an integrated network of neighborhood health centers and Children and Youth projects.

26 Infant Death: An Analysis by Maternal Risk and Health Care, p. 13 ff.
27 Infant Death: An Analysis by Maternal Risk and Health Care, p. viii.
31 There have been a number of evaluations of the demonstration programs that have reorganized the delivery of care. Of the studies that have focused on the effect on health outcome of improved organization and comprehensiveness of care, only two have failed to demonstrate a clear relationship. One compared two groups of infants and found no discernible difference in their health status after a year during which half of them received care in an organized setting while the other half received sporadic care. (Leon Gordis and Milton Markowitz, "Evaluation of the Effectiveness of Comprehensive and Continuous Care," Pediatrics, Vol. 42, November 1971.) Another study measured three specific kinds of illnesses in children and found that the incidence of these illnesses or their detection and treatment was not related to the children's source of care. (David Kessner, Assessment of Medical Care for Children, Vol. III, "Contrasts in Health Status," Washington, D.C.: Institute of Medicine, National Academy of Sciences, 1971.) The failure of these two studies to show positive correlations between type of care and health status is by no means conclusive. The variables chosen because they are measurable are narrow, and often do not represent the array of qualities one would like to know about in evaluating program effectiveness. Had other characteristics been measured, or had the measures themselves been more sensitive, different conclusions may well have been reached.
32 National Center for Health Statistics, Health Resources Administration, U.S. Department of Health, Education and Welfare, Selected Vital and Health Statistics on Poverty and
Evaluations of many maternal and child health programs taking active steps to enroll pregnant women, monitor their health carefully and provide regular infant care have shown remarkable reductions in mortality, prematurity and illness. \(^\text{33}\) In Providence, Rhode Island, for instance, the part of the city served by the Maternal and Infant Care Project at St. Joseph's Hospital showed a reduction in infant mortality from 47.4 per 1,000 live births in 1966 to 25.2 per 1,000 in 1970, while in more affluent census tracts the rate increased from 20.1 per 1,000 live births in 1966 to 21.4 in 1970. \(^\text{34}\)

Neighborhood health centers have been notably successful at extending health services in poor communities. Until recently there was a neighborhood health center in Lowndes County, Alabama, and the infant mortality rate was reduced from 46.9 per 1,000 live births in 1967 to 28.3 in 1971. Over that same period of time, infant mortality rates in neighboring counties changed little. Similarly, in Bolivar County, Mississippi, the infant mortality rate decreased from 48.5 to 31.0 deaths per 1,000 live births during the first four years a neighborhood health center was located there. Among Blacks, who comprised nearly all the patients served at the Bolivar center, the rate was reduced from 57.2 to 35.7, while the rate for whites increased slightly from 13.5 to 13.7. \(^\text{35}\)

In virtually every community where access to comprehensive care was improved, there was a substantial reduction in hospital admissions and in the inappropriate use of hospital emergency rooms. \(^\text{36}\)

In Boston, Massachusetts, among families randomly assigned to a comprehensive care program, there was a significant increase in receipt of preventive services and a significant reduction in laboratory costs, prescription medications, hospitalizations, operations and illness visits. \(^\text{37}\)

Health services make a difference in the incidence of death and disease, but they also make a difference in the quality of life we lead—a difference much more difficult to measure. Any parent who has sat up for a night with a feverish child or a child in pain knows that, although the illness may not be critical, and although it may go away by itself 80 percent of the time, if medical intervention can reduce that child's discomfort from five days to one, that is indeed a significant accomplishment. Any citizen who is concerned about the kind of society we live in must recognize that a full range of child health services should be available to all, rather than available to some on the basis of income or race.

Non-Poverty Areas of 19 Large Cities, United States, 1969-71. DHEW Publication No. (HRA) 76-1904 (Rockville, Ind.: U.S. Government Printing Office, 1975), Table E, p. 16. The differentials included a high of 22.3 in Pittsburgh (39.4 in nonwhite low-income areas and 17.1 for whites in the remainder of the city), and a spread of 19 in Indianapolis, 19.4 in Philadelphia, and 18.8 in Chicago. In only three cities was the spread less than 10: 7.5 in San Francisco, 5.8 in Minneapolis, and 2.8 in Denver.


\(^{34}\) Promoting the Health of Mothers and Children, p. 6.


Chapter 2

A Preliminary Word About Financing

This book is about ways to improve health care for children, and not mainly about financing traditional doctors' services. We do not think financial barriers to health care are unimportant or insignificant. Clearly, the costs of health services figure greatly in individual, family and governmental decisions. But much has been said and written about the problems of financing medical care, while relatively little attention has been given to the non-financial barriers that exclude children or diminish the quality of care they receive. The rest of this book will deal with these subjects.

This chapter, however, is about money. While money alone will not improve the availability or quality of health care, it is fundamental to everything else we discuss. A well-designed, comprehensive health care program is useless if a family's lack of money prevents it from using it. There is little point in dreaming up an ideal set of health services if they cost more at the outset than we as a society are willing to spend on health services or if their costs rise so quickly and steeply that public support promptly erodes.

The problem of how to pay for health care is probably the greatest single worry in most people's minds when they think about needed changes in our health system. Parents worry about their own ability to pay for the care they or their children will need. They worry about what an expensive illness will do to their family's finances. They worry about what any major new public health program will cost in terms of taxes and its effect on the national economy. And many worry about the quality of care they receive for dollars spent.

It makes sense to worry about the economics of health. More money is spent on health care in the United States now than ever before—an estimated $118.5 billion in 1975.¹ Nationally, of every $100 worth of goods and services produced, nearly $8 was health-related—a higher proportion of the gross national product than in any other country.² Over half of this amount is paid by individuals, either directly for services or to private insurance companies.³ The average American's annual health bill has risen from $78 in 1950 to $547 in 1975.⁴

With all this spending, what do we have?

—A VISTA volunteer doctor in eastern Arkansas tells of going to a neighborhood action council meeting: "I asked all those who in a time of need had not gone to a doctor because they couldn't afford it, to stand up. Fifty out of the 55 at the meeting stood up... People feel an obligation to pay and don't go to a...

² "National Health Expenditures: FY 1975, Research and Statistics Note No. 2," See Table 1.
⁴ "National Health Expenditures: FY 1975, Research and Statistics Note No. 2," Table 1. This includes the per capita share of research and facilities construction, as well as personal health services.
doctor if they know they can't pay, unless their situation is really desperate." 

—The Citizens Board of Inquiry Into Health Services for Americans was told this story by the aunt of a five-year-old boy:

"About a month ago out in California, while my brother was at work, the baby required emergency surgery. The doctor wanted to operate, but the hospital authorities would not allow it until my brother could show that he could pay for it. The doctor did not want to move the baby, because it was too dangerous, but he had to have surgery as soon as possible.

"Finally, my brother's employer stepped in and promised to pay the bill if he couldn't. His boss was furious with the hospital. The surgery was permitted, but not before the above red tape. An innocent baby would have been allowed to die in an emergency because his parents could not afford to pay the bill at that time."

While most people would not want an individual child to die because of lack of money, the questions about who pays for health care, for whom, in what ways and covering what services are rarely asked so that the lives of individual children are taken into account. Americans voluntarily send cash donations to help a poor child survive if the case is dramatic and heartrending, and if the news media bring it to their attention. But Americans have not yet acted to remove the financial barriers to health care for all children.

While some children do die because their parents lack the money for doctors, medicine, or hospitalization, many more suffer the slower, incremental toll that poor health care takes. We have already mentioned the price in human terms of symptoms ignored or illnesses untreated. There are many who paid that price because they did not have sufficient incomes to afford health care on their own. And the families who need the most help with their medical bills are the least likely to have insurance: in 1972, 10 percent of families with an income over $10,000 did not have any hospital insurance while 70 percent of families with incomes of $5,000 or less did not have insurance. Even these figures underestimate how difficult it is to pay medical bills because families who are insured often discover that many needed services are not covered. In 1974, only 26 percent of all expenses for personal health care (or 42 percent of all private expenditures) were covered by insurance.

"Theoretically, being poor and being without private insurance should not preclude mothers and children from obtaining care," notes the author of a survey of federal programs for young children. "Maternity and well-baby clinics are among the oldest activities of many state and local health departments, as are charity hospitals in many areas. However, studies have shown that even in clinics, financial factors can remain among the significant deterrents to prenatal care. In some areas, women who could not afford private care were also ineligible for clinic care on the basis of income. The persistent inflation in medical care prices," the study continues, "plus the variability among states in coverage for the medically indigent under Medicaid, are presently increasing this pool of persons above the poverty line but without adequate health care resources."

With inflation increasing by double digits since this study was done, the government is under continuous pressure to tighten its own belt and to apply increasingly rigid requirements for increasingly narrow Medicaid benefits. At the same time, many more people are jobless and hence have lost their health insurance. The number of people who cannot afford even minimal health care has grown.

10 The following are among the cutbacks made in state Medicaid programs between January 1 and October 1, 1975: Reduction in Medicaid Eligibles

—Maine and Alaska removed unborn children from Medicaid coverage so that first-time mothers became ineligible for prenatal care.

6 Heal Yourself, p. 11.
An incoherent financing scheme of private health insurance plans and fifty different state programs which pay for ever fewer services on behalf of selected children meeting increasingly rigid eligibility requirements cannot guarantee protection against the burdens of ever more expensive health care. That is why many people believe we need a program of national health insurance. Others say we cannot buy our way out of our present morass with yet another massive public program.

We believe the critical issue is whether whatever program or programs we rely on for financing health services are specifically designed to improve access and quality for everyone, and whether they are designed to account for and control their impact on the entire health system. Programs to finance health care must have at least six essential components: universal eligibility; comprehensive benefits; no charges to patients for primary care services; payment methods which include incentives to use the most suitable type of care and the most appropriate personnel; subsidies for necessary outreach and support services; and technical assistance and start-up funds for new providers in underserved areas.

- Oklahoma dropped coverage of families with unemployed fathers.

Limits on Basic Services for Welfare Recipients
- Physician visits have been restricted to one visit per month in Alabama and Georgia; Michigan is considering a similar move. Louisiana has restricted physician visits to 12 per year.
- Louisiana and New Mexico have placed restrictions on injections in physicians' offices.

Limits on or Elimination of Optional Services
- Some mental health benefits have been eliminated in Maine, Minnesota, and Texas.
- Eyeglasses have been eliminated in Florida and Georgia; restrictions have been imposed in New Jersey and Maryland.
- Hearing aids have been eliminated in Florida.

Reduction in Reimbursement Levels for Non-institutional Services
- Physicians, dentists, and other health providers have had reimbursement levels cut by 10 percent in New Jersey and Tennessee, by five percent in Georgia.
- Payments for drugs and pharmacists' dispensing fees have been reduced in New Jersey and Illinois.
- Payments for laboratory services have been cut by 40 percent in New Jersey.


Universal Eligibility

It is ironic that the word “eligibility,” which means to be chosen for or entitled to something, has become a mechanism of exclusion from health care services for certain segments of the population. Most programs—private or public—usually lack enough resources to benefit everyone, so they define who has the qualifications to get the benefits and who does not. In cost-effectiveness terms, establishing eligibility for a program enables you to select the most needy, set priorities for who will be served, and weed out those who need services less than others.

Narrow eligibility requirements for health care services on economic or many other grounds often make more sense in theory than in practice. How do you decide who needs health services less than someone else?

A federal education program supports special education services for poor children. Some states and school districts have interpreted the program so that related health services such as diagnostic testing, eyeglasses and hearing aids can be paid for by these federal funds. But only those poor children in special education classes are eligible for these related health services. If a low-income family had five children, all of whom were terribly nearsighted, but only two of whom were in special education classes, then only those two would be eligible for receiving eyeglasses. The other three children would have to go without them. 11

Clearly, the two children in special education classes did not “need” eyeglasses any more than their brothers and sisters, yet these are the kind of arbitrary cut-off rules that permeate eligibility requirements.
Eligibility policies result from two competing program goals. One is to target resources on those who need them most. The other is to make services available as widely as possible, with the fewest possible barriers to people in need. The more narrowly a program tries to focus on those in greatest need, the more complicated and exclusionary eligibility considerations become. They interfere with the efficient operation of the program, raise the costs of sorting out eligible people from ineligible people and deter even eligible people from using services because of the complexities and indignities of a means test.

For example, families eligible for Aid to Families With Dependent Children (AFDC) automatically qualify for Medicaid. But eligibility rules for AFDC create such a high turnover rate that during 1973 one out of every four AFDC families lost the eligibility for AFDC and Medicaid services during the year. If families who became eligible after the first of the year had been counted, the number of discontinued cases would be much higher since a family receiving AFDC for less than a year is twice as likely to lose its eligibility as one which has been in the program for two years or more. The effects of this turnover on the continuity and quality of health services children receive are serious. One analysis showed that in Rochester, New York, the health care received by the poor was not improved even though payment through Medicaid was made available. Poor families continued to receive less care and to have a higher proportion of medical contacts related to serious illnesses rather than preventive care. The co-director of that study suggested that one important reason why the use of health services was unchanged was that the eligibility rules of Medicaid resulted in rapid turnover of patients in the program. Relationships were often one-time encounters, and that kind of discontinuity failed to facilitate good health care.

Other grounds for eligibility may be equally frustrating from a mother's point of view. For example, separating services for sick and healthy infants may seem reasonable on an organizational chart, but if a mother has been bringing her baby to a well-baby clinic for a year, seeing one doctor or nurse practitioner since the child was born, it is counter-intuitive and probably downright discouraging to ask her to go to a strange new clinic if her baby becomes ill.

Other programs may have age limitations. Care may be provided in one place for infants 0-1 year; in another for children 1 year to 5 years; 5 years to 18; and so on. Again, from an organizational point of view, this may make sense, particularly if the incidence of some diseases or need for services change with these age groupings. But picture explaining to a mother whose child has just become 1 year old that the doctor can no longer see her. Or picture a mother with three children—ages 1, 4 and 7—trying to coordinate visits to the doctor for all of them. Three separate facilities, appointments, doctors and sets of forms may be just enough to dissuade her from using health services when she should.

Some have said that limiting eligibility to children “at risk” or who are “high risk” children in terms of their incidence of illness would ensure that those most in need get health benefits. But as a Director of Pediatrics at a big city hospital commented at a Conference on Early Intervention with High-Risk Infants and Young Children,

... the concept of high risk is useful only as a step toward development of full service programs for children. In fact, those children whom we currently label “high risk” or “at risk” are the ones who most easily fall through the cracks, who are always going to be the last to be served. Until full service programs for all children are in place and operational, we never will adequately reach the “high-risk child” with the quality of care to which they are entitled.

Eligibility requirements should not be used to exclude people from health care services. Until


there is a program with universal eligibility, however, an interim step would be to define "need" in terms of neighborhoods rather than individuals. A number of programs over the last decade, including Children and Youth, Maternal and Infant Care, and neighborhood health center programs, have targeted their resources effectively relying primarily on geographic eligibility. This approach eliminates the need for individuals to show proof of eligibility to receive services. Such displays of poverty in the past have been embarrassing and stigmatizing, and have discouraged people from using the services. Eligibility by neighborhood could identify needy families through less intrusive means.

Second, a neighborhood orientation to health care services and facilities makes sense in terms of proximity and transportation. Other resources in a community, such as hospitals or specialty clinics, could be woven into a comprehensive system of care.

Third, thinking about an entire—but discrete—population that needs health care may be a better way to plan for, provide and evaluate health care than the current ad hoc manner in which patients come to the attention of doctors. It would mean that planners would extend their "concern not only to those who seek care (who come through the door) but to those who fail to enter the system."15

Comprehensive Benefits

Most insurance salesmen convince people to buy their product by describing what will happen to their savings, home, car or lives should a catastrophic illness strike. Faced with thousands of dollars of hospital bills, insurance seems necessary. In fact, private insurance for hospitalization alone is the most common form of health insurance purchased by Americans.

While the arguments for insurance against catastrophic illness sound reasonable at first blush, they are less convincing on closer inspection. First of all, insurance—be it public or private—against high medical costs alone adds fuel to inflationary fires. Second, by simply putting more money into the system operating in the wasteful way it does now, catastrophic insurance does not even achieve the limited objective of providing economic protection against the high costs of serious illness as costs continue to escalate. Third and most important, catastrophic insurance puts even greater emphasis on expensive, highly technological care for illness after it has become serious. "Long experience has taught us that anything less [than comprehensive benefits] will influence the flow of dollars in the delivery of care toward that which is insured and away from that which is uninsured," a noted health economist has written. "[C]atastrophic insurance coverage will tip the delivery system towards hospitalization and away from ambulatory care, towards treatment and away from prevention, towards medicine as defined in the insurance policy and away from medicine as defined by people's needs."16

Insurance only for catastrophic illnesses is even less supportable when planning for children's health services, which are largely devoted to check-ups, immunizations, treatment for childhood diseases, simple medication, routine dental care, and so on. If we are serious about wanting people to use health care services appropriately for prevention and follow-up as well as for acute illnesses or emergencies, then we must provide the financial incentives that will enable people to get the full range of care. And if we are serious about wanting to see more medical personnel devoting their talents to primary care, and more resources going into services which maintain health rather than support ever fancier technological interventions, then we should not be earmarking either public or private health dollars for costly illnesses alone.

No Charges to Patients for Service

Many insurance plans profess to cover medical expenses, but in fact, patients still must pay for a whole range of services. For example, in the following excerpt from Hearings before the Senate

Subcommittee on Health, an insured family tries to explain why it had to pay enormous hospital bills:

Senator Kennedy. “What do you mean? Your insurance didn’t apply?”

Mrs. DeWitt. “No. We found that newborns are completely uncovered for the first 15 days, on our policy. Well, this was kind of bad because it was a critical time for Debbie. She has had surgery twice, and we wound up with a bill of $5,000. Our hospital insurance has been kind enough to provide something like $700 for the whole thing, so it’s been pretty much all but useless.”

Senator Kennedy. “How long have you had the insurance policy?”

Mrs. DeWitt. “Well, before I was married I had it for 3 years, and then we have had it 7 years as a family policy, so I have been with Prudential for 10 years now.”

Senator Kennedy. “You have had a policy with Prudential for 10 years?”

Mrs. DeWitt. “Yes.”

Senator Kennedy. “And it excludes the first 15 days of life. I guess this is a pretty common practice, is it?”

Mrs. DeWitt. “Well, apparently so, because I know I thought that we were the only ones caught by it. But I have run into many parents up there in the last month that have the same difficulty.”

Senator Kennedy. “Why do you think the insurance companies do that?”

Mrs. DeWitt. “Well, I think it’s a pretty handy way to get the premiums and get out of the dangerous part of a new baby. This pretty well fixes them up, because if the baby is sick when it’s born, this is the bill that’s going to be big, and usually it’s over by 15 days, and the companies get off pretty well...”

Senator Kennedy. “Let me ask Dr. Butterfield: Are you affiliated with Children’s Hospital?”

Dr. Butterfield. “Yes; I’m the acting medical director.”

Senator Kennedy. “Is Mrs. DeWitt’s situation unusual? How frequently does this kind of situation occur?”

Dr. Butterfield. “I’m also the director of the newborn center into which this child came for help, and we find that the insurance policy exclusion of the newborn during the first 14 or 15 days of life is not uncommon. In fact, we did a study recently and found that about 30 percent of the employers’ policies had the 14-day exclusion. So the newborn, in fact, is a forgotten American in a sense.”

Most insurance plans have “deductibles,” forcing families to pay the first $50 or $100 before the insurance takes over. But think what a negative incentive deductibles are for families to develop good, preventive health habits. Ninety percent of children’s health care needs are taken care of outside of hospitals, involving routine procedures, tests and examinations. All the services a child would need in a year may not exceed the deductible, which would mean no help from the insurance plan. Yet to a poor family, $10 for a lab fee, $15 for a visit, or even $5 for one round of a prescription medicine may be enough of a strain on the family’s budget that it foregoes using health services. An insurance program geared toward encouraging people to use services appropriately would have no exceptions to the services covered and no deductibles—that is, “first dollar coverage” for all maternal and child health services.

Payment Methods

We sympathize with the pleas for simplifying and expediting the process of paying providers of care. But we believe that the solution to most reimbursement problems cannot be found solely in more efficient administration. The ways in which services are paid for can influence the kinds of services offered, their price and even the tone of interaction between professional and patient. For example, if a doctor is paid for each particular procedure he or she performs (called fee-for-service),...
the economic motives are strong to be quick, fitting in as many individuals into a day as possible; to charge the highest possible prices for each procedure; and to prefer "profitable" procedures (such as lab tests or surgery) to less profitable ones (such as health support services like health education or counseling). Prevailing patterns of paying for care usually combine fee-for-service with payment only for certain services, such as surgery or services rendered in the hospital. This pattern has resulted in unnecessary expenditures for unnecessary care, and may help to account for our relative surplus of specialists compared to primary care physicians.\textsuperscript{19}

Rather than paying a fee for selected services, an insurance plan can pay a clinic or doctor a fixed annual sum for providing all necessary care to a person throughout the year (called capitation rates). Annual payments to organizations providing a full range of services seem to provide excellent incentives for comprehensive care at reasonable and stable prices.

In such settings it is also easier to pay for the services of a variety of health personnel—nurse practitioners, child health associates, health aides, physicians' assistants, and so on. The decision as to which health professional does the work should be based on training, experience, ability and particular circumstances—and not solely on tradition. Yet many state Medicaid programs currently have a series of restrictions making it difficult or impossible for programs to get reimbursed when they use a variety of personnel in flexible ways. Any insurance plan should provide financial incentives to approved organized settings which employ and supervise a variety of health care personnel.

**Subsidies for Outreach and Support Services**

Throughout the rest of this book we will elaborate on the many services which, while they may not fit a narrow definition of medicine, are intimately related to access and quality of health care for children and families. They include providing transportation to doctors’ offices and clinics, outreach workers for dissemination of information about the availability of care, education to help people maintain health and make the best use of health services, and a host of others. (A checklist of necessary support services is in Appendix B of this book.)

These services cost money. And while they will, in the long run, save more money than it costs to furnish them, if there are no subsidies specifically earmarked to cover them, the chances of their being available are slim. They are central to making a health care system work well, especially for those who have been excluded or neglected in the past. Probably the best way to guarantee these ser-

\textsuperscript{19} One dramatic piece of evidence that economic imperatives (resulting from such factors as insurance programs which emphasize high-cost procedures) may be more important in influencing physician decisions than are patient needs comes from a study by the American College of Surgeons and the American Surgical Association. That study found that in four geographic areas, each containing approximately one million people, the rate of common surgical procedures varied directly with the number of surgeons practicing in the area. The area with the lowest number of surgeons per population had less than two-thirds the amount of surgery as a similar area with almost twice as many surgeons. (Data from Summary Report of the Manpower Subcommittee, American Surgical Association and the American College of Surgeons, "Study of Surgical Services for the United States," 1975.)
vices is to make available continuing subsidies for this specific purpose to approved organized providers serving low-income or high need areas.

Technical Assistance and Funds for New Providers

To reduce the existing maldistribution of doctors, and to end the reliance, especially by the poor, on either solitary doctors in private practice or enormous, impersonal, hospital-based bureaucracies, the creation of new health care settings must be encouraged. Primary health services provided under auspices which are already part of a community's life, and which emphasize easy physical and psychological access, are particularly worth promoting. We have seen health services for mothers and children provided in connection with community-run day care centers, for example, reach families that have been totally unreached by services offered through larger and more formal organizations. Starting up new programs—even relatively small ones—can be complicated and costly. It is therefore important to make available both technical assistance and start-up money to a variety of organizational entities which show promise of providing responsive primary care in areas which have been underserved.

The Cost of Care

What are the cost implications of a program that pays for comprehensive care without financial barriers? One of the most startling findings in surveying health care costs over the past decade is that it is precisely those programs which have alleviated problems of access and provided comprehensive services which have also dealt successfully with escalating costs. While Medicaid costs have risen, often steeply, the costs of programs providing services in comprehensive, organized settings have been lower. These costs have been relatively steady for adults. They have gone down for children.

—Annual per capita expenditures for Medicaid recipients in the District of Columbia averaged $424 between 1972 and 1974; expenditures for the one thousand recipients (representing the same patient mix) enrolled in a prepaid group practice were an average of 21 percent lower, and rose less than a third as much over the three-year period.20

—Average annual cost per child decreased for children enrolled in 59 Children and Youth projects in 28 states. These children received continuous health supervision, including routine health assessments, follow-up treatment, and preventive care in organized settings emphasizing community involvement. Between 1968 and 1972 hospitalization rates went down significantly among the 475,000 enrolled children, and the average annual cost per child dropped from $201 to $125.21

The costs of comprehensive child and maternal health services are low, predictable, and controllable. Lower costs are partly the result of the lesser need among children for expensive hospitalization and the use of a wide variety of professionals, not all of whom need to be M.D.'s. Most estimates indicate that annual spending on children from birth to age 19 for comprehensive care would be about two-fifths of the amount needed by the average adult.22

More predictable costs result from the fact that a relatively large proportion of expenses for children and expectant mothers are for preventive care, a smaller proportion for serious and unpredictable illness. Costs are relatively controllable because there is a "ceiling effect" on health expenditures for children when families have ready access to comprehensive services. Costs sometimes rise at first when services are introduced, but they soon level off and remain constant over long periods of time.23

The experience of the City Hospital in Cam-

20 Office of Health Maintenance Organizations, Bureau of Community Health Services, "Evaluation of the Rates of Utilization and the Costs of Medical Care for D.C. Medicaid Enrollees in a Prepaid Group Practice," p. 1. (Mimeograph.)


23 Child Health and the Community, p. 176.
bridge, Massachusetts, demonstrates these cost principles. Cambridge was able to convert its disjointed and isolated child health services, which were offered through well-child conferences, school health programs and the Department of Pediatrics at the Cambridge Hospital, into a program of comprehensive care available to all Cambridge children. The program established a series of neighborhood health centers in areas of high population density and need, and used pediatric nurse practitioners as primary caretakers. This entire effort was funded without any additional funds, simply by reallocating already existing funds. 24

Dollars Are Not Enough

While financing is essential, we know from nationwide experience that the removal of financial barriers alone does not guarantee receipt of or even access to necessary services. In 1970, an HEW Task Force predicted that despite the financing available through Medicaid, “only about one-third of the 30 to 40 million indigent and medically indigent who could potentially be covered [by Medicaid] will, in fact, receive services.” 25 According to another estimate, only about half of the 12 million children eligible for the Medicaid program were receiving services by 1972, six years after the program began. 26 Even among those receiving services, Blacks received fewer benefits than whites, 27 and rural children received one-fifteenth the benefits (in dollars paid out) of urban children. 28

A review of Medicaid experience in upstate New York found:

Little change in source, frequency and purpose of care. . . . Poor families were still more likely to receive less care. . . and to have a higher proportion of illness-related than preventive medical contacts. Instead of diminishing socioeconomic differentials as intended by the legislators, the better financing of health care of the poor led to a solidification of the old separate two systems. 29

It is absolutely plain that steps beyond financing will be needed to make a difference in the quality of care children and families receive. We hope that as people look at proposals for financing health services, be they public or private, federal, state or local, that funding recommendations will be integrally related to the substantive ones outlined in the following chapters. But even without any new methods of paying for care, local action is possible now, with our present resources, to remove the barriers keeping some children from receiving care and to improve its quality.

28 “A Decade of Policy Developments in Providing Health Care for Low-Income Families.”
Chapter 3

More Effective Entry Into the System

If you believe that when a child is sick or in pain, a family ought to have a place where it can get immediate medical help; if you believe that there are services such as immunizations the medical system ought to be providing to everyone; if you believe that some diseases or conditions are more effectively treated before they develop into something more serious, such as a strep infection before it becomes rheumatic fever; and you believe that an ounce of prevention is worth a pound of cure, such as early examinations and proper nutritional advice for expectant women—then you ought to be concerned about children’s and parents’ access to the health care system.

Access or entry into the system is the first step toward getting health care services. Yet many children never make it through the front door. According to a recent national study, 25 percent of children aged 1 to 5 and 38 percent of children aged 6 to 17 had not seen a physician during the past year.¹ In part, this is because medical services are not universally available. Doctors are not distributed equally around the country and there are areas—notably low-income, inner-city neighborhoods and isolated rural communities—where there simply is no doctor.

Yet even where services are available, they are often not used or used well. Immunizations, for example, can be obtained free through most public health departments. Yet in 1974, nearly five million American children, or about one out of every three children aged 1 to 4, were not fully immunized against polio.² Prenatal care, too, is available at no cost through public health departments and many public hospitals, but in 1971 over 30 percent of pregnant women received no prenatal care during their first trimester of pregnancy. The proportion who did not receive care is even higher for minority group women: nearly 47 percent of black women did not receive care in their first trimester.³ And studies have shown that many low-income families remain entirely outside the health care system. One study noted that poor families in a central city area used medical services only 15 percent of the time their symptoms indicated they needed care.⁴ And another showed that poor children were more in need of medical care when they finally did see a doctor, even though they saw doctors less often than affluent children.⁵

Why do families needing health care not avail

¹ Lu Ann Aday, Ronald Andersen, Odin Anderson, “Development of Indices of Access to Medical Care, First Year’s Report: April 1, 1973–April 1, 1974,” Center for Health Administration, University of Chicago, April 1974, p. 57.
⁴ Alpert, et al., cited in John A. Butler, “Improving the Delivery of Primary Medical Care Services for American Children,” September 1975. (Unpublished draft report prepared for the Harvard Child Health Project.)
⁵ Data from the Health Interview Survey, cited in “Improving the Delivery of Primary Medical Care Services for American Children.”
themselves of services? First, for many families the enormous difficulties they face simply to survive are so overwhelming that it is often impossible to focus on any but the most urgent health needs. In addition, some parents do not know what health services are available in their community and may not know what signs to look for in their own or their children’s health that indicate a trip to the doctor is necessary. For these families, and for those for whom consultation with a doctor is neither traditional nor commonplace, a special attempt must be made by the health system to reach out, educate and bring in individuals in need of services. Outreach will have only limited success, however, unless we deal with other problems deterring people from using the health system.

A second deterrent preventing some parents from seeking health services is the long distances they have to travel and the time and money involved in getting to the doctor or clinic. Incentives need to be devised to distribute medical services more equitably. In places where distance makes access impossible, transportation should be provided.

Inadequate telephone access is a third problem. Some parents are cut off from getting immediate advice on what to do: whether to watch for other symptoms, to cope with the problem at home, or to come in immediately for care.

A fourth reason excluding some from receiving medical care is that most clinics or doctors’ offices are open from 9 to 5 hours during which many families cannot easily get there. Flexible hours of service, some of which do not conflict with work or school hours, would help many families to get care without undue sacrifices.

One of the most discouraging factors keeping people from seeking appropriate care is the long waits they must endure for an appointment or in the waiting room when no provision for an appointment is made. The prospect of the wait can be totally demoralizing. Appointment schedules should be planned to minimize the waiting and provide care as soon as it is needed.

Sixth, some parents cannot come or bring in a child for treatment because they have other children at home for whom child care is unavailable or financially prohibitive. When this is a problem, ar-

rangements for child care should be planned—either at a clinic or by some other community service.

Seventh, many parents cannot make their problems understood because health care professionals do not always understand the language and culture of the population they serve. For many people, dealing with the health system has been so discouraging that they would rather avoid contact with it, except in dire emergencies. Sensitivity to the whole pattern of a family’s lifestyle may mean the difference between treatment regimens that are ignored or followed.

Finally, for a large number of families, the only contact they have with a doctor is in the emergency room of a hospital. The quality, timeliness and attention to follow-up with which this emergency care is provided may determine whether parents and children will understand and follow advice, thereby becoming more efficient users of the health system, or whether they will wait until another emergency strikes before they again seek care.

Some will say that these obstacles to seeking or receiving adequate medical care are unfortunate, but they are not the responsibility of the health care system to alter. After all, the health care system is not in the transportation or in the child care business, is it? If the health system is committed to providing services in the most effective and efficient manner possible, the answer must be, “Yes.” These support services cannot be seen as auxiliary to health care, expendable in an economic crunch. If their absence keeps huge numbers of children from receiving care, then they are as intimately related to health care as the production of enough penicillin or enough doctors.

The following pages present examples of programs providing services from outreach to child care. Improving access is neither impossible nor impractical, and it has a pronounced impact.

**Outreach**

There’s a girl Betty who is sick, real bad sick she is, and she should go to a doctor in Inez [Kentucky] and Daddy says she belongs in Lexington, where they have a big hospital, but she’s never seen a doctor, and the teacher tried twice to have the nurse come over, but each time Betty didn’t come to school that day, and the
nurse said she couldn't go up the hollow and she didn't know which house it was that Betty lived in, and the teacher didn’t know, either. Betty told me one day that the doctors get you sicker, and her daddy has her eating herbs and things, and she's been prayed over a lot, and she'll be getting better soon, she believes. My mother said it's a shame, and besides Betty being sick there's her whole family: they're all sick with one trouble or another, and they don't have money, and Daddy says they're in the worst shape it's possible to be. . . .

While there has been increasing publicity about services available for children and pregnant women, some parents still do not know or understand what benefits early health care would bring them and their children. This problem is compounded for parents with little education or those from other countries where health care is organized differently. But well-educated, affluent parents, too, can be unsure whether a child's behavior or symptoms are normal or whether they require professional attention. They are more likely, however, to have family doctors or pediatricians whom they can call and from whom they receive advice, assurance or an appointment.

Sometimes health care programs must take the initiative to find, educate and help bring parents and children in to receive care. Only recently have health programs, especially those serving rural and low-income urban populations, found that the use of trained outreach workers can solve many problems of access. The experience of the Columbia Point Neighborhood Health Center in Boston, Massachusetts, is a good case in point. Located in a low-income housing area, one of its objectives was to encourage residents who had previously not used health services to seek medical care regularly and promptly. Outreach workers who were members of health teams were a central part of the strategy. While success cannot be attributed to the outreach and education efforts alone, after two years of the program, a substantially higher proportion of residents felt that general, preventive measures were important and showed an "increasing disposition to bring to the attention of health center staff symptoms at an earlier stage when they were less painful or disruptive." The proportion of families who reported that they or someone in their family had postponed medical care in the preceding six months declined from 23 to 10 percent.

The American Medical Association, in its Statement on Health Outreach, cites the variety of ways in which outreach workers, particularly those who live in the area served by a health care program, can improve services. Outreach workers:

1. tend to enhance professional standards of practice since such personnel can free physicians, nurses, dentists, and other health professionals to better utilize the time for which they are trained and extend the scope of services to a larger patient population;
2. provide an additional source of manpower to meet community needs, especially in those areas where there is a shortage of professional health staff;
3. obviate many of the traditional problems of understanding and communication in getting health services to those in need;
4. assist the professional staff in becoming more responsive and accountable to the community served; and
5. provide meaningful jobs and, as a result, benefit the community economically and socially.

We believe there are several principles which make a qualitative difference in how effective outreach efforts are. First, the best form of outreach is through personal contacts. Second, outreach should be performed by trained workers who share or are sensitive to the background of the families to be served. Third, outreach should be conducted in a variety of places in the community. Fourth, other people in the community can supplement and rein-

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force the outreach efforts initiated by health workers. And finally, outreach services should link children and their parents to a system of care that provides continuing, follow-up services.

**Personal contact is the most effective form of outreach.** The federal program which provides Early and Periodic Screening, Diagnosis and Treatment (EPSDT) to Medicaid recipients under age 21 has used various kinds of outreach, and there is substantial evidence that written notices alone are generally ineffective forms of outreach. A study prepared by the Regional Health Services Research Institute in San Antonio, Texas, found that screening centers which used only a flyer to inform parents of the EPSDT program "were surprised when very few showed for screening." According to the study, effective outreach depends on personal contacts by community aides, caseworkers or public health nurses who explain the content and purpose of the program to the eligible family. The study concluded that "penetration and show rates increase markedly [when] personal contact is made with the families." The Government Accounting Office's recent study of the EPSDT program cites experience from Idaho, Alabama, Illinois and Washington as a basis for recommending that states be encouraged to "use contacts, in addition to the required annual written notification." In addition, a survey of 240 families eligible for Medicaid in four Mississippi counties demonstrated that personal contacts with family members by the public health nurse or other individuals made a clear and "positive impact on the recipients' health behavior." That study concludes that "more availability of service with a few additional education or 'outreach' efforts made by providers is likely to result in continued low utilization of services." The study recommends that "personalized contacts should be initiated to communicate program services and potential benefits to the client.

According to the Medical Services Administration, which administers the EPSDT program, "the average 'show rates' have been highest in those areas of the country where personal visits with the family (either at the time of eligibility determination, intake for welfare, or the caseworker or community aide home visit) were made which emphasized the content and purpose of the screening tests." The Family Health Program in New Orleans has found that personal contact promotes effective use of the program for families who have never used health services, as well as for those who have. The program has tried various kinds of outreach including contact by phone, mail and home visits by community residents who are trained and employed as Family Health Counselors. The Counselors visit families who have contacted the Program or who have been referred by other agencies. Each counselor covers a neighborhood regularly, so that initial and follow-up home visits to a family are made by the same worker. During a home visit with a new patient, the Family Health Counselor discusses the services offered at the clinic, the importance of preventive health care, and helps the family set up an appointment and arrange for transportation or whatever else is necessary to help the family get to the clinic. Of the families contacted who had never used the program, 25 percent of those contacted by phone or mail kept their appointments, while 43 percent of those visited by the Family Health Counselors kept

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10 Regional Health Services Research Institute, University of Texas Medical School at San Antonio, EPSDT Impact and Evaluation Study: Summary of Findings—Phase II (September 1973), pp. 2–3.
15 "A Study of Broken Appointments for Pediatric Screening Examinations," p. 56.
16 "A Study of Broken Appointments for Pediatric Screening Examinations," p. 57.
theirs. For those who were not new to the program, 45 percent of those reached by phone or mail actually came for their return visit, while 54 percent of those visited at home came.\(^\text{18}\)

Outreach works best when it is performed by trained workers who share or are sensitive to the background of the people being served. One study on preventive health behavior concluded that influences in matters of health come from informal social sources, people with whom the individual can identify.\(^\text{19}\) For example, in an immunization project in Oklahoma, specially trained neighborhood workers recruited nearly five times as many people as public health nurses working in the same area.\(^\text{20}\) In another instance in Idaho, different kinds of outreach in the EPSDT program were compared for their effectiveness. Of the four regions studied, the one with the highest rate of people availing themselves of screening services were reached through personal service aides, mothers who had been receiving assistance under the AFDC program and were trained and hired with 90 percent federal matching funds from the Work Incentive Program.\(^\text{21}\)

Programs for new mothers have also found that outreach workers are most effective when they


\(^{19}\) Lawrence Green, “Status Identity and Preventive Health Behavior,” Pacific Health Education Reports, #1, 1970.


\(^{21}\) *Improvements Needed to Speed Implementation of Medicaid’s Early and Periodic Screening Diagnosis and Treatment Program*, p. 20.
have the same background as the women to be reached. The Maternal and Infant Care Project in New York City recruited, hired and trained women from local neighborhoods to be family planning counselors, working out of 32 voluntary and municipal hospitals in the city. These counselors contacted new mothers in the hospital, discussed contraceptive methods and helped the new mothers set up clinic appointments. Almost all of the 70,000 women counseled during the first year said it was the first time they had had a chance to talk about birth control with anyone who could give them informed advice about contraceptive methods and services.

Outreach should be conducted in a variety of places in the community. Considerations about the best places to do outreach include:

—Do the children or parents to be reached congregate in a central place?

—Are they receptive to being visited in the places considered?

—How important is it that most of the population be reached immediately? Does the urgency justify the added cost of contacting people individually? For example, most women of child bearing age who desire family planning services could be reached within 5 to 7 years by offering them services only on the postpartum ward after they have delivered a child. But postpartum contacts miss many women who may want family planning services before their first pregnancy occurs, and individual contacts, while more expensive, may be necessary.

—Are there other institutions or professions who see large groups of children who could refer them to health services? For example, should some sort of outreach be done regularly by or in schools, probation departments or juvenile detention centers?

Below are examples of the range of places where outreach has been effective.

(a) Outreach to New Mothers in the Hospital. New mothers while still in the hospital waiting to be discharged have been especially receptive to information about postpartum care for themselves and early care for their infants. Because nearly all women deliver in hospitals, postpartum counseling reaches most new mothers and infants, many of whom would not otherwise receive health care. Generally, a trained nurse, health aide or counselor visits each woman at her bedside or works with a small group of women about to be discharged. She discusses infant care and development as well as the importance of using health services for herself and her child. She helps the new mother make a convenient appointment for well-baby care and often gives her a reminder card or sends a postcard home with the date and time of the next appointment. A number of programs have reported that women are much more likely to return for clinic appointments and to avail themselves of family planning when health education is offered at the hospital. All this is obtained at a very low cost: based on pay scales of the late 1960's, approximately $1.65 per patient.

(b) Outreach in the Home. Outreach in the home can be an effective way to reach expectant mothers and children and also an opportunity for a health care worker to meet other family members, see the home and thereby help identify health needs which might otherwise be missed. In the Barrio Comprehensive Child Health Care Center in San Antonio, Texas, 85 percent of the clinic users heard of the clinic from community health aides, who visit homes in target neighborhoods and homes referred by community agencies. The aide explains the clinic services, schedules appointments if desired, takes medical histories and is prepared to make referrals for other problems which arise. She can demonstrate how to make formula and can provide a variety of advocacy services. According to the Project Director, although home visits are expen-

22 Telephone interview with Dr. Edwin Daily, Director, Maternal and Infant Care Project, New York City, October 1974.

23 Promoting the Health of Mothers and Children, Fiscal Year 1972, p. 79.


sive ($8.15 per person in 1973), they are used because the home is the only place to reach most of the women with young children. The program has five community health aides, each trained for approximately six weeks by the Center. Whenever possible, the aide schedules a family's clinic appointment for a time when the aide, too, will be in the clinic. According to the Director, the effectiveness of the outreach program is a function of the health aides themselves; they are highly motivated, sincerely want to help their clients and thus make the program work.

A program in Chapel Hill, North Carolina, has combined hospital and home outreach in a most successful way. Two health workers from the community make initial contact with mothers-to-be when they come to the prenatal clinic at the North Carolina Memorial Hospital Combined Clinic Program. The same worker visits the mother in the hospital after she has delivered her baby and spends some time discussing how to care for the new child. At that time the worker makes an appointment to visit the family at home, where she gives further instruction in child care and also makes an appointment for the mother and child to come in for well-baby care. The worker helps solve transportation and other problems so the mothers can come. Using both hospital and home outreach, 99 percent of the women kept their appointments at the clinic, whereas during the three years prior to these outreach efforts, the rate of kept appointments was 55 percent.

(c) Outreach in Other Settings. Places where community residents congregate can be sites for effective outreach. For example, the Guilford County Family Planning Program in Greensboro, North Carolina, hired a male outreach worker to give out family planning information and to counsel men in their homes as well as in poolrooms, bars, barber shops, prisons and cafes. In the same way, outreach workers can talk with community residents in laundromats, grocery stores, hair salons, day care centers and churches. The workers themselves can help decide where in the community their time is spent most productively.

Outreach can be supplemented and reinforced by training non-health personnel in the community. Many communities have limited health outreach because health care professionals are in short supply. But many people outside the health program could refer families to health services. Teachers, clergy, pharmacists and other well-accepted community members can be trained to recognize health problems and refer families to the proper place for health care.

In Alabama, in a cooperative arrangement among the state Extension Division, the state Health Department, and the University of Alabama's School of Community and Allied Health, county Extension Workers have added a "health extension" to their traditional agricultural extension jobs. The Extension Workers have developed channels for disseminating information. In most counties in Alabama, they write regular newspaper columns and do radio spots. Extension Workers have helped implement the new state law requiring immunization of children beginning school and have worked with parent groups, service agencies, churches and other groups to publicize the need for immunizations and to direct children to places giving vaccinations. HELP, the Health Extension and Learning Project, is training county Extension Workers and home economists to educate residents about diabetes and hypertension, and to refer people for care. The program will soon include an emphasis on cancer detection and prenatal care. The workers are pleased to learn new skills and, so far, local physicians are cooperating enthusiastically.

Outreach services should link people to a system of care which provides continuing follow-up ser-

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27 Telephone interview with Ora Prattes, Project Director, Barrio Comprehensive Child Health Care Center, San Antonio, Texas, November 1974.
28 Telephone interview with Jerry Hulka, M.D., Organizer, North Carolina Memorial Hospital Combined Clinic Program, Chapel Hill, North Carolina, December 23, 1975.
29 Telephone interview with Brian Greene, Director, Guilford County Family Planning Program, Greensboro, North Carolina, November 1974.
30 Telephone interview with Susan Massey, Director, Project Help, Birmingham, Alabama, October 1974.
Outreach can use campaigns focused around a particular service—such as immunizations, screening or the provision of nutrition supplements—to attract families who have previously been outside the health care system and introduce them to comprehensive care. For example, the federal Women and Infant Care Program (WIC) makes available vouchers for food supplements to high-risk mothers and infants. Vouchers can be obtained at health centers and, once there, the women can be offered prenatal examinations, family planning services and health care for other children in the family. Women can make appointments so that they can use these services at the same time they come to pick up their coupons.

Such a program is found in Lowndes County, Alabama. The Lowndes County Health Services Association, a community-based group, oversees a community clinic, which is the only public provider of health services in the county except for the Health Department, which offers only immunizations and family planning services. In 1974, the clinic received a WIC grant allowing it to do medical examinations for children and expectant mothers and to give out vouchers for supplemental foods to needy families. These services were announced to County residents by board members of the Health Services Association, religious leaders, staff of local health and welfare agencies and spots on television.

On the first day of the program, 250 women and children came to the clinic. They received vouchers for food and a medical evaluation. For prenatal care, immunizations and other health services, they were given the option of going to a physician of their choice, going to the Health Department (only several blocks away), or becoming patients of the clinic. Whichever they chose, their return to the clinic each month to pick up their WIC food vouchers allowed the clinic’s staff to help the mothers make sure they and their children got the care they needed. An estimated 60 to 70 percent of the young children and pregnant women who came to the clinic were not under any health supervision before they entered the WIC program.31

Too often, the definition of outreach has been limited to attracting people to use a health service for the first time. Experience with a variety of health programs has shown that helping a person get to a service once does not assure that needed care is received or that the habit of seeking appropriate health care is firmly established. Follow-up services must accompany outreach.

In the EPSDT program, effective follow-up is a prerequisite for success. In many of the states’ programs responsibility for follow-up was not explicitly assigned and rarely taken. In a sample survey conducted in 1973, fewer than 50 percent of the children who needed follow-up care actually received it. According to that survey, states which made clear provisions for follow-up services had the highest rates of children who actually received treatment. HEW found that children were most likely to get treatment when families were given a clear explanation of what was wrong and where to take the child, and when the program assigned responsibility for follow-up to a specific staff person.32

**Location of Services and Transportation**

An old man reminisced: "We did what we could, my wife and I. We brought seven children into the world. We lost three of them as little children. My daughter tells me we needn’t have lost them if there’d been a doctor to see them, but I say to her: that word ‘if’ is the longest word in the language, and the hardest to forget."33

For many people, the biggest problem in getting health care is simply that a doctor is unavailable. This can occur because (1) in some areas there is no physician available at all; (2) in others, care is available but so inconveniently located that parents are discouraged from using it; and (3) there is no transportation to the place where care is given.

31 Telephone interview with Steve Wilson, Director, Women and Infant Care Project, Hayneville, Alabama, January 13, 1975.
32 “Study of Early and Periodic Screening, Diagnosis and Treatment Programs,” p. 1.
**TABLE 1**
Number of Primary Physicians* and Ratio per 100,000 Population by Primary Physician Category for the United States
1931, 1963, 1971

<table>
<thead>
<tr>
<th>Physician Category</th>
<th>1931 (a)</th>
<th>1963</th>
<th>1971</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Ratio (b)</td>
<td>Number</td>
</tr>
<tr>
<td>General Practitioner</td>
<td>112,116</td>
<td>90</td>
<td>68,091</td>
</tr>
<tr>
<td>General Internist</td>
<td>3,567</td>
<td>3</td>
<td>21,144</td>
</tr>
<tr>
<td>General Pediatrician</td>
<td>1,396</td>
<td>1</td>
<td>9,255</td>
</tr>
<tr>
<td>Total</td>
<td>117,079</td>
<td>94</td>
<td>98,490</td>
</tr>
</tbody>
</table>

Population (000)
124,040 186,493 204,254

*Nonfederal, office-based physicians
(a) 1931 physician figures include only physicians in private practice. For this year, part-time specialists are added in with general practitioners, and the numbers of internists and pediatricians are estimated from the total number of limited specialists in a specialty.
(b) Number of physicians per 100,000 population
(c) Population per physician

Physician figures for 1963 and 1971 from American Medical Association, Distribution of Physicians, 1963 and 1971. Part of the decline visible in 1971 is due to a 1968 revision of the series which changed the definition of active physicians.

**No Care Available**

The total lack of needed services in some areas is the result both of a shortage of certain kinds of manpower, particularly of professionals providing primary care, and the maldistribution of that manpower. While the overall doctor-population ratio in the United States has been improving, more and more doctors become specialists, seeing relatively few patients and working in hospitals in large population centers. The proportion of doctors giving primary care (general practitioners, pediatricians, obstetricians and internists) in 1971 was less than half of what it was forty years earlier. And while there recently has been a renaissance of interest in family medicine, particularly among young medical students, need still outstrips availability.

The shortage problem is compounded by the fact that, as the report by the Southern Regional Council points out, "those areas with the greatest needs are the areas with the fewest resources." In 1970, the fifteen counties with the highest per capita incomes had seven times as many practicing doctors per capita as did the fifteen counties with the lowest per capita incomes. In 1971, one-third of all pediatricians in the country were in three

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34 Cited in William J. Bicknell, Diana C. Walsh, Marsha M. Tanner, "Substantive or Decorative? Primary Care Physicians’ Assistants in the United States," Boston, Massachusetts Department of Public Health, p. 15. (Mimeograph.)

35 "Return of the GP," Newsweek, 12 January 1976, p. 64.)


states: New York, Pennsylvania and Massachusetts.38

By and large, doctors choose to practice medicine where they and their families would like to live and where they can feel a certain degree of collegiality with their peers. This is not always where they are most needed. The American Medical Association reports that recent medical school graduates cited the following factors as important in determining where they set up practice: climate or geographic features, opportunity for regular contact with other physicians, availability of clinical support facilities and personnel, preference for urban living, opportunity to join a partnership or group practice, recreational or sports facilities and opportunity for regular contact with a medical school or medical center.39 While it is understandable that, given the choice, most doctors prefer affluent urban or suburban areas or the larger towns in rural sections of the country, this means that the poor—living in small, isolated rural settings or the undesirable sections of inner-cities—often have no doctor available to them. A study of 187 isolated towns in Minnesota, the Dakotas and Montana found that 90 percent of these towns had doctors in 1921. Gradually and steadily, they all lost them. In 1965, none of them had doctors.40

What does the absence of medical services mean? A considerable amount of hardship, death and disease that could have been prevented or alleviated.

There are exactly two (white) physicians in McCormick County, South Carolina. When they are called for help, they ask for a fee, and this is known by the mothers and fathers who are farmhands, occasional harvesters, or out of work altogether. . . . "In McCormick County we learned to do without doctors because there just wasn’t none around."41

—The midwives in one Arkansas county reported that their major problem was getting doctors to come when complications occur. One midwife told the following story: "Last year I had trouble getting a doctor, and the mother died. It was at night. I tried to get a doctor, but two of the three doctors was out, and the third wouldn’t come. The landlord tried to get him to come but he still wouldn’t. So the landlord and I tried to take her to a local hospital (a 15-20 mile trip). She died on the way—she bled too much."42

—"What particularly saddened and appalled us were the developmental anomalies and diseases that we know were easily correctible, but now are hopelessly consolidated: bones, eyes, vital organs that should long ago have been evaluated and treated are now beyond medical assistance, if it were available. We saw children clearly stunted, smaller than their age would indicate and drowsy or irritable. . . ."43

There are several ways to overcome the scarcity and uneven distribution of physicians who provide primary care for children and families. Some legislators and medical educators are trying to set up incentives for more medical students to choose family medicine and for the medical community to give that specialty as much status and prestige as it has given to others. Selection of students for medical school based on their interest in family medicine and on their commitment to work in underserved areas may also help. So would support by federal and state governments for the new health programs in areas that need them most. Even after all this is done, government and professional organizations may have to intervene more directly to place doctors in shortage areas. While such methods would reduce the degree of free choice a physician currently has regarding the location of work, doctors have been almost unique among professionals in this regard. A noted economist made this analogy: If a violinist


42 Heal Yourself, p. 5.

43 Southern Regional Council, Children in Mississippi (Atlanta, 1967).
lived in Boston, but the Boston Symphony Orchestra had no openings, he would have to choose between living in Boston but not earning his living as a concert violinist, or being a violinist but moving, say, to Minneapolis. We usually do not consider this a restriction of freedom but merely economic constraints of labor supply and demand. Doctors have not been subject to these constraints (in large part because they create the demand for their services), and it may be time for external controls and incentives to be applied so that population needs are better taken into account.44

There are other ways to increase the number of health professionals available to families, including using a wide variety of health care personnel who may be more able and willing than doctors to go into poor or rural communities. Such people can work with the back-up support of a physician or hospital and greatly increase the number of families served. We will discuss these possibilities in the section of the next chapter on the use of a range of health care personnel.

But these are changes that will probably require the intervention of the federal government, as well as time for training and implementation to take effect. There are, however, significant ways in which local community efforts can affect the availability of health care to children and families. A medically underserved area can make itself attractive to health professionals by creating organized settings which (a) offer combined practice with other professionals and expanded professional contacts and activities beyond the immediate area, and (b) provide support services which one professional on his or her own could not muster.

Several studies have pointed up the attractiveness of group practice to physicians, especially in underserved areas. A study of physicians leaving primary care practice in Virginia found that 90 percent of the doctors felt that the formation of a group practice would have enhanced the attractiveness of the situation.45 Another study which polled primary care physicians who work in six multispecialty group practices in towns of 12,000 or less and distant from metropolitan areas found that one of the reasons they decided to work where they did was because of the immediate access to other doctors for consultation and referrals in a group practice. In answer to the question, “Which form of practice would you consider if circumstances were such that you had to leave your present organization?” the doctors strongly favored multispecialty group practices over solo or two-physician practices.46

Developing group practices not only attracts doctors and other health professionals to underserved areas but also creates an environment which is more likely to result in quality care. A doctor or other health professional with broad professional contacts available has a way of keeping abreast of medical developments and has easier access to other professionals for back-up and for consultation.

There are programs all over the country trying to develop multispecialty group practices, opportunities for continuing education and opportunities for staff to work in varied settings. Franklin County, Maine, for example, is an attractive place to live, with fields and woods, lakes and streams. But many of the people are poor—almost one-quarter of the 30,000 inhabitants have incomes below the poverty level, and more than half the families have incomes of less than $5,000. There was no health care within a reasonable distance, and no way to get to what care there was, before Rural Health Associates was formed. Some people traveled as much as 100 miles to get care. The doctor-patient ratio was 1:2,000 and most of the 21 doctors in the County were middle-aged or older, semi-retired, and in some cases, unwilling to take people who could not pay. In 1969, after a local Community Action Program (CAP) poll indicated the dire need for medical care, a planning board of

44 A Right to Health: The Problem of Access to Primary Care.

CAP people, doctors and consumers was established to see what could be done. Almost every town in the county was represented throughout the planning. In 1971, with start-up grants from the Office of Economic Opportunity and other agencies, Rural Health Associates, a salaried, group practice, was founded. It is supported by fee-for-service arrangement for those who can pay and a prepayment plan for the poor which is underwritten by the federal government. It is staffed by six family physicians, two internists, a general surgeon, a pediatrician, two dentists, two ex-corpsman trained as Medexes, three nurses trained as physicians' assistants, seven family health workers, a social worker, a health educator and other supporting personnel. The central facility is in Farmington at a former nurses’ residence next to the Franklin County Memorial Hospital. Three prefab satellite clinics have been set up in small communities to the north and south. One of the doctors who was in solo practice in Farmington for twenty years before joining the group made these comments:

Though I’m nostalgic for my old practice, I wouldn’t go back. The wives of younger physicians won’t stand it to see their husbands burn themselves out trying, solo, to be available whenever patients need them. Some of us tried for ten years to get new doctors to move here, but as soon as the group was set up, there was no problem.47

One new doctor who came to Maine reports:

There are a lot of us . . . who want to live in a place like Maine. We want the country, the clean air, and the mountains for ourselves and our families.

To enjoy it, we are willing to give up many of the expectations other doctors may have about their lifestyles. But we aren’t willing to exhaust ourselves twenty-four hours a day seven days a week being the only doctor within twenty-five or fifty miles. That way we can’t practice the good medicine we know, and we can’t find time to enjoy our families or the place we chose to live.

Working together, the way we do here, in this kind of a group . . . it’s really great. We have each other’s company, we educate each other, and between us, we are able to give good patient care without working alone, around the clock.48

The isolation of rural practice is dealt with by formal and informal continuing education programs and chances to work in other settings. Everyone at Rural Health Associates who deals with patients’ medical problems is required to take two weeks continuing education a year. In addition, a monthly teaching session is conducted by an out-of-area specialist, and all area physicians and other health professionals are invited to participate. Additional in-house attempts to upgrade knowledge and care include separate sessions every two weeks in which physicians, Medexes and nurse as-

47 “In Family Practice, As Maine Goes . . .,” Hospital Practice (October 1973), p. 175.
assistants go over charts and the prescriptions each doctor has written. The group also has a student preceptorship program in which medical students come for two months during the summer to work with a physician or a dentist in the group and attend a weekly seminar on problems in rural health care delivery. The stimulation of having students around and the chance to teach is viewed as another form of continuing education for the physicians. One of the doctors also spends an hour or so a day at the school health service of the Farmington branch of the University of Maine. Another doctor has helped to set up a coronary care unit at the hospital. In short, the organization has created many outlets for the professionals’ skills which have given them diverse experiences despite the isolation of Farmington.49

Another approach to get health services to small, rural communities is the Health Systems Research Institute (HSRI), a non-profit organization which designs and runs medical programs. Started in 1973 as a rural health care project of the Intermountain Regional Medical Program, it now has programs in Arizona, Montana, Nevada, Washington and Wyoming. HSRI contracts with rural counties and communities to provide medical personnel and to organize a system of health care, including such things as specialists to come into the area and an emergency back-up system covering for doctors when they go on vacation or to medical education courses. HSRI also takes care of bill collection and bookkeeping. The county or community pays HSRI a set fee for providing health services and personnel, and the payments from patients, collected by HSRI, are returned to the community.

The first program was started in 1974 in Battle Mountain, a town of 4,000 in Landers County, Nevada. A full-time doctor came to practice, the first doctor the county had had for over a year. Specialists came in from Reno and Salt Lake City regularly. A hot-line and ambulance airplane were made available for emergencies. After eight months of existence, the program paid for itself.50

**Care Inconveniently Located**

The specific location of services has a crucial effect on their use. People use services within a geographic circle, the outer perimeter of which is determined by distance, time and energy needed to get to the services. Within the circle, use is not primarily related to distance but to more personal factors such as familiarity with the facility, language spoken, providers’ attitudes and feelings of acceptance.51 But studies show that as distance increases, use of services, particularly preventive services, tends to decrease.52

Very often decisions about the location of services have reflected the needs of the providers and administrators of services and have neglected to take into account the needs of the families who use the services.

—Until recently, in Portland, Oregon, many private doctors refused to treat Medicaid patients. As a result, the city’s poor had to get their medical care at the county hospital on “Pill Hill,” a base for three hospitals, on a high hill in southwest Portland. For some, Pill Hill was as far as 30 miles, several bus rides and hours away. When asked why the county did not establish decentralized clinics, the dean of the University of Oregon Medical School replied that it would be “inconvenient for medical students” to have to travel away from Pill Hill.53

—In New York City, the new $94 million, 412-bed North Central Hospital was built to replace the old Morrisania Hospital, which was a major source of primary care for poor people living in the South Bronx. “But instead of being put near the old Morrisania, which was conveniently situated in the midst of the population it served,

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49 Telephone interview with Donna Whitemore, Executive Secretary, Rural Health Associates, Farmington, Maine, February 7, 1975: “In Family Practice, As Maine Goes . . . ,” p. 175 ff; and “A New Kind of Family Doctor(s) Comes to Maine.”


52 Charles Brown, “Associations Among Distance, Patient Satisfaction and Utilization of Two Types of Inner-City Clinics,” Medical Care, Vol. XI (September-October 1973).

53 Heal Yourself, p. 4.
North Central Bronx was put right next to Montefiore so it could be convenient to the doctors who staff the municipal hospital on an affiliation agreement. Dr. Martin Cherkasky, the president of the 810-bed Montefiore Hospital . . . conceded that the new North Central Bronx was 'clearly not in an area of primary need for the poor,' which are the municipal system's main clients. But Dr. Cherkasky said the 'cheek-by-jaw arrangement of the new buildings is much more efficient as far as the medical staff is concerned.' 54

Of course the time of busy professionals should be considered. No one wants physicians to spend half their time traveling. But whenever possible, primary care services should be located in the midst of the target population, so that the barriers of distance are minimized. This can be done by (a) taking the needs of the target population into account in the original decision about where to build a facility, or (b) decentralizing the services of an existing program. Often the latter can best be done by (c) adopting a regional approach to the allocation of health resources.

In Watts in south central Los Angeles, it used to be common for people to travel two hours by public transportation to get to the County Hospital. There were some private doctors whose offices were a little closer, but most people couldn't afford to go to them. The public health clinic in the area provided only very limited primary care. The riots of 1965 brought this situation to public awareness. The McCone Commission, charged with delineating the circumstances and causes of the Watts riots, called for the development of a major health facility to correct the serious deficiencies in health services for south central Los Angeles' 400,000 residents. The response was the development of a new County Hospital, the Charles R. Drew Postgraduate Medical School, and the Watts Health Foundation, a comprehensive neighborhood health center, all located right in Watts. The school is responsible for directing the educational, patient care and research activities in the new Martin Luther King Hospital. Each department is affiliated with the medical school of either the University of Southern California or UCLA. A multiracial faculty has been recruited whose mission is to serve "the broad health needs of people in the surrounding community, at their point of origin in the streets, homes, schools, industries and other institutions of the community, as well as in the clinic and in the hospital." 55

Many other programs have developed a network where satellite facilities offer primary care in outlying areas and a central facility offers back-up services. For example, in Denver, Colorado, the Neighborhood Health Program was developed by the City Department of Health and Hospitals to provide comprehensive, continuous health care for more than 100,000 low-income people. Initial planning emphasized the selection of sites that would be conveniently placed in different neighborhoods. There are two neighborhood health centers, one on the east and one on the west side of Denver, each offering a full range of outpatient health services (adult and pediatric, maternity and family planning, dental, mental health, social services, nutrition, health education, environmental health, x-ray, laboratory and pharmacy). These centers are open from 8:00 a.m. to 9:00 p.m. Monday through Friday and from 9:00 a.m. to 5:00 p.m. on Saturday. Eight smaller health stations are located throughout the city's low-income areas and are open from 9:00 a.m. to 6:00 p.m. weekdays. They vary in size and staff depending on the needs of the area. All except one of the stations offer pediatric and adult medicine, maternity care and family planning services, social services and nutrition counseling. The one station located at the Children's Hospital is limited to pediatrics. If more specialized services are needed, the patient is referred to one of the neighborhood health centers or Denver General Hospital. Families are given appointments to see their own doctor at their primary care facility, though each family has the option of using any of the facilities interchangeably. If someone needs to be hospitalized, the patient's regular doctor follows the patient's progress in the hospital. A transportation system provides for


55 Telephone interview with Robert Schlegel, Director of Clinical Services, Charles R. Drew Postgraduate Medical School, Los Angeles, California, January 1975.
families who have no way of getting to and from one of the health facilities, with a two-way radio dispatch system among all sixteen health program vehicles in operation.\textsuperscript{56}

In New Orleans, family planning services are being delivered by the State Department of Health through a central clinic located in the downtown area close to public transportation, two medical schools and the community hospital. Women who live or work in the central city or who want evening services come to this clinic. Four satellite clinics in surrounding neighborhoods offer the same services to women who find it more convenient not to come into the center of town. These satellites are also easily reached by public transportation.\textsuperscript{57}

At the Children and Youth Project sponsored by the University of Texas Health Science Center in Dallas, a unique arrangement has been developed to put health services where the children are. Neighborhood clinics have been set up on or near the campuses of public schools. The Project leases space or buildings from the school system, sometimes adjacent to the school, and sometimes, as in the case of an adolescent clinic, in the school building. Each clinic is staffed by a team of health professionals including a pediatrician, two nurses, a social worker, clinical psychologist, dental hygienist and a nurse aide.

The association of the Project with schools and the parent-teacher association helps it register and supervise the health of the children it serves. Schools assist in registering pupils in the Project by (1) transferring children who become acutely ill during school hours to the clinics; (2) referring to the Project's health teams those children who have medical, social, nutritional, emotional or dental problems; (3) registering children in the Project at the same time physical examinations are done on incoming kindergarten pupils.

Statistics on the rates of hospitalization and absenteeism from school of Project registrants has shown that the Project is having a significant impact. Among registrants (infants to youths age 18), the hospitalization rate was 20 per 1,000 during fiscal year 1971-72. In contrast, the rate for non-registrants in the same age group living in the same area was 74 per 1,000 for 1971-72. The average health care cost of enrolled children is about $102 per year, including hospitalization, dental work, doctor bills, medication and specialty referrals.\textsuperscript{58}

Although it is sometimes difficult to link existing health services, each with its own vested interests, into a single system, it is evident that for many rural areas, pooling resources to develop regional health care systems is the only way that many small communities will have access to health care services. With a larger population base and resources from a broader area, cooperative planning and development can make services available to families in areas too sparsely settled or too poor to start or sustain them on their own.

Madison County, North Carolina, for example, is a poor area, with the average income between $3,000 and $4,000 a year. It has not been able to attract doctors or to support very many health services. Four townships in the County, however, got together and established three outpatient medical clinics. They function jointly, and all offer the same services, except that the central one also has administrative offices, the dental clinic and x-ray facilities which serve all of the towns. Each clinic is staffed by a full-time nurse practitioner and two community people trained as clinical assistants to do laboratory work and to be receptionists. A doctor splits his time among the three clinics. The clinics also run their own pharmacies since there are none nearby, with the pharmacist shared by the three clinics. Transportation services are provided by two vans which take people to and from the clinics and twice a week go to Asheville, the

\textsuperscript{56} Telephone interview with Peg Harder, Project Secretary, Neighborhood Health Program, Denver Department of Health and Hospitals, Denver, Colorado, October 21, 1974.

\textsuperscript{57} Telephone interview with Benjamin Lewis, Director, Family Planning Services, Louisiana State Department of Health, November 6, 1974.

\textsuperscript{58} Telephone interview with Thomas Moore, Project Director, Children and Youth Project, University of Texas Health Science Center, Dallas, Texas, November 6, 1974; telephone interview with Aileen Edgington, Chief, Social Work Services, Children and Youth Project, The University of Texas Health Science Center, Dallas, Texas, January 20, 1976; "Producing Healthy Children is Dallas School Clinic Aim," \textit{Pediatric News} (March 1974).
nearest major city, where there are two community hospitals, a specialty hospital and a mental health center, with a total of 200 doctors who provide a full range of specialty care.

The University of North Carolina has helped the clinics by recruiting a doctor, a dentist, nurse practitioners and a pharmacist; training the nurse practitioners who staff the clinics; and providing professionals when the regular ones are on vacation. Such cooperative efforts among towns, the medical complex in Asheville and the University make available to these four townships health care of a kind and quality which they could not develop individually. 59

Where it is impossible to offer comprehensive primary health services in a conveniently located facility, other approaches may have to be used, including the placement of individual practitioners, usually non-physician professional personnel, in outlying areas, or the use of mobile clinics. While the care being given in the following examples is not comprehensive, it at least overcomes the barrier of distance and is a chance for entry to a more complete range of health services.

In the strip-mined hills of eastern Tennessee and Kentucky, seven communities—Frakes, Kentucky, and Clairfield, White Oak, Stinking Creek, Norma, Petros, and Stony Fork, Tennessee—have established small, community-owned, rural health clinics. Nurse practitioners and physicians’ assistants see all the patients and perform all physicals, Pap tests and other routine procedures, referring patients on to the doctors who ride circuit among the clinics on a regular basis. One of the practitioners’ primary functions is to coordinate the care that is available from many different sources in the surrounding area and to talk to parents about their concerns, medical problems, medical procedures, medication, therapy or preventive measures. These coordinating and interpreting functions are stressed in the training of nurse practitioners and physicians’ assistants. In the clinics, they are assisted by aides (family health workers, patient assistants, lab technicians) and sometimes by a pharmacist, who circulates among the clinics. Each clinic is visited by a doctor at least one full day a week. In the interim, the nurse practitioner works under pre-arranged standard protocols and talks with the doctors by telephone. Currently there are two doctors serving these clinics: one is a National Health Service Corps doctor and the other is an employee of four clinics which have joined together in a cooperative organization, the United Health Services of Kentucky and Tennessee. 60

Although Rhode Island is a small state, there are people in Washington County, the rural, southernmost part of the state, who are unable to bring their children some 30 or 40 miles to Providence for health care. Many people are too poor to have their own cars and there is a lack of public transportation. The county public health nursing association runs well-child clinic sessions several days a week, but some families cannot even get to them, and the problem of getting more extensive health care, except in emergencies, persists.

To cope with the problem of health care for the children in this area, the Child Development Center at the Rhode Island Hospital got a Maternal and Child Health grant from the Rhode Island State Department of Health to purchase and operate a 27-foot mobile home equipped as a clinic. Three times a week, this van goes into areas with a scarcity of health care services and provides well-child care, including routine physical examinations, immunizations and health education. Local visiting nurses from the county public health association and school nurses identify the children who need care most. Visiting nurses are also in charge of referrals to other health and social agencies and follow-up.

The van is staffed by a pediatrician and a nurse from the Child Development Center. The clinic usually begins at 10:00 a.m. and the families are notified of appointments in advance by mail. The van returns to each site about once a month. If a child is in the hospital in Providence, the nurse in


60 East Tennessee Research Corporation, Jacksonboro, Tennessee, “Community Health Services in East Tennessee, East Kentucky and Southwest Virginia,” Background paper, December 1974. (Mimeograph)
charge of the van also visits the child in the hospital to ease the trauma of hospitalization, since many parents are not able to make the trip to Providence. After being discharged from the hospital, the child’s health is monitored by the staff of the mobile clinic again.\textsuperscript{61}

\section*{Lack of Transportation}

Sometimes doctors and facilities are theoretically available, but for those who must rely on public transportation, the trouble and cost of getting to care become severe barriers. This is true in many rural areas:

“On the map, Martin County in Kentucky looks a short distance from Logan County, West Virginia, but ordinary maps tell little about high, near impassable hills and mountains and valleys that run north to south rather than east to west—and therefore form a barrier to someone moving across rather than up and down the Appalachians. ... there are five of us brothers. ... There were nine to start. We had one sister and she died of pneumonia when she was four. ... my brother Peter any my brother Ronald, they died like our sister; they took ill and all of a sudden they were gone. No sir, there’s no doctor we could get them to. We didn’t have the money and we didn’t have a car, and we were up the hollow, and if you’re up the hollow and it’s in the winter—well, sir, you’re just up there, and that’s that, it sure is! Even in summer, there’s not too many cars, even now, that can get up. ...” \textsuperscript{62}

\textsuperscript{61} Telephone interview with Elizabeth Tighe, Planning and Program Specialist, Division of Child Health, Rhode Island State Department of Health, November 7, 1974; Delores Amistrano, “A Clinic on Wheels,” \textit{Supervisor Nurse} (March 1973).

But the cost, inconvenience or absence of public transportation can be just as great a barrier in the middle of cities. As one urban dweller put it:

"Sometimes it's just impossible for me to get to the hospital for medicine since I can't even pay for the bus." When she does have bus fare, the visit to the hospital for the necessary treatment is likely to take most of the day. The only bus routes which serve the Second Ward run to and from the downtown area. . . . Thus, every time she leaves to visit the hospital, she faces the possibility of an hour and 40-minute trip each way, in addition to the usually long wait for treatment at the hospital itself. 63

In rural areas there is very little public transportation, many people do not own cars and weather conditions often make roads impassable. Having to depend on friends and relatives for transportation also has its problems. In urban areas, the parent seeking health care often finds it at the last stop of a circuitous trip of many miles, transfers, changes, much time and considerable expense. For both rural and urban areas the transportation problem is compounded by the fragmentation of services which makes it necessary for parents and children to travel not only from home to doctor, but to many different places to get complete care, including maternity clinics, well-baby clinics, hospital outpatient departments, private doctors, pharmacies, emergency rooms, after-hour care, and so on.

Where health care services exist but are difficult or impossible to reach because people do not have adequate transportation available, transportation services should be provided or arranged. This can be done by (a) urging officials to modify existing public transportation systems to arrange schedules and routes that efficiently link patients and health care facilities; (b) reimbursing families or patients for transportation they can find themselves but cannot afford; (c) contracting with other agencies to provide transportation to health services; or (d) developing a program-run transportation system.

The Children and Youth Project at the University of Texas Medical Branch has worked with the Galveston department of transportation to make sure bus service is available in the areas where people depend on the Project and at the times they come to the clinic, including evening sessions. 64 At the centrally-located Provident-Druid Comprehensive Pediatric Center in Baltimore, reimbursement is provided for families with financial need who have to take taxis because of some acute situation or because the number of children they have to bring in with them makes it difficult to use public transportation. 65

In Florence County, South Carolina, children and families eligible for EPSDT are provided transportation to the appropriate medical source through a contract between the Department of Social Services (DSS) and the local Community Action Program. DSS authorizes transportation and sends a card with the time of appointment and notification that a driver will pick up the family. The Community Action Program hires the drivers and pays their salaries from DSS reimbursement. There are currently four full-time drivers in Florence County transporting children to and from health services and keeping track of ones who miss appointments so DSS can follow-up. 66

The Kaiser Foundation Medical Care Program, a prepaid health maintenance organization in Portland, Oregon, provides special transportation, outreach and support services to some of their members who are enrolled under a federal grant. It uses a combination of a van, taxicabs and public transportation to meet the needs of the poor families who are distributed over a large geographic area and may need help in reaching any one of five different facilities at any time during the week. Taxicab service is used mostly in cases of medical emergency after regular clinic hours. Vans are used


64 Telephone interview with Donald Uran, Associate Director, Children and Youth Project, University of Texas Medical Branch, Galveston, Texas, October 15, 1974.

65 Telephone interview with Mr. Hollins, Administrative Project Director, Provident-Druid Comprehensive Pediatric Center, Baltimore, Maryland, October 15, 1974.

66 Interview with Blanche Harold, Outreach Worker, Neighborhood Service System, and Ms. Anderson, Driver, EPSDT Transportation Program, Florence County, South Carolina, October 1, 1975.
during clinic hours. Bus tickets are dispensed for the public transportation system. The program has been working with the Portland Metropolitan Steering Committee to centralize and coordinate the transportation services with other projects and agencies in the city in the hope of increasing efficiency and decreasing the costs through central van leasing, gas purchasing and mechanical repairs. It is estimated that fully 40 percent of the poverty population enrolled in the program uses program-sponsored transportation services.67

At the comprehensive Pediatric Clinics based at Baltimore City Hospital in Baltimore, Maryland, hourly transportation is provided between the hospital and the housing project it serves. The bus is rented from the city of Baltimore. The clinics are reimbursed for transportation costs by Title XIX (Medicaid), which covers 65 to 75 percent of the people who use this service. At night, minibuses and taxis are used.68

The Beaufort-Jasper Comprehensive Health Services program in Richland, South Carolina, serves two counties where most of the eligible population lives in rural swamplands or on one of 61 islands which line the coast. There is no public transportation; most of the people do not own cars. Eighty percent of the families using the program rely on the program’s transportation services. When an appointment is made and transportation requested, a slip noting the appropriate day and time is given to the patient, with a copy held to arrange transportation. Each day a list is made from these slips for pickups and given to the appropriate


68 Telephone interview with Zsolt Koppanyi, Director, Pediatric Clinics, Baltimore City Hospital, Baltimore, Maryland, October 7, 1974.
driver for that area. When patients are not picked up, the transportation request slip is returned to the receptionist with the reason. This mechanism provides a chance for follow-up on missed appointments. Providing these services calls for 17 vehicles (buses, cars, trucks) and a boat. All are equipped with two-way radios which can notify a hospital about emergencies. Transportation is a central service for making health care available to the people of Beaufort-Jasper. Indeed, it is the one function which allows all the other services to happen.

**Telephone Access**

Telephone access to information and advice concerning health problems is critical. In an emergency, being able to reach health care personnel immediately may be a matter of life or death. In less urgent situations, the family that can easily and quickly reach a doctor by telephone is more likely to raise questions about a health problem early in its course. This may prevent the problems from becoming serious and helps parents use health resources most appropriately.

Without telephone access, patients flood emergency rooms. Perhaps one-third to two-thirds of all care now being given in emergency rooms is for patients who are there not because of an emergency, but because going there was the only way they could find out what to do about their or their children's health problems.

Telephone access is particularly important for parents. The pediatrician in private practice spends at least 10 percent of his time advising parents on the telephone. But this is largely a privilege of the middle- or upper-class parent. It is accepted practice for these mothers to phone in and report a fever, a rash, or other troubling symptoms and receive guidance about what to do. Such access is rarely available to families of lower income.

Some poor families, it is true, do not have telephones. But even those who do have a phone or who can use a neighbor's often get their health care from a public clinic or a hospital outpatient department which makes no provision for giving advice on the telephone. If parents who use a clinic try to call for guidance, they are usually told quite routinely to bring a child in. When they do, bundling up the sick child and traveling to the clinic, often spending hours to get there by public transportation and enduring a long wait once they arrive, they may be seen briefly and told something they could have been told on the telephone.

While most group practices have some kind of telephone access, its absence in the clinics and outpatient departments serving the poor is a common by-product of fragmented, episodic, crisis-oriented care. Children may be seen by a different doctor each time they are brought in, and doctors are reluctant to give telephone advice to patients they have never seen, do not know, or do not remember. The problem is compounded by the fact that many health professionals believe that clinic patients have difficulty communicating over the telephone. The professionals doubt that the symptoms are accurately described or that telephone instructions will be followed accurately.

Actual experience has shown that each of these difficulties can be successfully dealt with, particularly within a setting where comprehensive care is being provided.

A study of medically indigent families receiving comprehensive pediatric care from the Family Health Care Program of the Children's Hospital Medical Center in Boston, Massachusetts, shows that the families offered telephone access learned quickly how to use it effectively for resolving medical problems. They soon adopted a pattern similar to that seen in a middle-class, private practice. They did not make unusual or excessive demands on their doctors and were able to communicate the condition of their children accurately over the phone. The effective use of the telephone for

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69 Telephone interview with Susan Carter, Former Program Planning Specialist, Beaufort-Jasper Comprehensive Health Services, Inc., Richland, South Carolina, October 16, 1974. One of the difficulties, however, is that any one patient coming in has to wait for the other people on the same route to finish before transportation is provided home.

70 "Dimensions of Primary Care: Blueprints for Change," p. 33.

parent-physician communication continued to increase over time with the family’s participation in the program.\textsuperscript{72}

\textit{In every community there can and should be 24-hour, 7-day-a-week access for emergencies, and day and evening access for acute health needs. There should also be some time during the day when families can consult with health professionals over the telephone concerning more general areas of concern.} Telephone advice may be given by a doctor, a nurse practitioner or other health worker, but \textit{the person who responds to the call must be able to communicate effectively with the caller and be able to provide the caller with appropriate instructions.} Whenever possible, the medical personnel giving telephone advice in non-emergency situations should have a continuing relationship with the caller.

At the Dr. Martin Luther King, Jr. Health Center in Bronx, New York, patients can call one of the members of their assigned health team (a doctor, nurse or family health worker) or other personnel in the Center. Since the Center is open long hours (8:30 a.m. to 9:00 p.m. on weekdays and 8:30 to 5:00 on weekends and holidays) telephone access to the Center is available a significant proportion of the time. After hours, patients can call a private answering service which reaches a doctor on call. For consultation or more lengthy discussions of health problems, some of the doctors set aside certain hours of the day during which they accept telephone calls. One such doctor has noted a decline in the number of “no shows” for appointments, a decline in the use of the emergency room and a decline in the number of repeat visits to the Center since specific telephone consultation hours were instituted.\textsuperscript{73}

The Genesee Hospital in Rochester, New York, has instituted a telephone access system as part of its attempt to improve the primary care poor children in the area were receiving. During the day, a parent can call anytime and speak with a nurse, nurse practitioner or a doctor who is free to answer questions. Parents can have longer discussions between 5:00 and 6:00 p.m., after doctors have finished seeing patients. Several nurses and at least one doctor speak Spanish, and an effort is made to match the Spanish-speaking population and staff. At night, one doctor from each health area (pediatrics, gynecology, obstetrics, etc.) is on call to answer phone questions and to see children whom parents and doctor find it necessary to bring in.\textsuperscript{74}

In the Los Angeles County-University of Southern California Medical Center diabetic program, a “hot line” is available around the clock for patients in the program. The line is answered on the ward, where complete outpatient files are kept. A doctor is called to the phone if that seems indicated, but many patients can easily obtain advice, have their prescription refills verified and make appointments for future visits through other personnel. Not only is the patient served conveniently, but there has been a consequent reduction in hospitalization.\textsuperscript{75}

\section*{Hours of Service}

Traditionally, medical care has been available on a Monday through Friday basis between 9:00 a.m. and 5:00 p.m. But people don’t always get sick between these hours. What’s more, the most realistic time for people to use services may be quite different from the time most convenient for providers. Services that interfere with work or school attendance or which require complex personal arrangements for such things as babysitters and transportation are, in effect, inaccessible for many.

These obstacles help explain the surprisingly

\textsuperscript{72} “Use of the Telephone by Low-Income Families,” p. 743.
\textsuperscript{73} Telephone interview with Deloris Smith, Project Director, Dr. Martin Luther King, Jr. Health Center, Bronx, New York, October 7, 1974.
\textsuperscript{74} Telephone interview with staff member of Genesee Hospital Department of Ambulatory Services, Rochester, New York, January 5, 1976.
\textsuperscript{75} “The Dimensions of Primary Care: Blueprints for Change,” p. 51; and telephone interview with Robert Samarin, Area Administrator, Diabetes Board, Los Angeles, California, November 4, 1974.
high rates of evening emergency room use for what are medical non-emergencies: the evening is often the only time a family can seek medical care and the emergency room is the only place open. For instance, the emergency room at the Yale-New Haven Hospital, like those in many other hospitals, sees almost as many people in the evening shift as in the day, and it has been estimated that 70 percent of its cases are of a non-emergency nature. 76

Flexible scheduling may be a problem, but health services should be organized so as not to conflict with work or school hours. In many places this has been successfully done. Specific patterns of convenient use need to be determined in each particular community, but generally the early evening hours have been most widely used when care was made available. Methods of compensating doctors and other health care workers for extending hours include time off, financial incentives, and if necessary, hiring part-time professionals for evening and weekend sessions.

The added expense is usually well worth it. In discussing the problems of fitting "a twenty-four hour community into an eight-hour outpatient service," the American Hospital Association pointed out that regular evening and weekend clinics not only improve the availability of care, but also cut down significantly on the number of people who come to emergency rooms for non-emergency care—a net savings for a health care system more appropriately used. 77

The Health Insurance Plan of Greater New York has found that expanded hours are so central to effective service that its contractual agreements with providers stipulate that services must be made available at least two evenings a week from 5 p.m. to 7 p.m. and for three hours on Saturday. 78

At the Lee County Cooperative Clinic in Arkansas, the doors are open from 8:00 a.m. to 6:00 p.m., with full staff on weekdays. From six to midnight, seven days a week, a nurse and a nurse practitioner are at the center to receive calls and deal with drop-ins. A driver is on call to pick up patients with acute health problems. After midnight every night, there is telephone access to an answering service and a doctor is on call. 79

At the Children and Youth Project in Galveston, Texas, families can receive care from 6:00 p.m. to 9:00 p.m. two evenings a week at a satellite clinic. While attendance is lower at the evening sessions than those held during the day, project personnel agree that if the evening sessions were not available, these families, however few, would probably not receive any care at all. 80

At the Beaufort-Jasper Comprehensive Health Center, evening clinics are held in all but one of the satellite clinics in response to the recommendation of consumer representatives on an advisory council. The council surveyed each area served by the clinics to find out which evenings tended to be free for the communities, i.e., evenings when church or school meetings were not being held. These clinics are well attended by working parents whose cars are available for transportation to the clinic only after work. In one clinic, it is particularly noticeable that the evening clinic attracts the whole family as it is the only time all members can come. 81

Appointment Systems

Here, I don’t know what to do. There’s the city hospital, but it’s no good to us. I went there with my husband, no sooner than a month or so after we came up here. We waited and waited, and finally the day was almost over . . . And they wanted us to come back and come back, because it was something they couldn’t do all at once—though for most of the time we just sat there and did nothing. 82

76 Herbert Paris and Desmond Callan, "City Families Need Hospitals That Offer Full Outpatient Care at Night," Modern Hospital (January 1968), p. 88.
79 Telephone interview with Ron McLean, Director, Lee County Cooperative Clinic, Marianna, Arkansas, October 15, 1974.
80 Telephone interview with Donald Urnan.
81 Telephone interview with Susan Carter.
One of the most common complaints about health care services is the long, dreary hours spent in the waiting room. Long waits have fallen unevenly to the poor and to minorities, who largely rely for their health care on emergency rooms, outpatient departments of large hospitals, health department clinics—places that are often overcrowded and that rarely use scheduled appointments. On the basis of their past experience, most patients who get health care from such institutions expect that they will have to wait their turn when they get there, and that the wait may be very long indeed.

The problem of waiting time is really rooted in two fundamental situations. First, many families turn to inappropriate sources such as emergency rooms for routine health care when they cannot afford a family doctor, when care is not available at convenient times or when there are long waits in non-emergency clinics. Of course, the result of overcrowded emergency rooms is inefficiency and poor health care delivery: the presence of non-emergency patients in emergency rooms interferes with providing immediate attention to real emergency cases and the waits for the non-emergency patients grow longer as well.

A second problem is that, traditionally, the time and convenience of those who provide health care services have been valued quite out of proportion to the time and convenience of consumers. Professional time is expensive. In an attempt to use health staff most effectively, programs have insured a constant flow of patients while the staff is present. For example, patients have been asked to come well before the doctor is scheduled to begin seeing patients so none of his time will be wasted by latecomers. In many instances, the doctor arrives late, and that prolongs the waiting time. If an efficiency expert measured only how productively doctors' time were used, such arrangements might seem reasonable. But if he also measured the lost time and money of patients, or took account of all those in need of services who do not come to receive them to avoid the long waits, thereby exacerbating their medical problems, then the balance might tip in favor of arranging appointments to minimize patients' waiting time.

A case in point is the outpatient department of a university hospital serving a rural area within a 120-mile radius. It can take close to two hours to get to the medical center by ambulance and as much as half a day by bus from many of the outlying areas. The outpatient clinics at the hospital use a "block" appointment system, which means that "all patients are given an 8:00 a.m. appointment even though most will not be seen until later in the day. This forces bus riders to leave the day before their appointment is scheduled." The poor suffer particularly from the attitude that their time has little value in comparison to that of professionals, or even of more well-to-do consumers. For instance:

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84 Heal Yourself, p. 10.
A well-dressed white middle-class woman in Washington, D.C., took two black children she was tutoring on a volunteer basis to a hospital outpatient clinic for vision tests at the appointed time, 9 a.m. After waiting four hours, the girls were finally tested. The nurse who ushered the girls into the doctor’s office was surprised at the woman’s presence and asked her who she was. Upon finding out her role, the nurse replied, “If only we’d known (who you were), we would have taken your girls first thing.”

Appointment systems can assure the smooth, efficient flow of patients while at the same time reducing the needless time they must wait to see a doctor. The exact design of appointment systems depends on local circumstances, but experience has shown that certain elements should be incorporated. First, appointment systems should allow people a number of ways to make an appointment, such as through outreach workers or health aides in the home or hospital, through staff making referrals from other agencies, through telephoning directly to the clinic or through making a future appointment while in the clinic or emergency room.

For example, the Dr. Martin Luther King, Jr. Health Center in New York City has worked closely with the emergency room staff of the Montefiore Hospital to help guide non-emergency patients to physicians or appropriate units of the health center. There has been consistent staff acceptance of this practice and, despite expanded emergency room hours, the percentage of total Center patients being seen by the emergency room has been reduced since 1970 from 52 to 32 percent.

Second, the design of the appointment system should accommodate the habits and practical daily problems of patients and their families. Many people have relied on sources of care which, until recently, have not employed appointment systems. Unaccustomed to using appointments, particularly if the system is newly instituted, people often come to the clinic without them. In a study of approximately 50 neighborhood health centers, 42 percent of the visits were such walk-in patients. In addition, an estimated 20 to 40 percent of patients who make appointments are unable to keep them and need to reschedule them. Therefore, a system should provide sufficient “slack time” for walk-in patients and for patients who want to reschedule their appointments soon. The schedule also should be flexible enough for families who need lengthy attention or who may arrive late. It should be possible to accommodate them without causing excessive delays for the other patients. Many programs have found ways to make such provisions.

The Minneapolis, Minnesota, Maternal and Infant Care and Children and Youth Programs have a good system designed to accommodate missed appointments and walk-ins. Generally, individual appointments are scheduled every fifteen minutes, but new family planning patients, for example, who will need more time for consultation, are scheduled to come at the same time for an education class about contraceptive methods. Staff have learned that between 20 and 30 percent of all patients are unable to keep their scheduled appointments, and this is figured into the scheduling for any one day. In addition, a certain number of time slots are left open so that families who come to the clinic without appointments can be seen.

Staff who help individuals set up appointments can use this opportunity to find out whether transportation or child care will be needed in order to keep the appointment. Program staff can help arrange for these services or might arrange the appointment at a time when these related problems can be most easily solved. Where getting to the clinic is difficult and where sharing transportation can ease the problem, special provisions in scheduling can allow people who live near each other to come to the clinic at the same time. For example, the Beaufort-Jasper Comprehensive

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85 Heal Yourself, p. 12.
87 Telephone interview with staff member of the Evaluation Unit, Department of Community Health, Albert Einstein College of Medicine, New York City, January 1975.
88 Telephone interview with Ellen Alkon, M.D., Director, Minneapolis Maternal & Infant Care and Children and Youth Program, Minneapolis, Minnesota, October 30, 1974.
### CLINIC SCHEDULE

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Location</th>
<th>When Held</th>
<th>Time</th>
<th>Under 21 Only</th>
<th>Children &amp; Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiac</td>
<td>Health Center Town #1</td>
<td>2nd Friday each month</td>
<td>1 p.m.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Chest</td>
<td>Health Center Town #1</td>
<td>4th Saturday each month</td>
<td>9 a.m.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Conservation of Hearing</td>
<td>Health Center Town #1</td>
<td>3rd Friday each month</td>
<td>9 a.m.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Conservation of Vision</td>
<td>Health Center Town #1</td>
<td>1st Tuesday &amp; 3rd Wednesday (every other month)</td>
<td>9 a.m. X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EEG (Brain Wave)</td>
<td>Health Center Town #1</td>
<td>1st Thursday each month</td>
<td>9 a.m.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Family Planning</td>
<td>Health Center Town #1</td>
<td>2nd Tuesday &amp; 4th Tuesday</td>
<td>9 a.m.</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Town #2</td>
<td>1st Monday &amp; 4th Friday</td>
<td>9 a.m.</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Town #3</td>
<td>1st Friday &amp; 3rd Monday</td>
<td>9 a.m.</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Mental Health</td>
<td>Health Center Town #2</td>
<td>Mon., Tues., Wed., and Thurs. each week</td>
<td>10 a.m. X</td>
<td></td>
<td></td>
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<tr>
<td>Neurology</td>
<td>Health Center Town #1</td>
<td>3rd Monday each month</td>
<td>9 a.m.</td>
<td>X</td>
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<tr>
<td>Orthopedic</td>
<td>Health Center Town #1</td>
<td>6 times a yr. 1st Friday every other month</td>
<td>9 a.m. X</td>
<td></td>
<td></td>
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<tr>
<td>Pediatric</td>
<td>Health Center Town #1</td>
<td>1st Thursday each month</td>
<td>9 a.m.</td>
<td>X</td>
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<tr>
<td>Seizure</td>
<td>Health Center Town #1</td>
<td>4th Wed. each month</td>
<td>10 a.m.</td>
<td>X</td>
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<tr>
<td>V.D.</td>
<td>Health Center Town #1</td>
<td>Mon.-Fri., open door</td>
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### CHILD HEALTH CLINICS

<table>
<thead>
<tr>
<th>Town #1</th>
<th>Hall</th>
<th>3rd Thursday each month</th>
<th>9 a.m. to 2 p.m. by appointment</th>
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</thead>
<tbody>
<tr>
<td>Town #2</td>
<td>Health Center</td>
<td>1st Friday each month</td>
<td>&quot;</td>
<td>X</td>
</tr>
<tr>
<td>Town #2</td>
<td>Health Center</td>
<td>3rd Tuesday each month</td>
<td>&quot;</td>
<td>X</td>
</tr>
<tr>
<td>Town #3</td>
<td>Methodist Church</td>
<td>4th Thursday each month</td>
<td>&quot;</td>
<td>X</td>
</tr>
<tr>
<td>Town #2</td>
<td>Health Center</td>
<td>2nd Wednesday each month</td>
<td>&quot;</td>
<td>X</td>
</tr>
<tr>
<td>Town #4</td>
<td>Immaculate Conception Church</td>
<td>1st Thursday each month</td>
<td>&quot;</td>
<td>X</td>
</tr>
<tr>
<td>Town #5</td>
<td>Fire House #1</td>
<td>4th Friday each month</td>
<td>&quot;</td>
<td>X</td>
</tr>
<tr>
<td>Town #6</td>
<td>Fire House #2</td>
<td>2nd Tuesday each month</td>
<td>&quot;</td>
<td>X</td>
</tr>
</tbody>
</table>

*This schedule, typical of schedules of many public health clinics, separates clinics according to people’s health needs, and forces families to go to locations depending on their health problem at fixed times of the month regardless of when their illness strikes.*
Health Services in South Carolina provides buses for people living in outlying areas and makes sure to schedule their appointments together so they can make use of the bus.\textsuperscript{89} These measures have helped assure reasonable patient flow in the clinic and minimal waits for users.

Third, \textit{the design of appointment systems should promote continuous care}. One of the advantages of a good appointment system is to make it possible for patients to be seen by the same staff. Most health care professionals agree that this continuing relationship improves the quality of care. There are elements which promote continued use of services which can be built into the appointment system:

1. The chances that an appointment will be kept are greater if a patient can have an appointment within a short time after she or he asks for it. Therefore, appointments should be scheduled as promptly as possible, ideally within a week.

2. The use of appointment reminders, by mail or telephone, often helps people keep their appointments. For example, the Children and Youth Dental Clinics in Detroit reduced their overall broken appointment rate from 28 to 8 percent by instituting a reminder system.\textsuperscript{90}

3. When appointments are missed, however, the system can be designed so that follow-up by program staff allows rescheduling for those who want new appointments. At the Family Health Program in New Orleans, the total number of women who received service was increased 22 percent because of conscientious follow-up of missed appointments.\textsuperscript{91}

4. The practice of routinely scheduling the next appointment, if needed, before the parent and child have left the clinic, is another scheduling device which encourages continued use of needed services.

\textsuperscript{89} Telephone interview with Susan Carter.


\textsuperscript{91} "The Orleans Parish Demonstration Program," see part 1.
Fourth and finally, the design of appointment systems should facilitate the efficient provision of related health services. It is often possible to schedule children or parents with similar needs at the same time so that certain services can be provided on a group basis. For example, mothers seeking prenatal care or family planning advice can be scheduled at or near the same time so that classes or discussions can be held. In the Adolescent Clinic of the University of California Medical Center in San Francisco, new mothers have appointments scheduled so that they are able to participate in group discussions with the nurse practitioner and social worker about a variety of topics like nutrition, immunization, care of sick children, available child care and family planning services and specific problems or worries about their infants. Each new mother and her child come to the Center approximately once each month for the first few months after delivery. They are scheduled to come at 1:00 p.m., and each day at that time, six to eight new mothers are present. The new mothers seem to appreciate being with other new mothers and infants who share their concerns and joys. The discussions are quite unstructured; however, staff try to introduce new topics each month so that returning mothers hear new information. The discussions last about 30–45 minutes and, when they end, patients' private appointments with the doctor begin. The nurse practitioner remains with the group while they wait so that they can continue to talk with her individually or as a group.92

Care for Other Children

Many parents who need to bring a child in for care have other children at home. Babysitters are normally hard to find during the day when older children are in school. Even if one is available, many people cannot afford to pay a sitter. In the evenings, when a family member could take care of other children, health care facilities are usually not open. As a result, many parents either put off getting care except in acute or emergency situations or bring all of the children to the clinic. The burden of taking several small children on public transportation and waiting with them, particularly when one of the children is sick and needs comforting, is stressful for everyone involved—parents, children, people giving care and other people waiting to receive care. Sometimes a simple thing like the lack of child care—especially on top of other difficulties—prevents families from getting health care altogether. As one mother said:

My kids they get sick. The welfare worker, she sends a nurse here, and she tells me we should be on vitamins, and the kids need all kinds of checkups. Once she took my daughter and told her she had to have her teeth looked at, and the same with Peter. So, I went with my daughter, and they didn't see me that day but said they could in a couple of weeks. And I had to pay the woman next door to mind the little ones, and there was the carfare, and we sat and sat, like before. So, I figured it would take more than we've got to see that dentist. And when the nurse told us we'd have to come back a few times—that's how many, a few—I thought that no one ever looked at my teeth, and they're not good, I'll admit, but you can't have everything, that's what I say, and that's what my kids have to know, I guess.93

In situations where the lack of care for other children is one of the factors preventing families from getting health care, the health care programs themselves must intervene on behalf of their patients. This can be accomplished in several ways:

1. providing a child-care room right at the clinic where children can spend the waiting time pleasantly without disturbing others;

2. paying for babysitters which the families themselves find; or

3. forming or arranging with a group of babysitters in the community to go to homes as needed. These can be paid for by the family or the health program.

92 Telephone interview with Charles Irwin, M.D., Director, Adolescent Program, University of California Medical Center, San Francisco, December 1974.

The experience of many programs suggests that the most easily managed and most helpful arrangement is to have a playroom as part of the clinic facilities—provided that it is realistic, in terms of location and transportation, for the mother to bring the children along. Such a playroom should be under the supervision of a person trained to manage small children. Whatever provisions are made for the other children, the mother should be told about them specifically before she comes to the clinic, either by an outreach worker, a receptionist who makes appointments, or some other member of the program staff.

In Minneapolis, Minnesota, the Family Planning clinics, Children and Youth projects and Maternal and Infant Care projects all have play areas for children, staffed by mothers or grandmothers from the neighborhood who provide safe, reliable care. This care is available whenever the clinics are open, including the evening sessions. The health care professionals report that everyone is more comfortable without the chaos of children waiting with the parents and sick children. A beneficial side effect is that the children who play at the clinic enjoy themselves, forming positive impressions which may reduce their anxiety when they need to be taken to the doctor.94

At the Children and Youth Project at Roosevelt Hospital in New York City, the playroom is staffed by a person with considerable experience teaching young and handicapped children. If she notices any developmental or health problems during the play period, she talks to the doctor responsible for the family. In addition, this program provides financial reimbursement if needy parents arrange for their own child care rather than using the Project’s playroom.95

In the Pediatric Clinics at the Baltimore City Hospital, a college graduate with training in early

94 Telephone interview with Dr. Ellen Alkon.
95 Telephone interview with Dr. Schwab, Director, Children and Youth Project, Roosevelt Hospital, New York City, October 30, 1974.
childhood education staffs a child development-oriented playroom. The director of the project reports that the children and parents like the playroom program. One specific indication of its usefulness is that the incidence of injuries and other troubles among waiting children increases when the staff person is unable to be present.96

A volunteer group of 24 mothers was formed at the Children and Youth Project serving the Las Animas-Huerfano district in Colorado. When a mother took a child to the hospital or was separated from the child for other reasons such as domestic problems or child abuse, one of the mothers from the volunteer group was sent to the home to care for the children. She was paid a minimum wage by the Children and Youth Project. In this case, the service was not used solely as a means of facilitating the use of primary care, but was adapted to such situations.97

Reducing Cultural Barriers

"Med school, internship, and residency," one doctor wrote, "orient us to disease while blinding us to the need to recognize patients as individuals with different sociocultural backgrounds. Those differences deeply affect how they interpret and react to what we say and do. That's why doctors with the best of intentions often embarrass, confuse, frighten and anger minority-group patients."98

For many parents—particularly members of ethnic minorities—dealing with the mainstream American medical system is an alienating experience. They are asked to comply with regulations and follow procedures stated in a language they do not understand and to reckon with attitudes that offend their pride and sense of worth. Most health professionals are white and middle class and are ignorant of or insensitive to the cultural and environment of poor and minority group children. This insensitivity and ignorance often result in poor health care.

"If I had to go to the County doctor, I just wouldn't go, I just wouldn't go," a 35-year-old Indian mother told us. "I went once because both my baby and I had a fever. When the doctor called by baby a brat, I bit my tongue because I wanted the medicine. Then he just looked at my eyelids and told me I had syphilis. I went home and cried." The next day she was able to scrape together enough money to go to another doctor. He treated her for an abscessed tonsil.99

A resident of Watts explains why he rarely sought medical care: "We are fed up sitting on a hard bench all day in a crowded clinic far from the neighborhood, waiting to see a doctor who treated you like you were a burden on him or a chisler. We only went to the clinics when we were desperate."100

Racial discrimination in the provision of health services is still widespread.101

96 Telephone interview with Susan Lewis, Assistant to Director, Pediatric Clinics, Baltimore City Hospital, Baltimore, Maryland, October 7, 1974.
97 Telephone interview with Dr. Clifton Govan, Pediatric Consultant, Family Health Division, Colorado State Department of Health, Denver, Colorado, October 30, 1974.
One of the doctors in a Southern county has segregated waiting rooms. Black residents feel he does not treat them as well as whites: "He takes white folks who just come ahead of colored folks who have been waiting all day, and when he finally sees us he don't examine us as good and he always gives shots. I don't like him 'cause he has a segregated waiting room. We have to wait longer than whites. Whites get to go first, and once in a while the nurse comes for a colored person to keep us calm." 102

In addition to insensitivity and discrimination, language can be a barrier adding to the difficulty of communicating and getting care.

A Spanish-speaking mother recalled a visit with an injured child to the emergency room of a large city hospital. She was repeatedly put at the end of the line while an interpreter was sought from another section of the hospital. By the end of the day, no interpreter had come, and she was told to take the child home and return the next day if she wished.103

And as Fernando Chevez, a Chicano who testified before the Senate Subcommittee on Health, said:

The reason I made my presentation in Spanish is because another one of our gripes, not only with this institution but other private institutions within East Los Angeles, is a problem with the language barrier. And I would say that 85 percent of the total working force in this institution cannot understand nor speak Spanish, though about 45 percent of all the patients that enter this hospital, and private hospitals within East Los Angeles, are either Mexican or Mexican-American. Of the 45 percent, 25 percent cannot speak English at all. In this institution itself you have approximately, or a little over 8,000 employees. You have less than 6 percent with Spanish surnames. . . . We have seen people wait here anywhere from 4 to 8 hours. And a little longer, if you cannot speak the English language.104

The language barrier is felt not only by a Spanish-speaking person: the Black in the rural South or the inner city and the white inhabitants of Appalachia may speak many of the same words, but not the same "language" as the middle-class white doctor. Families have different ways of presenting problems, different attitudes towards the body, different perceptions of health and sickness, and different remedies that are acceptable to them. It is crucial that medical services have on hand people who understand these differences and help doctors communicate effectively with children and their families. For instance, for the traditional Navajos, illness is thought to be caused by some transgression by the sick person or someone in his family which results in a disharmony between the sick person and the supernatural powers. Though an Anglo doctor can provide symptomatic relief, the medicine man must cure the cause of the illness.105 A doctor who understands this concept can work with the medicine man relieving the patient’s anxiety and hastening recovery.

One doctor describes his awakening to the fact that the cultural gap diminishes the effectiveness of care.

I came to realize that even when I made the right diagnosis and prescribed the right treatment, half the time the patients didn’t understand me. Very likely they wouldn’t buy the medicine or wouldn’t take it. Often I was giving impossible instructions—for instance, how do you stay on a salt-free diet if you eat at lunch counters? What’s the use of telling a cardiac to rest if he needs his job and has to climb four flights of stairs at home? I was a highly trained scientific doctor, able to do all the right tests to diagnose obscure diseases, but I wasn’t really making the connection with the people who needed me.106

Another physician commented on how important it is to understand cultural patterns of decision-making, particularly when prescribing treatment. He said:

A mother might bring a child to one of our clinics with a running ear. . . . The physician

102 Heal Yourself, p. 13.
103 Heal Yourself, p. 2.
104 Hearings Before the Subcommittee on Health, Part II, pp. 2570–2571.
says, "We have to treat the ear, and when it's finally stopped running and the infection gone, the child will need surgery... a tympanoplasty." The mother might say, "All right, treat my child," but when the time comes for the surgery, she might say (if she's a truly traditional person), "I have to discuss this with my mother or grandmother."

Now, if we understand the tradition, we'll say, "Fine. We'd love to have your mother come in and talk about it," and then through an interpreter, we can help the mother to understand the situation and make a good decision. But if the physician gets defensive and says, "Hell, I'm the doctor, I know what I'm doing... forget all this nonsense, about asking your grandmother...," he loses that case. ¹⁰⁷

Information is often given in a manner unacceptable to the patient. It is taboo among traditional Indians, for instance, to give advice. One doctor got around this problem by adopting the story-telling method Indians use to illustrate points and found she could get information about child care or medication across to a mother this way. She also told us that it was a long time before she realized why Indian mothers weren't following her advice not to make a fresh formula for each feeding, but to make it once every 24 hours and refrigerate it. The problem was simply that they had no refrigerators. ¹⁰⁸

Hospitalization often increases feelings of alienation and insecurity. If the health professionals do not recognize and do something to allay the fears of parents and children, they find that children are not brought into the hospital for care until their condition becomes really critical. In Cincinnati, Terry McAllen from Wolfe County, Kentucky, who refers to himself as "a minister in khaki pants," said:

When I first started my work it was summer, and hot and sticky in Cincinnati. I was talking with a family and their little baby needed a doctor, I could tell. I wanted to take the mother and child to the hospital, but the mother was obviously afraid of going there; she thought "the hospital people" would keep the child, and that would be more than she could bear. She asked me what to do, and I was honestly frightened myself. I knew the child needed a doctor, but I also knew how hard it would be on that family to go to a hospital and see their child "taken away," that's what they'd say and feel and think. ¹⁰⁹

¹⁰⁷ "Indian Health Service Modernizes Medical Care on Reservations," p. 516.
¹⁰⁸ Telephone interview with Jean Smelker, M.D., Director, Community-University Health Care Center, Minneapolis, Minnesota, December 13, 1974.
Health programs should make special provisions to assure that there is no discrimination among patients by race and that services are responsive to the different cultural and socioeconomic backgrounds of the families they serve. The ways in which this can be done include: (a) hiring staff from or with knowledge about the communities being served; (b) providing language interpreters where needed; (c) hiring patient advocates from the communities to ease entry to health services and to allay fears; and (d) providing for a grievance system and consumer participation in decision making.

While many programs have developed ways of dealing with cultural barriers, the following three programs provide good models because they use several of these mechanisms.

The Dr. Martin Luther King, Jr. Health Center in the Bronx, New York, serves about 90,000 people, 62 percent of whom are Black, 36 percent, Puerto Rican. The goal of the health center is to provide family-oriented, team-centered, comprehensive care "that is delivered in an atmosphere agreeable to patients, with dignity and sensitivity to their economic, cultural, psychological, medical and social needs." Ninety percent of the total staff is Black or Puerto Rican. Forty-five percent of the staff relating to the community (including family health workers, receptionists, medical assistants) speak Spanish.

Each of the Center's health teams has six family health workers, hired from and with knowledge of the community.

Recognizing the importance of humane health care as well as the legal rights of patients, the Center has developed a Patients' Rights Manual and a grievance procedure for patients who are unhappy with any of the health services:

We have defined and attempted to insure the following rights of patients: the right to courtesy and respect; the right to refuse treatment; the right to have a clear explanation of procedures and treatment; the right to privacy . . . the right to choose time for appointments; the right to transportation to and from the Center when disabled; . . . and the right to informed consent regarding the exchange of information between the Health Center and other agencies, for example, schools and referrals.\footnote{110} \footnote{111}

In East Oakland, California, the Clinica de la Raza serves a largely Chicano and Latino population, most of whom have little money and work in local restaurants, a few nearby factories and canneries. It is an area of high mobility, where those who manage to make some money move out, leaving the poorest behind. Most of the people speak only Spanish. To provide effective health care under these circumstances, Clinica de la Raza has included the following special provisions in its program:

- The clinic runs health education workshops to educate the community in common health problems. As a result, patients have more information; they are able to evaluate health situations more independently, understand more of what the doctor is saying, ask more informed questions, and judge more readily when there is a need for seeking care. One recent session, for instance, was on children's colds and diarrhea—what to watch for and when to call the doctor.
- All written materials are in Spanish as well as English.
- All doctors, including the Anglos, must speak Spanish as a condition of being hired.
- Eighty percent of the total staff are Chicanos. As much of the staff as possible comes from the immediate area.
- The clinic employs community aides who act as a liaison between the health professionals and the families.
- Clinica de la Raza has a Board of Directors which is responsible for overall clinic policy. Four of the seven members must be from the patient membership. Proceedings are conducted in both Spanish and English. There are overall membership meetings every two months. Problems people have in using the clinic are aired and whenever possible acted upon at these meetings.\footnote{112} \footnote{113}

In a ten-square-mile area in central Miami live some 22,000 Bahamian, Cuban, Haitian, Puerto Rican and black children. The majority of the children speak Spanish, and many are recent immigrants who feel isolated and foreign. Other than the local hospital, there was only one pediatrician to serve this group of children prior to 1967. To meet their needs, the University of Miami Comprehensive Health Care Program for Children and Youth was started. It is bilingual: all directives, pamphlets, and instructions are in Spanish and English; the doctors on each team are bilingual; the health aides on the teams come from the same communities as the children they serve and are sensitive to the constraints under which the families live; the switchboard operators and receptionists are bilingual and are given special training so they are patient and helpful with parents who call in. Students from the psychology department and nursing school of the University of Miami, as well as community members who are given specific training, have formed a volunteer program to give supportive counseling and "a chance to talk things out" to the families who use the Children and Youth Program.

Members of the health staff participate in an in-service training program run by University of Miami faculty and the Health Ecology Project, a university-based project which gathers information on the health-related beliefs and values of various cultural groups. The point of the training is to increase the sensitivity, awareness and knowledge of the health care workers to the traditions of the families they serve and the manner in which these traditions affect the way the families live, eat, use health care, and talk about health problems.

Emergency Care

A medical emergency is one of the most feared and threatening situations that can arise for a family. We are all vulnerable: national statistics show that each American is likely to need emergency care at least twice during his or her life. Children are especially susceptible to emergencies as a result of falls, dog bites, poisoning, traffic and other accidents. Many acute diseases which affect children also may require emergency treatment. Lack of emergency transportation, mistakes made by an untrained or overworked attendant, incomplete information about a child's health history, or a delay while financial and eligibility information is sought can mean the difference between life and death or permanent disability.

But why is emergency care, albeit crucial, discussed in a chapter on entry into the health system? The sad fact, often repeated in previous sections of this chapter, is that for many children and families, the emergency room is the initial point of entry into the health care system. Worse, it is often the only source of care for many poor and minority families. The barriers of access to health care described in the previous section of this chapter result either in health problems being ignored until they become emergencies or in people misusing the emergency room as a source of primary care. Last year alone, there were fifty million emergency room visits in this country, an increase of 10 percent over the previous year. An estimated one-to-two-thirds of these visits were of a non-emergency nature.

114 Telephone interview with Lydia Shifman, Chief Social Worker, Comprehensive Health Care Program, University of Miami, Miami, Florida, February 7, 1975; letter from Lydia Shifman, Chief Social Worker and George Colmer, Assistant Director, Comprehensive Health Care Program, University of Miami, Miami, Florida to the Children's Defense Fund, March 19, 1975.


The frequent use of emergency rooms for non-emergency care leads to confusion, noise, crowding and makeshift care for both the emergency and non-emergency cases. Care is often given abruptly and with little explanation. Too often medication and treatment begun in the emergency room are not monitored and needed follow-up care is never received. Further, without intervention and successful attempts to link families to more appropriate primary care, they continue to use the emergency room the next time they need to see a doctor.

Given this reality, what can the health care system do? Obviously, the best solution (and the most ambitious to accomplish) is to see that reforms in other areas of the health care system are undertaken to reduce substantially the numbers of people using emergency rooms for non-emergency care. This is an elegant example of how improving one aspect of the system (e.g., location or hours of services) would lead to improvement of another (e.g., overcrowded emergency rooms).

While these reforms are under way, health care professionals working in settings with the right incentives can capitalize on their encounters with people in an emergency room and begin to change their patterns of health care use. Emergency services should be designed to introduce patients to a regular source of care if they do not have one. For example, additional staff can be on hand to talk with non-emergency patients or parents to find out the specific reasons they resorted to using the emergency room and to give them information, appointments, telephone numbers, and supportive services so they can use more appropriate sources of care.

Approximately nine years ago, staff at the City Hospital in Cambridge, Massachusetts, took a close look at the reasons which brought families to the hospital’s emergency room. They found that over 50 percent of the cases were not true emergencies and that the majority of these problems could be handled by nurse practitioners who staffed the five neighborhood health centers around Cambridge. So nurse practitioners were placed in the emergency room to take care of the families who came with non-emergency problems. The nurse-practitioner treated the patients for their complaints and spent time discussing the importance of using the neighborhood health centers for routine problems. If follow-up care was needed, the nurse practitioner referred the family to the appropriate place—to the neighborhood health center if the problem could be handled by a nurse practitioner or to a specialty clinic at Cambridge City Hospital if it required care by a physician.

Follow-up was an important part of this arrangement. Whenever a family came to the emergency room, the neighborhood health center in the family’s neighborhood was notified so that health aides and nurse practitioners in the centers could make home visits, contact the specialist clinic to which the child was referred, or do whatever other follow-up was needed.

As a result of this effort, families have learned to use the health centers and the emergency rooms more appropriately. Samples of emergency room use show that substantially fewer non-emergency cases are being brought there. During the sample periods there were no increases in emergency room use at the two other major hospitals in the area, so project staff are confident that they have not encouraged families simply to rely on different emergency rooms.

The Southeast Ohio Emergency Medical Services (SEOEEMS) has also helped many people who have relied on emergency care to seek more appropriate ongoing care in outpatient centers. An example of this kind of progress is the O’Bleness Hospital in Athens, Ohio, one of the hospitals participating in the emergency service. When SEOEMS began in the fall of 1972, the hospital’s emergency room was expanded into an outpatient, ambulatory care center which saw both emergency patients and non-emergency patients. Non-emergency patients could be seen at the center for a whole range of primary health care needs. After being treated, emergency patients could receive needed follow-up care from the center. In this way, both emergency and non-emergency patients, many of whom had no other source of health care,

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118 Telephone interview with Judy Fellow, Public Health Analyst, Child Health Services, Department of Pediatrics, Cambridge City Hospital, Cambridge, Massachusetts, January 26, 1976.
gained a regular source which could take care of most of their health problems. Prior to SEOEMS and the development of the ambulatory care center, there were 7,000 visits per year for hospital outpatient services by local residents. Two years later, there were two-and-a-half times as many.\textsuperscript{119}

After appropriate use of emergency rooms has been dealt with, other problems may remain which can diminish the quality of emergency care and hamper its use. One is emergency transportation; the other is the adequacy of personnel, procedures and equipment.

Often a person who seeks emergency medical assistance does not know where to call to find emergency transportation. In some localities, no emergency transportation exists. In other places, strings may be attached. Some ambulance services are restricted to one county or city and cannot transport patients across county or city lines; others refuse to pick up people who cannot pay. According to a United Press International report:

Authorities confirmed . . . that an ambulance dispatched to a dying mother eight-months pregnant was stopped because the family had not contracted for village police and ambulance service. The mother of five children, Mrs. Jean Pettee, aged 36, collapsed at home; her husband, a self-employed businessman called the local police and asked for an ambulance. An ambulance carrying a paramedical team was sent out, but stopped "on the apron," when it was determined that the Pettees did not subscribe to that particular service. Another ambulance was called from another jurisdiction, six miles away. Mrs. Pettee was dead on arrival at the hospital.\textsuperscript{120}

Accepted standards for providing immediate care while in transit to the emergency room are seldom met. In contrast to the impressive scenes of efficient emergency care we see on weekly television shows, recent surveys have shown that only 5 percent of the nation's ambulance personnel have finished the recommended training and only 7 percent of ambulances have equipment for communicating directly with hospital staff about the conditions of the patient.\textsuperscript{121}

In an effort to improve the quality of emergency care, federal legislation (for example, the Emergency Medical Services Act and the Highway Safety Act), has tightened the standards for victim care and transportation. But the problems remain. What is bad in cities is often worse in the country where hospitals are few and far between and accidents may go untreated for long periods of time. Statistics show that the consequences of illness and accidents suffered by residents of rural areas are generally more serious because of the time lost in summoning and waiting for emergency care.\textsuperscript{122}

In the emergency room itself the organization, personnel and equipment to deal with acute problems often leave much to be desired. The following testimony before the Senate Subcommittee on Health describes a frustratingly common experience:

Senator Kennedy. "And you went to the emergency room of St. George's Hospital and you asked for service?"

Mr. Johnson. "Yes."

Senator Kennedy. "That is, you asked for someone to take a look at your boy, is that right?"

Mr. Johnson. "Yes, but in the meantime they interviewed me before."

Senator Kennedy. "When you did this, in effect, your son was actually in the process of dying and they were asking you questions about where you lived?"

Mr. Johnson. "Yes."

Senator Kennedy. "And about the kind of insurance you had?"

Mr. Johnson. "Yes, sir. 'Do you own your own home?' and this and that, and 'who do you work for?' and 'how long?' "

Senator Kennedy. "And then after that when you pleaded with them to get some kind of help—"

Mr. Johnson. "Yes, I asked them if they needed further information and what not they could call out to County Hospital, that he had been a patient there. . . .

\textsuperscript{119} "The Communicator," monthly publication of O'Bleness Memorial Hospital, Vol. 18, January 1975, p. 2.

\textsuperscript{120} \textit{Washington Post}, 13 January 1976.

\textsuperscript{121} House Report #93-601, pp. 3-4.

\textsuperscript{122} "Southeast Ohio's Answer to the Emergency in Emergency Medical Service," p. 4.
"They would have given them the information if they needed it but he didn’t even try to do anything.

They would voluntarily—they had voluntarily told me also that if anything happens to Carl, even to have a tooth extracted or a tooth filled or anything, to call them and they would give the doctors the information that is necessary so it wouldn’t be fatal to him."

Senator Kennedy. "Then you took your son over to the other hospital, to County Hospital, is that right?"

Mr. Johnson. "Yes."

Senator Kennedy. "Going by all of these other hospitals?"

Mr. Johnson. "Yes, because I was afraid to stop. I think the same thing would have happened if I had stopped at one of the other hospitals which were St. Bernard’s and there was another hospital up there, and they were associated and they are run by the same staff, and I would say it would be a waste of my time. I might as well try to make it to the County."

"I drove down the expressway with my oldest son, while my other son was in pain. . . . I laid him down in the car."

Senator Kennedy. "He was hysterical and the doctor said ‘If you don’t like the service here, take him elsewhere!’"

Mr. Johnson. "Yes. He told me that ‘he couldn’t be sick with a heart condition if he is able to scream and holler like that,’ that is what he said."

Senator Kennedy. "So then you went to Cook County Hospital?"

Mr. Johnson. "Cook County Hospital and they decided right away to put a pacemaker in and what not, but he went into a coma and passed before they got a chance to insert it."

Senator Kennedy. "Now, did you ever hear from St. George’s again?"

Mr. Johnson. "Yes, I heard from them. I paid the emergency room bill."

Senator Kennedy. "From St. George’s Hospital?"

Mr. Johnson. "Yes."

Senator Kennedy. "They sent you a bill after this?"

Mr. Johnson. "Yes, two bills."

Senator Kennedy. "They sent you two bills?"

Mr. Johnson. "Yes, one was a doctor’s bill and one was the emergency room bill."

If a hospital denies emergency services to an individual because of inability to pay, it is probably acting illegally. Beyond the question of a hospital’s legal responsibility, however, are questions about the quality of emergency care people receive. Residents in every location should have available to them a system of emergency care which includes public information about how to get emergency help, emergency transportation and communication with a health center or hospital, health staff in the ambulance and emergency room who are trained in emergency care, high-quality emergency room facilities and provision for needed follow-up services.

Local community efforts and federal demonstration grants are beginning to result in quality emergency services in some parts of the country. Since the enactment of a federal Emergency Medical Services program in 1973, upgrading of services has begun on a much larger scale than in the past. As of June, 1975, approximately 120 regional service networks had been funded.

Three counties in Southern California, for example, have been working for several years to set up comprehensive emergency medical services. The counties comprise a 15,700 square mile area, larger than all the New England states put together. The tri-county area is checkeried with affluent and low-income sections. Farming and mining are the only employment. With the help of a federal grant, each county has designed an emergency program which aims to provide uniformly high quality care throughout the diverse region.

123 There are a variety of legal approaches that can be taken, and have been taken, to affirm hospitals’ obligations to provide true emergency services to people without requiring advance guarantee of payment: (1) The Joint Commission on the Accreditation of Hospitals requires that hospitals that have emergency rooms must offer emergency services to everyone; (2) Many states have licensing regulations or other rules stipulating the same thing; (3) An IRS policy ruling for hospitals that are tax-exempt says that they have to provide emergency services without requiring advance payment.

125 Experts generally agree on the steps necessary for offering good care in an emergency room. These include the following standards, as formulated by the Community Health Institute in New York:
The San Diego service, in one of the three counties in this program, serves 1.8 million people spread over 4,217 square miles. Privately-operated ambulances with radios and two mobile intensive care units serve the metropolitan area. Services to the rural and mountainous eastern part of the county are provided by sheriff's deputies who live in those areas and have been trained in first aid and use of rescue equipment. Emergency care has been added to their job responsibilities. Ambulance services are close at hand to take people to the nearest emergency facility, each of which has been inspected and often upgraded to meet the standards set by the tri-county Emergency Medical Services program. Newborn infants who need intensive care are transported quickly to one of the two specialty hospital units in the county. A burn treatment center and poison information center are also part of the program. Staff at the poison information center make a follow-up phone call to everyone they advise to make sure the situation is under control. In addition, many public servants such as forest rangers and firemen have received training from a local community college in basic first aid and emergency care. Through a conscientious public information effort, county residents hear television and radio spots describing the service and how
to use it. An information specialist with the program talks to community groups and has helped establish, through the community college, a short course in emergency care for county residents.\textsuperscript{126}

The SEOEMS program in Ohio mentioned earlier also fills the void left when funeral homes in the area, which had provided 80 percent of the emergency transportation services, discontinued services. This regional program serves seven counties in rural Ohio through seventeen emergency care stations. Its goal is to have no injured or suddenly ill person more than twenty minutes from medical care. All participating emergency medical technicians are carefully trained in emergency victim care by the Ohio Division of Vocational Education. In contrast, only 5 percent of the volunteer and municipal ambulance attendants and only 3 percent of the 135 funeral-home attendants formerly offering ambulance services were trained and certified. The ambulances serve as mobile emergency rooms, equipped with necessary gear for handling many kinds of emergencies.

Contact is made with the ambulance through one toll-free number for the entire area. This number hooks up to the central dispatcher who routes the emergency vehicles closest to the scene. A special communication system is being designed which will enable ambulances to talk with central headquarters, to monitor other public service networks such as local fire and police departments, and to be in direct contact with hospital emergency rooms and medical staffs. Individual attendants in ambulances will be able to talk with a doctor at his home or office or to talk simultaneously with any of the other ambulance stations or attendants. Equipment for radio transmission of vital signs to doctors is also being included.

Emergency room equipment and staffing are also being improved. Prior to the program, only one hospital in the area had a physician to cover the emergency room at all times. The project has helped hire emergency room physicians and has upgraded emergency room facilities to meet uniform standards set by the project and in accordance with federal regulations.\textsuperscript{127}

Improvements in emergency care need not rely on massive federal support. Interested citizens in Rockforge, West Virginia, set up emergency health services where practically none had existed. The local mortician stopped his service, the city ambulance service was restricted to city boundaries, and the one private service demanded $30 before picking people up. Through a community-based effort, the Seven Areas Council for Health was established in West Virginia in 1972. It has planned a subscription service for the 75,000 residents of the area. Each family which can afford it pays $15 per year for all needed emergency transportation, which covers expenses for those unable to pay. By the end of 1974, 150 families had signed up and more were being recruited to meet Council’s goal of 500 enrolled families. Additional funds were raised through a music festival and through a “Walk for Development” in which residents agree to pay a certain amount for each mile walked by local citizens.

Nearly 20 people from the community were trained by the West Virginia Department of Health as emergency medical technicians and a second group will soon be trained. These people volunteer three or four hours per week as rescue workers and ambulance drivers. They are to transport patients to the two nearby hospitals in Morgantown. One used ambulance was donated to the program and a second was to be in use shortly through a grant from the federal Department of Transportation.\textsuperscript{128}

\textsuperscript{126} Telephone interview with Ms. Sara Garcia, Coordinator, Office of Emergency Medical Services, San Diego, California, January 3, 1975.

\textsuperscript{127} “Southeast Ohio’s Answer to the Emergency in Emergency Medical Service,” p. 10. Also, telephone interview with Cay Cross, Public Information Coordinator, Southeast Ohio’s Emergency Medical Service, Athens, Ohio and Mr. Jim Boyce, Administrator, O’Bleness Memorial Hospital, Athens, Ohio, January 1975.

\textsuperscript{128} Telephone interview with Jim Harner, M.D., Volunteer for Seven Areas Council for Health, Rockforge, West Virginia, January 3, 1975. \textit{NOTE:} Through the efforts of this citizen’s group, the county has developed a plan and has applied to the federal government for funding for a county-wide emergency services program. The small subscription program we have described has been discontinued and the Seven Areas Council for Health hopes it will be replaced by a federal grant to the county. (Telephone interview with Council Staff, January 1976.)
Chapter 4

Improving the Content of Care

If our suggestions for helping families to enter the health care system were implemented around the country, we would have achieved a considerable amount of progress in getting needed health services to more families. There are additional aspects of health care which need to be addressed, however, if children are to get the greatest possible benefits from the complicated array of services that the health system offers. Too often a parent who has been contacted by an outreach worker, who has had an appointment made, who has been seen by a doctor and who has been given a prescription, will not purchase the medicines, see the specialist, return for an appointment or be seen again until an emergency strikes. The reason: the overwhelming sense of mystery and frustration in trying to fit all the pieces together is just too much to handle. With no one akin to the family doctor of old who provided many services in his own office, set up contacts with other personally recommended physicians, took the time to explain exactly what was going on, often acted as an ombudsman for his patient, got hospital accommodations and coordinated everything that happened, the family of today often cannot orchestrate the available services or find the appropriate avenues for help. Both the health care system and families and children are the losers, the former through lack of efficiency, the latter through lack of care.

We have identified five aspects of change which are crucial to improving the content of health care. First, the fragmented, categorical, piecemeal way health services are provided needs to be unified into a comprehensive whole. It may make sense to focus on individual aspects of care from the point of view of planners, researchers, government officials, people who teach one area of medicine or doctors who want to practice a subspecialty. But from the patients’ point of view the resulting array of services, rules, buildings, forms, requirements, locations, people and appointments can be a nightmare. A fully healthy person would need all the energy and stamina possible to figure it out, remember all the variables and go to all the different places. For someone who is ill, or who worries about a sick child while keeping a family together, the lack of a comprehensive system of care may be an insurmountable barrier.

Second, even if services were unified, a patient may still require many different procedures, treatments and supportive services to deal successfully with a health problem. One health professional needs to be responsible for the coordination and continuity of care for an individual or a family. The family doctor, with his faded file cards of each and every visit, phone call, complaint, symptom, treatment and its outcome played a crucial role, for medicine is as much an intelligent use of a patient’s history and reactions as it is an application of the latest research. If we devise alternative systems to replace the family practitioner, then some one in the new arrangements must retain his function in assuring continuity.

Third, the interactions between those who provide the care and those who receive it must become more personal, more human. It seems odd to think this is not the case, since attending the sick is a role which should be filled with compassion, and the doctor-patient relationship historically is one of the most intimate. Yet shortages of doctors providing
primary care, the ensuing scarcity of time for personal contact and the emphasis on specialization and sophisticated technology have made the treatment of human suffering a hurried, alienating experience for the majority of people in this country.

Fourth, the health system must recognize that treatment of specific problems brought to doctors is often not effective unless broader needs of patients are met. These range from the need for someone who can help a family follow a doctor's instructions to advocacy in areas like housing and food which impinge on the health of families and children. Organized programs are the key to providing many of these services because doctors alone are not in the best position to deal with these non-medical problems.

Fifth and finally, the number of professionals taking care of people's primary health needs should be increased; the kinds of people recruited and trained as professionals should be diversified; and the array of professional tasks should be redistributed among them. The growth of allied health personnel may have originated to augment the skills of too few doctors, yet these workers have brought added resources that should be acknowledged and built upon. Innovative positions such as nurse practitioners, physicians' assistants, pediatric nurse practitioners and community health aides, as well as rejuvenated roles such as midwives or Army medics have done more than increased the number of patients that doctors can treat. They have added skills and qualities such as knowledge of the community and culture of the patients; more time for compassion, for involving patients in decisions about their health, and for education; and more identification with an advocacy role to help patients deal with related problems, which make the provision of medical care more effective.

Before addressing each of these points in detail, we think it important that those who undertake efforts to assure equitable care to all mothers and children should be alert to some of the key issues related to the quality of medical care.

Virtually all studies of the adequacy of medical care reveal a great unevenness of practices from one region to another, from one town to another, from one hospital to another, from one doctor to another. These variations reflect many different things: differences in the way health care is organized and paid for, which affect decisions on what procedures are followed; different levels of sophistication or knowledge of professionals; and different perceptions among professionals about what medical action is appropriate and effective. Many medical leaders believe these variations in medical competence and practice expose people to unnecessary risks. For example:

— A child has nine times the chances of undergoing a tonsillectomy if he or she lives in one hospital service area in Vermont, where tonsillectomies are most common, compared to an area where they are done less frequently.¹

— A child whose health care is paid for under the Federal Employees Health Benefits Plan has four times as great a chance of undergoing a tonsillectomy if he or she is enrolled under the fee-for-service Blue Cross-Blue Shield program than if he or she is enrolled under one of the prepaid health maintenance organizations.²

— In one urban community, more than 7 percent of children wearing glasses had incorrect prescriptions and therefore did not benefit from them. Inappropriate antibiotics were given to 20 percent of children diagnosed as having middle-ear infections.³

— A national survey of physicians showed that, of more than 4,000 doctors completing a national quiz on antibiotic use, half scored fewer than 69 percent correct.⁴

— In one university hospital, if decisions had not been made to induce labor or perform Caesarian


³ Assessment of Medical Care for Children, Vol. 3, “Contrasts in Health Status.”
sections only because of patient or physician convenience, a significant proportion of respiratory distress syndrome in newborns would have been prevented.

A five-year examination of surgery by the American College of Surgeons and the American Surgical Association, which examined data about patients treated at 95 hospitals in seven states, found that 78 percent of the preventable complications were due to surgeons’ errors, with one-half resulting from faulty surgical techniques.

Some of the problems related to poor quality medical care could be solved through changes in the organization and financing of care. Doctors practicing in groups and paid in ways other than fee-for-service have markedly better records on a number of quality measures. When providers are paid per patient on an annual basis there are no economic incentives to provide unnecessary services. Doctors working in groups have easy access to informal consultations and supervision from peers. Many groups also make it easier for professionals to keep informed about new medical developments, whereas it may be more difficult for the doctor practicing by him or herself to take time for continuing education. The solo practitioner may be more dependent on drug companies, for example, for information on the effectiveness, use and dangers of new drugs, although the drug company may have a vested economic interest in the information it is conveying.

Some problems with quality of medical care could be solved if there were more effective monitoring of professional activities by the profession itself, more efforts to identify which procedures are effective under which circumstances and better communication among professionals. This would result in fewer individual variations in treatment when there is widespread and sufficient agreement about what works and what does not.

Some problems with quality of medical care could be solved if consumers were more knowledgeable and active in monitoring professional activities, both on an individual and an organized basis. Trust between doctor and patient is essential, but it need not be blind trust. The more consumers know, the more intelligently they will be able to listen to and question the professional, and the more effectively they will be able to participate in decisions about their own health.

There will nevertheless remain some quality problems which arise simply from the nature of the practice of medicine. Although considerable funds and talents are being devoted to biomedical research, there is still a paucity of knowledge of the underlying nature of most diseases, so that in many instances diagnosis and therapy can only be based on subjective evaluations of symptoms and other factors.

**Unifying Fragmented Services**

Consider the case of a young woman whose family is receiving Aid to Families with Dependent Children. Assuming that she is well-motivated she will seek prenatal care as soon as she finds that she may be pregnant. She seeks this care from her local health department clinic. When the time comes for her to deliver the baby, she is transferred (theoretically with her records but actually most likely not) to a public hospital. There she encounters a new set of documents and personnel for delivery of the baby. Before discharge, the baby will be examined by a pediatrician who will never see the child again. Now this young woman will take her baby to a well-child clinic operated again by her health department but at a different place from where she received her prenatal care and at a different time. After several such visits to the well-child clinic, the baby may become ill. When the mother takes the baby to the clinic where the doctors and nurses have been providing care, she is informed that she cannot obtain care there any longer because the child is sick. She is advised to take the child to a physician near her home who is paid by the welfare department. This new physician establishes still another record for the baby and provides care in his or her office. If the child becomes sick enough to require hospitalization, the physician


6 "Study of Surgical Services for the United States."
tells the mother that (s)he is not able to admit her
child to the hospital where (s)he practices be­
cause she is on welfare and she must take the
baby back to the public hospital. She turns again
to the public hospital care for her sick child, but
in a few days she is informed that the child has a
special condition making the baby eligible for
crippled children’s sources, which must be pro­
vided at still another resource. . . .7

Any parent having to figure out and go through
this complicated maze of services might easily give
up in confusion or exasperation. The burden of in­
convenience, however, falls disproportionately on
the poor, who must rely on a host of unrelated ser­
vices for their health care. It is no wonder that poor
children are less likely to see a doctor for prompt
attention to their medical problems. Parents faced
with the prospect of multiple offices to visit, ap­
pointments to make, bus trips, waits, forms to fill

7 Nathan Glazer, “Paradoxes of Health Care,” The Public

out, records to transfer and the same questions to
answer again and again might well decide to post­
pone a visit to the doctor until there is no other alter­
native.

Why are our health services so fragmented? For
one thing, medicine in the United States is consid­
ered a private commodity that is not regulated,
planned or managed in any coordinated or coherent
way. For another, we have not introduced incen­
tives for changing the way care is organized and
delivered even when new programs are legislated.
For example, Medicaid has paid for services
exactly as they were being delivered rather than
using its funds as a lever to encourage the develop­
ment of new arrangements.

Thirdly, when government has gotten into the
 provision of health services, it has traditionally
done so through narrow categorical programs
which identify and separate care into specific ser­
vices focusing on selected health needs. Such
programs are easier to convince legislators and the
public about since a dramatic case can usually be
made for particular problems with particular solutions. Resources can be targeted on specific populations, giving a feeling of rationality in the setting of priorities for care.

But the health outcomes are not at all as tidy as the reasons for categorical delivery of care would predict. Only those categorical programs specifically designed to provide comprehensive and continuous care (such as Children and Youth and Maternal and Infant Care projects, and neighborhood health centers) have avoided the disadvantages of narrow categorical grants. For the health care system generally, categorical support for uncoordinated, fragmented services has produced duplications of services and chaos that are highly uneconomical and inefficient. In a study in a low-income neighborhood in Pittsburgh, only about half of the families in the sample showed an unduplicated use of services.

For the patient, fragmented services not only waste time and money—they result in inadequate care. When the frustrations of navigating the system are great enough to discourage parents from seeking care at all, children's health problems may escalate until they are more complicated and costly to cure, or become permanent or chronic disabilities which might have been prevented through early detection and treatment. Discouragement is not unlikely. A nationwide household survey of 11,800 people of all income levels showed that dissatisfaction with coordination of care ranked third (behind access and cost) as a cause of discontent with health care services.

Fragmentation may also mean that detection and treatment occur in different places, often resulting in diagnoses not being acted upon. A survey in eight states showed that during fiscal year 1973 less than half of the children screened under EPSDT who needed follow-up care received it. Of children examined in school health programs in 1963, 19 percent were referred for further care, but only 8 percent received it. In a study of school health programs in New York City, it took an average of six to eight weeks for children to get referred for follow-up care, and even then, 44 percent of the children who got care did not receive a satisfactory level of care. The many children who fall between the cracks in a fragmented system are missing needed care.

The quality and efficiency of care will be improved if most primary health services are available in one place and under one set of administrative auspices. Primary care centers like Neighborhood Health Centers and Children and Youth projects have shown that great benefits result from offering comprehensive care through one place and under one administration. These centers generally provide the whole range of medical services as well as educational, social, nutritional, mental health and other related services. Many of the programs have features like outreach and provision of transportation which contribute to their impact. There is considerable evidence to suggest that the full scope of services, especially when accompanied by these other program elements, makes a crucial difference.

—Reduced use of the emergency room. In 1968 a neighborhood health center was established in Rochester, New York, in a location which had previously been the site of a clinic with limited services. Within two years after the center was opened, there was a 38 percent decrease in emergency room visits from center area children. During the same period, pediatric visits to the emergency room from other areas increased by 29 percent.

8 This discussion of the disadvantages of categorical funding for selected health services should not be misinterpreted to mean that we favor bloc grants. We believe care should be taken to identify for support those programs which offer comprehensive (not categorical) services.


10 "The Public's View of the Crisis in Medical Care: An Impetus for Changing Delivery Systems," p. 191.


—Reduced hospitalization. In the 12 months before the neighborhood health center at Columbia Point, Boston, opened, the demand for hospital beds by the community to be served approximated the rate of the U.S. population. After two years, health problems were generally treated at an earlier stage with the result that the number of hospital admissions was reduced by 70 percent and the number of hospital days by 80 percent.15

The experience of the neighborhood health center in the Mile Square area of Chicago was similar. During the years 1971 to 1973, while the number of patients served increased by 24 percent, the number of days of hospitalization decreased by 26 percent.16

—Increased consumer satisfaction. In the words of a woman referring to a comprehensive center in her neighborhood: “It’s such a security to know it’s there. At the clinic you get a complete physical, and they will find out everything about you all at once. It’s more convenient to go to the clinic. It’s like pulling teeth to get my husband to go to a doctor, yet he has been to the clinic.”17

The services available through one source of care may not always be provided at the same site. For example, a center may send outreach workers into the community, public health nurses or family health workers into homes and its psychologist to the local school to work with children with learning disabilities. Where different sites are used, the program must set up effective ways to coordinate care given to an individual in these various places. Beyond coordinating these services, each source of primary care needs to establish easy working connections to more specialized care.

One person should have the responsibility of coordinating the diverse services a child or family needs. When needed services are not available as part of a health program, effective links between services should be instituted. For example, there may be times when families will need specialized services—such as hospitalization, examination by specialists, complicated therapy or use of expensive equipment—which are not provided directly in a primary care facility. When these services are not available at the families’ local source of health care, the professional responsible for the patient should arrange and monitor the connections with other sources of care. While nearly every program professes to do referrals and to coordinate care, as we have shown above, most do not do a good job of achieving this. Where coordination has worked, the programs had the following characteristics:

—Clear assignment of who, among the cooperating group of providers, has responsibility for case management.

—Sufficient explanation to the patient or family by the person making the referral of why it is necessary and what is likely to happen. Families who regularly come to one source of care may view a referral to another provider as a rejection, a criticism or a runaround. Staff at the local health program should spend sufficient time to explain the reason for the referral so that it is not misinterpreted.

—Appointment reminders and follow-up contacts for missed appointments by postcard, telephone or home visits.

—A written report from the professional to whom the referral was made to the patient or his or her parents, the person who made the referral, and other providers involved in the health plan for the child.

—Referral to the most comprehensive and best organized array of services possible.

For example, in Rochester, New York, two types of health referrals were tried for children who were screened for health problems in public schools. In one school, children with detected health problems were referred to the nearby neighborhood health center which had comprehensive services. In another school, children who needed treatment were referred to health departments, hospital specialty clinics or private physicians’ offices. The students at the first school, who
went to the comprehensive clinic, had a higher percentage of their problems treated than those who went to less comprehensive sources of care.\textsuperscript{18}

\textit{Fragmented services can be reorganized to provide comprehensive care.} For example, in New York City, 76 child health stations run by the City Health Department, serving over 110,000 children from low-income families, traditionally provided only well-child care. But as the families did not have ready access to other care when their children became ill, the limited scope of the stations was not meeting the actual needs of a great proportion of the children.

In 1972, the Health Services Administration of New York began to assist the child health stations to plan and convert services toward more comprehensive care. Health Department doctors and nurses began to treat common ailments like acute respiratory conditions, diarrhea and skin infections, and full-time staff were added to keep the stations open for longer hours. In some of the stations, laboratories were added on the premises; in others, arrangements for lab services were made with nearby hospitals or medical facilities. Small-scale pharmacies were set up in the stations. Referral arrangements were established with nearby hospitals for serious conditions, x-ray and other procedures requiring equipment which not all the stations had.

These changes did indeed improve access to care. At six new comprehensive health stations studied, registration climbed 5 percent during a one-year period while it decreased 11.5 percent in the city's health stations overall. Data show that community residents began to identify the centers as their usual source of care, whereas formerly many said they had none. The use of the clinics increased for treatment as well as for preventive services.\textsuperscript{19}

More ambitious strides toward providing comprehensive services have been taken at the Genesee

Hospital in Rochester, New York. Until July 1972, care had been provided through a variety of outpatient specialty clinics. But a coalition of community groups, staff physicians, the Hospital’s board of governors and the Office of Economic Opportunity (which provided financial support through the Rochester Community Health Network) decided to phase out the hospital’s fragmented clinics and combine them into the Genesee Health Service, a comprehensive service center housed in a professional building next to the hospital. Both the new Genesee Health Service and the Emergency Division of the hospital were administered by the Director of Ambulatory Services, a new position created to ensure coordination. Regular meetings and education programs for consumers were conducted to acquaint them with the new services and to encourage them to suggest ways for improving care. The program offered comprehensive health services through a group practice employing full-time, salaried physicians and a variety of health workers including physician associates, nurses in expanded roles, a psychiatric social worker and outreach workers. Hospital facilities are used for the more serious or specialized problems that arise.

Among patients who formerly had used the fragmented clinics, the presence of the Health Service has reduced their use of the Emergency Division for non-emergency services by 71 percent.\textsuperscript{20} The same population indicated universally greater satisfaction with the new Health Service, especially with respect to comfort, convenience and the degree to which their children’s health care was personalized.\textsuperscript{21} Greater percentages of children born at the hospital used the Health Service for well-child care than had used the old clinic system, and significantly more Health Service users were up-to-date in preventive procedures than families who had used the clinics had been.\textsuperscript{22}

While in most cases health services should be unified rather than fragmented, there are specific circumstances in which separate, categorical services may be more effective. Questions to ask in making such decisions include: (1) Is the service likely to be more acceptable when provided separately? For example, many health centers serving entire families have found that adolescents are reluctant to use their services. Teenagers may feel that the staff is not sensitive to their special problems, or that their parents will learn that they have come in for a pregnancy test, treatment of venereal disease or another problem they may want to keep confidential. Specialized clinics for adolescents may find their health services more widely used.\textsuperscript{23} (2) Might a special program reach people who would otherwise remain unreached, and, if so, can it be made an effective entry point to other needed services? A screening program using EPSDT funds that is organized by a welfare rights group may be able to reach different children than a similar program offered by the local health department. The advantages of finding ways to get children into a health care system should not be overlooked. However, when a categorical approach is used, systematic referral and follow-up to comprehensive sources of care are crucial.

Finally, (3) is the cost of providing the service in a fragmented way so small, the benefits so great, and the connection to comprehensive care so readily established, that the separate effort becomes worthwhile? For example, certain screening tests for vision and hearing problems can be done so efficiently in a school setting that, when coupled with effective follow-up, such screening makes sense.

\textsuperscript{19} Lloyd F. Novick, Anthony Mustalish, Gary Edisvold, “Converting Child Health Stations to Pediatric Treatment Centers,” Paper delivered to the American Public Health Association’s 102nd Annual Meeting, October 1974.
\textsuperscript{20} Ralph Ullman, James Block, William Stratmann, Ned Boaright, “Impact of a Hospital-Based Primary Care Group on Emergency Room Utilization,” Health Services Research Center, The Genesee Hospital, Rochester, New York, 1975, Table 4, p. 12.
Providing Continuity of Care

Closely related to unifying fragmented services and to having one health care professional to monitor a patient or family is the notion of continuity of care. Continuous care means regular checks on a person's health, the use of accumulated information about a child's or a family's health, systematic use of preventive health measures, prompt treatment for problems as they arise and ongoing follow-up to make sure treatments are working and good health maintained. Whatever the shortcomings of the solitary general practitioner of old, the feeling that someone knew everything medically about you and was responsible for you throughout your life generated a feeling of confidence that is missing for most families today, whether they rely for care on a host of private specialists, a public health department or a hospital. As a patient at a clinic in a city hospital said, "... they keep on having you come back and back, and they don't know what each other says. Each time they start from scratch."24

Continuity of care is more than a sentimental preference of patients. The bulk of research on the subject demonstrates that continuity is an important factor in both the quality and economy of care. The Journal of the American Medical Association, for example, reported a study of the outpatient department of a large teaching hospital which showed that doctors caring for patients in specialty clinics were not aware of from 28 to 98 percent of abnormal laboratory findings which might have affected their handling of the patients.25 This problem is not unique, of course, to hospital outpatient departments, but it dramatically points to what can happen when there is no continuity of care.

Other studies show that when care is continuous, a physician can detect complications at an earlier stage because of his familiarity with the patient;26 patients are more likely to keep appointments and, if they can't keep their appointment, they are more likely to notify the clinic that they won't be there.27 Patients with a regular doctor or medical team member are more diligent about following instructions concerning medication.28 This sense of trust, built up through repeated visits, often prompts mothers to give more complete information about their children for medical records and to take the initiative in reporting problems that have come up.29 In a one-time visit with a new professional, a mother or pregnant women is more likely to answer only the questions that are asked and to volunteer little else.

A family with a regular doctor at a clinic is less reluctant to seek care when it is needed than the family which has been shunted from one doctor to another at each clinic visit. The family which identifies with a specific doctor is also less likely to make unwarranted visits to the emergency room.30

From the physician's vantage point, knowing the patient makes an appreciable difference in the quality of the professional decisions. After sharing the course of an illness with a patient, the doctor knows the patient's particular responses to treat-
ment. As a result, it has been shown that fewer diagnostic procedures are ordered and it is less likely that the patient will be hospitalized unnecessarily.31

Providing continuous care is not easy. But it is possible. The creative use of personnel and the intelligent use of medical records can help promote continuity of care.

All health programs should be designed or reorganized so that each patient has a continuous relationship with a physician, nurse practitioner or other trained health worker. The Pediatric Clinic in the Baltimore City Hospital has three full-time pediatricians, each working with a regular team of other health workers. Until recently, each family was assigned to one pediatrician whom they could see through scheduled appointments during regular clinic hours. If a member of the family walked in without an appointment or needed medical help evenings or weekends, the pediatrician or resident on duty had access to the family’s records and, if necessary, could supplement this information by consulting the family’s regular physician. Limited funds, however, have forced the project to cut back and reorganize its staff, with the result that patients cannot now always have a regular doctor. Since the time when this change was made, compliance with medical instructions has deteriorated, the rate of kept appointments has decreased, and the use of emergency rooms has increased. While the results cannot be attributed solely to the changed system of doctor-patient contact, the Clinic’s director believes that the lack of continuous care has been the most important factor.32

Family members should have options about which particular doctor or other professional will be the continuing source of care. For example, in the Kaiser Permanente program, patients choose their own physician from among the doctors in the program and are encouraged to see the same person each time they make an appointment. If they find they cannot establish good rapport with the doctor they have chosen, they are free to change physicians.

32 Telephone interview with Dr. Zsolt Koppanyi, November 1, 1974.
Another model which can be adapted to assure continuity is the use of health teams. These are now a fairly standard practice in many maternal and child health programs. The needs of the population served determine who make up a team, but generally it consists of a physician, nurse practitioner, family health worker, nurse aide and clerk, with social workers, nutritionists and mental health specialists available if needed. When teams are used, patients develop ongoing relationships with various members of the team. A case in point is the Children and Youth Project at Children’s Hospital in Columbus, Ohio, which has five satellite clinics in the city and a sixth in a rural area nearby. Each patient is assigned to a multidisciplinary team. The nurse on the team provides continuity because she is also a public health nurse who has home visiting duties in the same neighborhood served by the satellite clinic.33

Many health programs have experienced a fairly rapid rate of staff turnover which thwarts providing care by the same professionals over time. One of the most successful ways of guaranteeing continuity in such circumstances is by hiring and training health workers who live in the neighborhood. These workers are known by the residents and tend to stay with the program. As a result, their friends in the community associate them with the service and an ongoing link to the program is established. A nurse practitioner at the Anthony Jordan Health Center in Rochester, New York, said that the family health aides and assistants, who are trained community residents, provided the main source of continuity for patients in the program. Nearly all the aides and assistants are still with the program after six years.34

Medical record systems should be designed to promote continuity of care. Many advances have been made in recent years in the design of forms for medical records and computer systems for their easy retrieval so that information about a patient can be used by any health care professional. Accurate and thorough case histories which only need to be recorded once, vital information about sensitivities to medication or other pertinent facts can help a new doctor or nurse know a patient in sufficient detail to provide quality treatment.

In the Denver Health and Hospitals program, comprehensive health services are offered through eight health stations around the city, with well-baby clinics and hospital services integrated into the system. The medical records used in all the services are designed so that they are compatible and can be easily understood by professionals at any health center. They are housed at the facility where the family receives primary care and are forwarded as needed to hospitals, medical specialists or other providers of care.35

Systematic continuity through records need not depend on the resources and sophisticated system found in Denver. The East Coast Migrant Health Project is achieving similar results by forwarding educational and health records for children in a school program along the migrant stream to any other part of the country where the families have moved.36 Important information from the patients’ health history, including personal or cultural attitudes that may be relevant to treatment, can be taken into account in determining the services children receive in diverse places and from various people.

33 Paul Ertel, J. Philip Ambuel, Bruce Graham, “What is a C and Y Project?,” University of Minnesota Systems Development Project, #8-10 (11), 1968.
34 Interview with Deborah Williamson, Nurse Practitioner, New Orleans, Louisiana, October 23, 1974.
35 Telephone interview with Peg Harder, October 31, 1974.

The record transfer procedure used by the East Coast Migrant Health Group is known as the Uniform Migrant Student Record Transfer System. This system is funded by the U.S. Office of Education and operates through a central computer in Little Rock, Arkansas. Health and education data on migrant students throughout the United States is stored at this location. When a pre-school or public school program receives a new migrant student, they notify the computer and are sent any information which the central bank has on that child from schools which that student has previously attended. The new school is then asked to forward any revisions, updates or new data to the central bank so that the most recent information on the child will be available to schools that may receive the migrant student in the future. Detailed health data is separated from educational test data and is only sent to health personnel at the school.
There can be problems, of course, with keeping records containing many kinds of information related to health and making them available to increasing numbers of personnel in and outside the health care system. Safeguarding patients' confidentiality—one of the most important components of the doctor-patient relationship—should not be overlooked when designing medical record systems. Especially dangerous are entries which could be used to label children and stigmatize them, opinions or assessments which become outdated but which remain in a permanent record, or access to unexplained or fragmentary information by agencies or individuals beyond the health team or patient (e.g. schools, credit companies, insurance companies, law enforcement officials, etc.). The potential value of medical records for providing continuity should be considered together with careful attention to the problems of patients' privacy. Procedures to ensure privacy would include: (1) patient access to the medical record (parent access for young children's records); (2) a system for periodically deleting outdated, erroneous information; (3) strict controls against access by third parties to health records, requiring the written consent of patient or parent; (4) prohibiting unauthorized computerization of personally identifiable health data outside the place where primary care is provided; and (5) in-service training for all health personnel who handle health records to apprise them of privacy considerations. For a list of groups and guidelines dealing with issues of record keeping and patients' right to privacy, see Appendix D.

**Humanizing Care**

My classmates and I had cadavers as first patients—with no preparation for the emotional impact of dealing with dead bodies. We learned to objectify patients, marking out their lungs with wax crayons, 10 of us queued up to listen to a heart murmur or feel a rectal tumor. The message was to become distant. Feelings and empathy were ignored and the grand-old practitioners demonstrated "bedside manner" by warming up the head of the stethoscope, ignoring the fact that the patient lay unclothed in an amphitheatre pit—a "case" to 150 medical students. 37

This is a doctor's description of his medical education. The distance he speaks of is often explained as a doctor's psychological defense against daily encounters with human suffering and death. But when it results in inattention to patients' anxieties or emotional stress, it can seriously diminish the quality of care. People's psychological and physical problems are often inextricably intertwined. So must be the way their problems are treated.

This personal dimension of health care is becoming increasingly important in treating children. Whereas doctors used to spend most of their time with infectious diseases and serious illnesses, an increasingly significant portion of the health problems of children are what the noted pediatrician, Dr. Robert Haggerty, terms "the new morbidity." 38 This includes learning difficulties and school problems, behavioral disturbances, allergies, speech difficulties, child abuse and the problems of adolescents in coping and adjusting. Because their roots are in the complex interaction of biological, social, cultural and environmental factors, solutions to these problems cannot be approached in a narrow technological way but require a health system which can provide human support.

Finding ways to provide this support are complicated. For example, some would say that one way to get more sensitive doctors is to select medical school students on their ability to relate to people in addition to their scores on tests or proclivity toward research or academic achievement. But medicine has always been highly technical, and it is becoming an even more demanding science. The proper balance between intellect and understanding, between technical efficiency and human empathy, may be difficult to find or maintain in medical students.

Another way to make medical services more humane is to make the hours doctors are available fit more with patients' needs and to reimburse them in ways that would not discourage time spent with patients. This is most effectively done through

38 Child Health and the Community, p. 316.
group, rather than solo, practice, where several doctors can share the burden of long hours and where income need not be so closely tied to services rendered. But some studies have shown that group practices, while achieving many desired reforms, are perceived by patients as providing less sensitive, less humane care.39 Somewhere along the line, the goal may have been subverted.

Solutions to these dilemmas, however, must be found, for most experts now agree that attention to the human side of medicine is an integral component of diagnosis and treatment. They have noted, for example, that very often when a patient comes in with physical symptoms, although an examination finds “nothing wrong,” something is very wrong with another part of the patient’s life. Failing to ask the questions or to set an atmosphere which would allow the patient to tell the doctor what really is “wrong” can result in wasted tests, ineffective treatments, repeated visits and unalleviated anxiety which may lead to greater physical problems.

Researchers have also noted that stress is highly correlated with people’s susceptibility to disease.40 Knowing the circumstances in a family’s life—poverty, divorce, a new marriage, a relative’s death, sudden unemployment, and so on—may provide valuable clues to a physician trying to pinpoint the cause of a child’s illness or to plan a treatment regimen. Such information is not usually included in a standard medical history but can be elicited during the course of an examination or talk if a physician remembers to ask.

But even though this research is well-known and the importance of a “bedside manner” is a recognized fact, studies have shown it often gets lost in practice. One survey of well-baby clinics revealed that the physicians stuck to a highly structured, stereotyped interview, with little opportunity for true communication with the mothers, either to hear questions or to assess the mother’s resources to carry out the health care plan.41 Another study found that half the questions about child behavior raised by mothers in well-child visits were not dealt with or even acknowledged.42 Time, a setting, caring to ask and the skills to listen, must be an integral part of medicine. More than half of a pediatrician’s time is spent on problems involving psychological factors which require skills in perception and communication rather than medical technology.43 Most studies support the conclusion that:

The parents ... know their child far better than those trying to help care for him. Listening to parents, carefully noting their observations, putting them at ease, and hearing out their worries even if they appear unrelated can provide a way to help them with the emotional resources needed to help their child. Impatience or misunderstanding with parents can impede their inclusion in the therapeutic process, particularly because parents will continue to have caring responsibility for the child after his illness—a point easily overlooked during the time of acute intervention.44

The effects of providing care in a human, personal manner are real, measurable and significant. Studies have shown that treatment outcome, compliance with prescribed therapy and the way services are used are all affected by the nature of the


interaction between doctor and patient. Satisfaction and compliance with recommendations of pediatricians increase when parents perceive the doctor to be warm, compassionate, respectful and easy to talk with. Dr. Haggerty contends that "... there is no doubt that this skill to become involved as a human being with patients clearly results in improved diagnosis, better compliance, and improved outcome of therapy. I would add that it also is related to the greater pleasure of the provider."\(^47\)

The effectiveness of much health care depends on parents and children following medical recommendations, whether that means taking antibiotics for the prescribed period, doing certain kinds of exercises faithfully and correctly or maintaining a special diet. Instructions are not always followed. For example, in Monroe County, New York, a study was conducted in three private pediatric group practices of how systematically children took oral penicillin prescribed for a strep or middle-ear infection. The compliance rate was unrelated to the age or sex of the child, duration of symptoms or the doctor's estimate of the severity of the infection. It was related, however, to factors in the doctor-family relationship. If penicillin was prescribed by a member of the pediatric group other than the child's usual doctor, the child was less likely to get the full course of treatment (five days of oral penicillin for strep and nine days for middle-ear infections). The authors of the study suggest that the increase in compliance may be due to the warmer, closer relationship between the regular doctor and the family.\(^48\)

Doctors must be aware of their patients' level of understanding and ability to carry out their orders. Failure to comply with instructions in most cases is not caused by apathy or recalcitrance, but by not fully comprehending what is wrong, or the importance of following instructions to the letter, or simply not being able to purchase the medicine, isolate the youngster, stay out of work, etc.

All people need this kind of understanding, time for explanation and help in managing compliance with doctors' orders. An educated, middle-class parent may be more likely to have a regular pediatrician who explains why he is recommending certain things and that parent is more likely to know what to ask or has sufficient experience with professionals to demand time and explanations when something remains unclear or frightening. Still, dissatisfaction with the quality of information shared and the willingness to talk or allay fears is a common experience of middle-class parents. The situation is even worse for the poor parent. Usually using a clinic irregularly, often seeing different personnel each time, a poor parent is less likely to get that kind of personal attention, less likely to ask about all the things he or she needs to know and less likely to demand sufficient explanations.\(^49\) Professionals and planners must be responsive to this need.


\(^{49}\) In Ancient Greece the relationship between the doctor and the patient was determined by the patient's status as a free person or a slave. The slave was never talked to individually nor allowed to discuss his complaints but given orders for a remedy based on the experience of the doctor. On the other hand, the free person was consulted at great length and first persuaded that the remedy was the correct one before any cure was begun. Medical practice in the U.S. today clearly reflects a similar distinction. (Suzanne Loebl, "A New Way Must Be Found to Safeguard Medical Privacy," New York Times, 7 December 1974, p. 29.)

"Once access to a source of adequate care has been obtained, it is reasonably likely that all patients will receive an attention that takes into account the appropriate scientific and technological aspects of present medical knowledge. It is not at all likely that all patients will receive care equally appropriate to their needs as persons. Empathy, concern, kindness, understanding, respect—are not equally available to all patients. Disadvantaged groups include the poor and unemployed; the non-white and non-English-speaking; women; "hippies" and other persons who appear not to respect prevalent standards of dress or behavior; and many of the aged and handicapped. The disadvantaged may include, in fact, everyone but the physician's re-
Health services can be made more humane in several different ways. In planning how physicians allot their time, leeway must be included for the possibility of leisurely consultations with patients or families. The design of a clinic or office should be conducive to easy, private communication. Many situations requiring this extra time and privacy are predictable. For instance, when a complicated medical condition is diagnosed or a procedure is recommended that will produce pain or fear, or during the first prenatal visit or the first visit after a baby is born, doctors and other health workers should expect to spend extra time with patients and parents. When this is done, the results are impressive.

Among children undergoing tonsillectomies and adenoidectomies at Yale-New Haven Hospital, some were given the opportunity for a full discussion with a special nurse before the operation. Compared to a control group, the children with special preparation had a faster rate of return to normal temperature and a greater reduction of nausea, vomiting and blood pressure. The two groups had had abortions, but only half received counseling. Of the group receiving counseling, nine out of ten women accepted and continued contraception following their abortions while only six out of ten of those who were not counseled ever returned for post-abortion checkups and contraceptive devices.

Much more frequent than explaining serious medical problems, of course, is the need for more than a routine conversation during a routine visit. Some programs and some physicians design their appointment systems in such a way as to leave time for longer conversations as the need arises. Others set aside specific times each day or week during which patients or parents can return for a more relaxed consultation.

Some may say that a highly trained professional’s time is not well spent in a leisurely chat with patients or explaining the reasons behind medical decisions. It is inefficient, they argue. But they overlook the fact that the professional’s warmth and clarity of explanations are directly related to how well patients comply with treatment regimens. In one study of eight hundred outpatient visits to Children’s Hospital of Los Angeles it was found that when mothers perceived the doctor as unfriendly, non-compliance with prescribed instructions increased from 11 to 24 percent. 

Supportive counseling and therapy provided for mothers with a history of spontaneous abortion in a hospital in New York City was found to increase the likelihood of delivering a full-term infant. An experiment at Children’s Hospital in Washington, D.C., found that support and training by public health nurses for mothers of medically high risk infants during the early years of life have significantly enhanced the child’s nutritional status and mental development. And in the San Francisco General Hospital, two groups of patients were compared to evaluate the difference talking to health personnel would make. All 198 women in

Reference group: white, male, middle-class, educated, employed and achievement-oriented. (Mary C. Howell, M.D., “Nurturance in the Delivery of Primary Health Care,” Child Health Station, York Corner, p. 1. (Mimeograph.))


As one doctor observed about those who advocate narrow cost-efficiency criteria to the exclusion of other considerations, if we “encourage limiting the time and effort of health care personnel to as little as the public will tolerate ... we are clearly in danger of exchanging the short term goal of lowered costs for the longer term effect of better health.”\textsuperscript{56}

Humanizing health care will lead to more knowledgeable use of the medical system. A greater emphasis on talking, listening and explaining makes possible \textit{educational efforts enabling parents and children to become active and knowledgeable partners with health professionals in the process of patient care and health maintenance}. It may seem paradoxical that we are urging health professionals to be more supportive, helpful and accessible to patients while at the same time urging that patients become more self-sufficient and less dependent on doctors. The inconsistency is only superficial. Patients who know enough about their health and who understand what they can and cannot do themselves will exercise better judgment in when to use professional services, and they will be more likely to carry out and benefit from medical advice.

For example, at the University of Vermont College of Medicine, two programs have provided patients with their medical records or summaries and evaluated the consequences: Could patients understand the medical terminology? Would they have more anxiety about illness with more detailed information? Would they challenge physicians’ decisions? How would the records be used?

Both programs showed marked advantages after sharing records with patients. At the Given Health Care Center—a group practice of five internists offering comprehensive care to families—all the patients were overwhelmingly in favor of receiving the more detailed information and 78 percent indicated they had made changes in their patterns of living, eating or drinking after reviewing their re-

\textsuperscript{56} “The Boundaries of Health Care,” p. 110.
The most significant response was that 97 percent of the patients indicated less worry about their health after receiving their record. The physicians concluded that the fear of increasing anxiety on the part of the patient and family, misinterpretation of technical language and the fear of increased litigation around problems identified in the record are largely professional myths, not substantiated by experience.

At the University's Department of Rehabilitation Medicine which treats patients with more complex physical disabilities, copies of admission notes (which contain descriptions of the patients' problems, historical information, objective findings and plans for therapy) were given to all members of the health team, including patients. Every two weeks there were conferences with doctors, patients and their families, and summaries of medical progress were made available to all. This system was initiated because patient education is a crucial factor in determining how successful the treatment will be. The physicians in this program have written:

We have had no significant problems using this system and have noted dramatic improvement in the trust between patients and staff. Patients who have a part in deciding upon their own care will also be more cooperative in following through with that care. We have found that this system is especially helpful in resolving behavioral and emotional problems since our honesty with the patient helps him to be more honest in his own evaluation of his problems. . . . We have had some problems with medical terminology where the dictates of time have prompted us to use medical language not easily understood by the patient. This problem has usually been resolved by the physician briefly discussing the report with the patient and giving him a general explanation for the medical terms.

“Self-help” or “self care” classes can also be useful. For example, both the Duke University Medical Center in Durham, North Carolina, and Georgetown University and its three associated health plans in the Washington, D.C. area are offering classes open to the public in practical procedures for doing self-diagnosis and treatment. They emphasize that, with minimal training, people can rely on themselves to prevent much illness and treat many of their simple health problems. Students are taught how to take vital signs and use standard equipment (stethoscope, otoscopes), to report relevant observations to health professionals when seeking advice or care, to practice preventive measures and to recognize their own limitations.

Self-help techniques are useful in a variety of areas: self examinations of the breasts; detection of the early signs and symptoms of venereal disease; awareness of signs of possible trouble during pregnancy; and recognition of ear, nose and throat problems in children due to colds, flu, allergic reactions. The Georgetown University program reports that the course has increased participants' feelings of confidence in dealing with health issues and health professionals, reinforced the importance of preventive action and created a group of lay leaders to whom others are turning for advice.

In Durham, North Carolina, the Community Health Education Program of the Duke Medical Center is helping to build the skills of carefully selected community leaders who are not employed by the health program but to whom neighbors go for informal advice about a number of things. The Center is training approximately twenty such leaders about health care and use of health services so that when friends turn to them with problems, they are knowledgeable and can be helpful. These people have regular jobs in the community as auto mechanics, farmers, housewives or whatever. They attend evening training sessions through the

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University program for about three months while continuing with their regular work. The only real expense, then, in the services they provide are the costs of initial training and some supervision by the project staff. They are taught how to detect signs and symptoms of disease, which disorders lend themselves to certain kinds of self diagnosis and treatment not requiring professional attention, and what facilities in the area can handle health problems which do require special attention. Once trained, each "health facilitator" meets once a week with a member of the University staff to discuss who they have been in contact with during the week, what kinds of problems were brought to them and what their advice was. Presumably, as they get more experience there will be less supervision required.

The prepaid health plan which serves the residents of Columbia, Maryland, in affiliation with Johns Hopkins School of Medicine instructs parents how to take throat cultures from their children at home rather than making office appointments when there are indications of a possible strep infection. Parents are taught the indications that an infection might be present, the techniques of swabbing and are provided the necessary equipment so they can take the specimen directly to the laboratory. When the culture is positive the parent is called by the clinic to bring the child in for an examination and treatment.

A study of the program shows that parents obtaining cultures from their children at home detect strep infections as accurately as health assistants in the clinics. Two-thirds of the families felt the home culture approach improved medical care and stated it reduced anxiety, decreased contagion and eliminated unnecessary visits for children and their siblings. No parent thought that the quality of care had been diminished by the program. The study concluded that a trained mother—at least in the kind of population and the kind of health plan studied—"can play a major role in promptly and accurately identifying streptococcal throat infections without consulting a health care provider," possibly resulting in a "significant reduction in pediatric utilization of clinic facilities." While there is no quantifiable evidence as yet, it also seems reasonable to conclude that the new skills of the parent are likely to enhance an effective collaboration between parent and physician in other areas as well.

Support and Advocacy from the Health Care System

There is a paradox in children's health care. Nothing makes parents want to act more swiftly than their child's illness, and yet there is often little or nothing parents can do to make the health system be responsive to their needs. Just when they need reassurance and advice the most, they face a maze of harried, impersonal providers with little time to offer support or advocacy. Their child's illness can make them fearful, less able than ever to cope with complex rules, yet they must figure out eligibility and other requirements and manage to comply with orders requiring unusual expenditures of time, energy or money. If the health need involves the entire community—such as protecting children from rat bites or lead paint or contaminated water—it may be even more difficult to make the needed changes. Here, too, those who need help the most are in the poorest position to get it.

Health care professionals are faced with a paradox, too. They say they are frustrated because the people who need their care the most often have so many other problems that medical advice is not followed, and even when it is, it does not make a dent in the surrounding conditions that contribute to poor health. Doctors treat children for iron deficiency anemia again and again, even though they have told parents what foods children should eat to prevent its recurrence. They prescribe drugs to control chronic conditions only to find a mother not purchasing them, or giving half as much medicine so that it will last twice as long. As we have seen from the words and descriptions of many rural and urban parents, but particularly those in poor

62 Telephone interview with William Beery, Ex-Program Director, Community Health Education Program, Duke University Medical Center, Durham, North Carolina, October 1974.

families, they are equally frustrated by their inability to do better for their children.

This stooped, grey-haired woman had watched four of her twelve children die from diarrhea, a common disease in children who suffer from malnutrition. ... Seeing us looking at the plaster dust which was sifting through her ceiling into the pots on her stove, and at her grandson who was sleeping on what served as a bed while flies and mosquitoes rested on his face, she said, "It's such a struggle to just keep things where they are without them getting any worse."  

The American public and health care professionals must recognize the fact that the health system needs to help people cope with a great variety of problems and needs. From the point of view of the poor, healing may need to take a broader definition in order for even the more limited one to work. A broad range of health support and advocacy services need to be a central part of a comprehensive health program. Such services belong in a health system for several reasons. First, support services can prevent certain illnesses or disabilities more effectively than they can be treated. For example, malnutrition in children frequently comes to the attention of health professionals only after it has reached an acute stage. Traditional medical techniques cannot really solve the problem. The need is more likely to be met by helping families obtain food stamps, food commodities or financial support; by educating parents about what constitutes an adequate diet; and by joining in community action aimed at assuring decent nutrition to groups of children or expectant mothers. Similarly, a child can be poisoned by lead paint repeatedly unless education and pressure to enforce housing codes and home repair services are available along with medical testing and treatment.


65 Appendix B of this report contains a list of recommended support services.
Second, support services can provide treatment for children's problems which is more effective than traditional medical approaches. Take learning difficulties, for example. Often effective treatment does not require drugs but may require health professionals to leave their offices or clinics and work with teachers to change things at school or with parents to explore doing things differently at home.

Third, support services can help people make better use of traditional medical services. As we have seen, the effectiveness of much health care depends on parents and children following medical recommendations correctly. Education and support from a health aide or other worker may be needed so that the parent or child will be able to carry out the instructions.

Finally, support services can put people in touch with resources to solve problems which are not strictly medical but which affect people's health and which would otherwise go without help. People who seek health care often come with problems that have their origins in non-medical situations. A health program that can help people who are threatened with eviction or who need homemaking help because they are temporarily unable to carry out family responsibilities has real advantages. It can lessen the physical distress accompanying these non-medical problems and, through its ability to help with these situations, make itself a trusted resource in a community.

Several programs around the country have recognized the importance of support and advocacy services and are trying in different ways to provide them.

In the Barrio Comprehensive Child Health Care Center in San Antonio, Texas, health aides are trained to do a variety of tasks including nutrition education and helping families obtain needed food. One aide visited a home to follow up on screening tests the Center had performed on a nine-month-old baby who had iron deficiency anemia. The aide learned that the baby was on a diet exclusively of milk. There was no food in the house, no shoes and few clothes for the children. To help correct this, the aide visited the home regularly, instructed the mother about basic child care and dietary needs, took the mother to the People's Community De-

velopment Corporation for food and clothes and enrolled the family in the Food Stamp Program.66

In Washington, D.C., the Child Health Advocacy Project of Children's Hospital is working with local agencies and community groups to launch a campaign against lead paint poisoning in the District. The emphasis of the program is on prevention, providing public awareness about the dangers of lead paint, as well as specific ways to prevent and treat poisoning. It encourages parents to have their children tested and treated if necessary. Through work with individuals and community groups, it tries to get landlords to comply with city ordinances which require safe lead levels in the interiors of buildings. Community residents learn how to have the lead level of paint in their homes tested. The Project has received funds to train people in the area to remove lead paint and repair deteriorating housing. Once trained, the workers are supported through a federal employment program.67

The Cuba Checkerboard Rural Health Project, which serves primarily Native Americans, Chicanos and Mexican-Americans in a medically underserved area of New Mexico, has placed emphasis on follow-through care and advocacy measures which help patients carry out the necessary health measures the doctor prescribes. Well-trained Certified Comprehensive Care Assistants travel long distances to assist families with follow-up care, to record effects of treatments and to do simple vision and growth assessments for children. For the many people in this area who have great difficulty getting to the health center or even calling in for advice, the Assistants provide the only opportunity for additional information or help.68

67 Telephone interview with Frederick Green, M.D., Director, Child Health Advocacy Project, Children's Hospital, Washington, D.C., November 1974.
68 Medical Services Administration, "Field Staff Information and Instruction Series, F4-74-30, Cuba Checkerboard Rural Health Project Filmograph," October 24, 1973. (Memorandum).
In a very different setting, the program of the Kaiser Foundation Health Plan serving Portland, Oregon, has demonstrated that home follow-up by health aides in selected cases can significantly enhance the value of physicians' care. After a training program of six weeks, home health aides have successfully provided and supervised a range of medical, physical therapy and social services in the home. The aides are able to recognize problems and changes in patient status very quickly, to provide advice in addition to direct medical services and to obtain appropriate supervisory help when indicated.69

Many families are threatened with disintegration because simple homemarker services are difficult or impossible to find. A health program that can arrange for the provision of homemaker services can help keep a family together and hasten recovery from an illness or disability. The need for this service may be more quickly recognized when a patient is hospitalized but, in fact, many families with less traumatic health problems may greatly benefit from homemaking services. Health programs can identify such families and press for high-quality homemaker programs to meet these needs. In Connecticut, for example, the state Health Department has trained volunteers to serve many homemaker functions. They are given a 35-hour training program, followed by an additional 160 hours of work on the job, leading to certification as homemakers. They act as "friends, companions, housekeepers, cooks, and nurses."70 The Maternal and Infant Care project in Cincinnati, Ohio, meets a similar need by using program funds to pay for homemaker services through a separate agency, the Home Aid Service Agency.71

Another example of successful intervention by nontraditional health personnel was found in Eastern Kentucky. There, a team comprising a psychiatric social worker and nurse working in the community was successful in reducing the need for hospital care among the mentally ill and also reducing their rate of readmission to the hospital. It had been noted that residents of the four Appalachian counties farthest from the Eastern State Mental Hospital stayed longer and returned more frequently than people from other parts of the region. Through a federal grant, the team was stationed full-time at a mental health center in the area and counseled former hospital patients and others in the community. After two years, the rate of readmission from the four counties dropped 67 percent and the first admission rate dropped 40 percent.72

Some programs have found that, especially for services provided in the home, it is important to employ nonprofessional staff with cultural or language backgrounds similar to the persons being served. Others have found that persons with professional training and without close ties to the immediate neighborhood are more easily accepted. In either case, it is important that the health worker relate well to the families being served, and is knowledgeable, supportive and not judgmental.

When programs are unable to employ the range of health workers needed to provide the necessary support services, they can tap a number of other resources in the community. In fact, to insure that these vital services are available, especially at a time when funds are limited, it may be necessary to be quite ingenious in finding any resources in the community which can help. Many health-related needs fall within the mandate of other agencies or organizations like the Welfare Department, Agriculture Extension Service, Vocational Rehabilitation Agencies, Headstart, public schools, Red Cross, Home Health Agencies, PTAs and a number of other volunteer agencies. Staff in other agencies who are in contact with patients served by

71 Matthew Tayback, "Evaluation Studies on Maternal and Infant Care Projects," Grant No. MCR-240036 from the Maternal and Child Health Service, Department of Social and Preventive Medicine, University of Maryland School of Medicine, September 1973, p. 276.
the health program can help with health-related functions. Extension workers can discuss hygiene and nutrition. Or a PTA group might conduct a lead paint campaign.

In the provision of all health care services, but particularly in related support services, there is an important caveat. A health program must be very careful to assure that the services are provided in ways that respect the dignity and privacy of all patients and their families. This means emphasizing the availability of services rather than imposing them. For example, a family with an infant who has just been diagnosed as mentally retarded should be informed of all the special services which the program can provide directly or arrange access to, including counseling, homemaker help, and so on. None of these services should be furnished automatically by virtue of the category of diagnosis or risk to which the family may have been assigned.

The People Who Provide the Health Services

Who will provide the kinds of services we have been describing? In the 1950's and 1960's it was thought that increasing the number of physicians by expanding the number of medical schools around the country and the size of their entering classes would solve much of the problem of inadequate health care. The perceived shortage of doctors (as measured by physician-patient ratios), plus the growing trends away from practice in some geographic areas and away from primary care, all were blamed for the fact that good health care was often hard to get.

Between 1966 and 1971 over $1.9 billion in public funds were spent to increase the supply of physicians. There were measurable results: a 16 percent increase in the number of medical schools; a 25 percent increase in the number of medical students enrolled; and a 40 percent increase in the size of the graduating classes. During that same period, almost 48,000 physicians were added to the medical manpower pool in this country.

But what effect did these increases have on the pattern of doctor distribution? The number of physicians in urban areas increased by 42,500; those in rural areas increased by 3,785. Medical specialties gained 15,200 physicians; the number of family practitioners decreased by 13,500. Of the 48,000 new physicians, only one-third went into direct patient care.

The conclusion is inescapable: merely increasing the number of physicians will not have a major impact on the kind and quality of health care available. There are other factors needing attention and support. The first is the kinds of people recruited into the health professions. While there have been stepped up attempts to find qualified minority and women students, students from rural areas who expect to return there, and students who are not only scientifically talented but are also warm and nurturing, they continue to be scarce on the front lines of medicine.

"Physician know thyself" is not an idle aphorism, for inevitably, the physician must draw upon his own life experience to develop understanding and empathy for his patients. But physicians do not share the life experience of low-income patients; they cannot use their past experience to understand these patients. This social distance can be an impediment to communication and to relations, but it need not be, if the physician is aware of its existence and has the humility to learn from his patient.

As we have discussed previously, barriers of culture, race, insensitivity, or lack of time can significantly impede the appropriate and effective use of health services. A start toward overcoming these barriers can be made by modifying how students are selected for training in the health professions, and how they are trained. People in the community have little control over these factors but they can more easily influence who will be selected to pro-

74 A Right to Health: The Problem of Access to Primary Care.
vide care in local programs and the design of the setting in which professionals and their associates work.

It is absolutely crucial that the criteria for selecting people to provide primary care should include a high level of technical competence. Equal attention should be given to the capacity to deal with children and parents in a compassionate, supportive, caring and respectful manner, and to work easily with others of different backgrounds and training. Furthermore, the emphasis in program design should be on a setting in which sensitivity, supportiveness and mutual respect can flourish, and where a variety of health workers can each do those tasks for which he or she is particularly suited by training, experience, skills and personal qualities. Particularly in the delivery of services to children, a highly trained pediatrician is not always needed; for many functions a well-trained, qualified and compassionate nurse practitioner may be preferable. Studies have shown higher patient satisfaction, better compliance with instructions and reduction of disability among patients served by a team including a nurse practitioner. Since such a large part of children’s health care is for routine, preventive measures like check-ups and immunizations, and since parents find they can get comparable quality care and improved rapport and communication from allied health personnel, there is reason to press for the expanded training and use of such personnel.

The integration of physicians’ assistants, child health associates, nurse-midwives and nurse-practitioners into the health care team can have a significant impact on the quality of services, as well as on their cost and availability. The cost of training allied health personnel is considerably less than the cost of training physicians. Working as part of an organized health program, they can extend health services to greater numbers of people while keeping overall costs down. They can do especially well many of the jobs which are important to monitoring and improving the health of mothers and children.

A particularly striking instance of the effectiveness of nonphysician professionals emerged from “an unintended experiment” in Santa Clara County, California. From July 1960 to June 1963, two nurse-midwives were given temporary permission to perform normal deliveries at the county hospital. They also provided complete prenatal care, and care of mothers and infants after delivery. The services of the midwives were withdrawn in 1963, when their permission to practice was rescinded. The program statistics dramatically reflect the work of the nurse-midwives. Before their participation, 11 percent of the hospital births were premature; prematurity fell to 6.6 percent while the nurse-midwives were there; it rose again to 9.8 percent after they left. The newborn mortality rate prior to the program was 23.9 per 1,000 live births; it fell to 10.3 during the program; it rose to 32.1 afterwards. The prematurity and mortality rates among those receiving private care in the county during the same period were lower and remained constant during the same years. The authors conclude that the increased and more effective prenatal care was a key factor, and note that “the nurse-midwives had succeeded in overcoming many cultural and educational barriers to motivate many more indigent women to seek prenatal care.”

There is much evidence that health professionals other than physicians have the capacity to treat patients competently and to provide effective listening, support and education. In a study of child health nurse practitioners in private pediatric offices, the patients who saw the nurse-practitioners and doctors on alternate visits were most satisfied with the child-rearing advice they got than those patients who saw the doctors only, even though the latter group saw the doctors twice as often as the former. In the Dr. Martin Luther King, Jr. Health Center in the Bronx, New York, a study showed that families who had received care


from a health team were more likely to make appropriate decisions about the selection of types of health services, and to comply with them, indicating understanding and motivation. This was particularly true for services to children and attitudes toward home care. 78

Allied health personnel can be used to extend care to children who do not have a regular source of care. After a study by the Cambridge City Hospital in Massachusetts showed that many of the city’s children were using the emergency wards of the hospital for general pediatric care and that many more were totally without care, the City Council and the Department of Pediatrics at the Hospital established five neighborhood health centers in four elementary schools and one remodeled house. The centers were staffed by pediatric nurse practitioners to provide primary care to children from birth on. In the Model Cities area of the city, 95 percent of the children are involved in this care program. The nurse practitioners are responsible for the health maintenance services (immunizations, physicals, screening) as well as caring for minor injuries and illnesses. They also function as community health nurses and visit homes, schools, day care centers and other agencies involved with children and their families. The nurse practitioners are particularly involved in the early detection and referral of children with learning difficulty or classroom adjustment problems. Because they are responsible for the child from birth through the school years, they also do maternal counseling and home visiting beginning one week after the baby is born. If the children need more specialized care, they are referred to the Hospital specialty clinics or members of the pediatric staff at the Hospital. 79

“Data collected since the inception of the . . . program show substantive qualitative changes in patterns of health facility utilization, indicating both the community’s willingness to use the center effectively (i.e., an understanding of what the pediatric nurse practitioner can do) and also its increasing awareness of the desirability of ongoing pediatric care.” 80

Under the auspices of the Tri-City Citizen’s Union in New Jersey, a pediatric nurse practitioner and three health aides from the neighborhood provide complete physical examinations and health counseling to children, most of whom had previously gone without primary care. The nurse practitioner works with a physician who is available by phone, and she refers children with acute health problems to him. News of the unique personal attention available from the nurse practitioner and her aides has spread. Program administrators estimate that 30 percent of the children now under their supervision had never before received non-emergency health care and 90 percent had not been completely immunized. 81

Pharmacists can also be trained to give more patient education and back-up services to physicians. In the acute disease clinic of the Children’s Hospital of Buffalo, New York, only 5 percent of the patients were fully complying with a 10-day course of antibiotic treatment for acute middle-ear infections. When this low rate of compliance became known, a program was implemented in which hospital pharmacists gave parents detailed verbal and written instructions when medications were dispensed for children having otitis media. In addition, labeling of medicines was precise and detailed, and parents were given a calibrated measure for the medication and a calendar to record doses. Without changing any other aspect of medical care, full compliance was raised to 51 percent, as compared to 8.5 percent in a control group studied

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81 Interview with Rebecca Andrade and Mary Battle, Tri-City Citizens’ Union, Newark, New Jersey, September 17, 1975.
concurrently who obtained medications at neighborhood drugstores.\textsuperscript{82}

The use of other health workers to augment the ability of physicians to provide good health care is not without its problems. Definitions of roles still remain vague; licensing procedures lag behind training programs and need for personnel; training programs and credentials vary widely; and physicians' resistance to relinquish some of their traditional authority and share patients and knowledge with others is great in some places. In addition, settings which support these health workers are all too scarce. Reimbursement plans often do not cover services performed by non-physicians in these settings. And, if the training, payment and working conditions of non-physicians take on the qualities which have constrained traditional medicine, some of these workers' most precious qualities are likely to be lost.

These problems need to be dealt with. The value of a group of professionals—each having different strengths relating to children's and mother's health needs—has been acknowledged by professionals and the public. It is time that their contribution to delivering primary care is recognized by policy makers and supported by the health care system.

Many of the proposed changes in existing health care arrangements and the good programs described in this book make so much common sense one wonders why they are not replicated all over the country. Many have improved children’s health, saved money, made more efficient use of doctors and hospitals and encouraged people to develop better health habits than they ever had before. Why then has there not been a groundswell of public and professional support, urging large-scale reassessment and fundamental reorganization of health care services in all communities?

The fact is that those who have made and continue to make the decisions about the way health care is organized, paid for and delivered are well-organized, affluent and influential. The people whose interests are vested in the current arrangements remain unconvinced that change is needed. Professionals who have tried to advocate change have met with a wall of resistance, and lay citizens who have sought to be involved in decision making about health care—even their own—have met with condescension, reluctance to share information and little help in understanding the technical complexities of the field. Health care is complicated to think about, discuss and reform. Unless parents can be educated about what is possible in the field of health care and become a knowledgeable, effective counterforce to the vested interests, a few effective demonstration programs will continue to exist in a few isolated places, facing cutbacks in times of economic retrenchment. The children and families who desperately need services will be born, will live and will die without them.

Arguments You Will Encounter

There are a host of professional or bureaucratic excuses given whenever reforms in health care are suggested. There are also telling arguments made by people who simply believe it is not worth investing further energy and resources in health care. They should no longer be accepted with equanimity nor left unchallenged. Here are some of the challenges you are likely to hear:

1. “We’re the experts. Only doctors can understand the complexities of providing medical services. Peer review and professional assessment are the only proper vehicles for change.”

If professionals could solve all these problems by themselves the inequities cited earlier about the delivery of health care would not be as appalling, costs would not be escalating as sharply and maldistribution of doctors and health services would not be as critical. It is true that medicine is a highly technical field that few average citizens understand. We are not advocating that laymen interfere with the practice of medicine, but that they have a say in the organization and funding of systems in which it takes place. Few people can play concert piano or would tell a pianist how to play, but the public certainly can help decide whether symphonies should get private or public support, whether a tour to smaller communities could profitably be arranged or whether enough children were interested in classical music to provide concerts for young people. It is entirely appropriate for citizens to have a say in these matters. The medical profession has enjoyed an extensive amount of au-
onomy in this country for years, with little evidence that it will address itself adequately to issues of scarcity, poor quality and unequal access to services. It is time the experts heard from the parents whose children they serve.

2. "Services cannot be made more widely available because there is a scarcity of doctors, and you cannot increase the number of doctors without seriously diluting the quality of medical care provided, thereby eventually endangering your and your children's well-being."

The apparent scarcity of doctors is increasingly the result of their geographic maldistribution and their preference for specialties, rather than their lack of numbers. With the creation of many new medical schools and the increase in class sizes over the past decade, the shortage of doctors is rapidly coming to an end. We continue to have a shortage of doctors delivering primary care, however, which is worse in rural and inner-city areas than elsewhere.

Perhaps the solution with the greatest promise is the training and use of other kinds of health personnel—physicians' assistants, child health associates, nurse practitioners, nurse midwives, and so on. Not only can they do many of the routine, time-consuming, but necessary ministrations currently done by doctors, they can also work with parents and children more effectively than many doctors can. The training and widespread use of such personnel should be embraced by the medical profession so that children no longer have to live with the "scarcity" of competent medical attention to their needs.

3. "Good services and universal coverage cost money. Where will it come from?"

This argument is really a smokescreen. When we consider health insurance proposals with universal entitlement, it is not as if we are suggesting the creation of a costly new program from scratch. This nation—all of us through direct payments, insurance payments and current taxes for public health programs—already spends over $115 billion on health care. As one economist has said, "Can we, as a people, afford national health insurance really means can we afford to spend what we are already spending, and surely the answer is 'yes.' The issue is not whether we are spending more than we can. The issues are whether we are getting what we should for our money and whether the present arrangements which make health expenditures depend on a family's income are fair, just and humane."

In fact, many of the programs reviewed in this book that provide model services to children and families have produced overall savings in per patient costs. Good services don't necessarily cost more money, provided changes are made in the arrangements under which they run. For example, services provided in hospitals or by physicians who charge fee-for-service rates are likely to be the most costly. But the overwhelming need of children and families is for care best given outside of hospitals, often without requiring expensive equipment or personnel, by professionals working in groups or teams along with allied health personnel.

In addition, as we pointed out in Chapter 2, programs for mothers and children are among the least expensive in the field of health care. They are not bottomless pits into which never-ending amounts of money will be poured. Costs tend to rise somewhat initially as more comprehensive services are made available, but then they level off, staying at a level which can be predicted and planned for.

But even if more money is needed to improve the quality of health care our children receive, is it not worth it? We spend enormous amounts now on health care. A comprehensive insurance system could redirect the money now coming from public and private sources, improve the arrangements under which it is spent, add minimally to it and use the total to pay for decent health care for all American children. If more is needed, we ought to see it is provided.

4. "Massive federal programs do not work. Even if the goals of universal health services and insurance were good ones, there is no evidence that a new governmental program will not fail."

1 Rashi Fein, "Health Care Cost: A Distorted Issue," The American Federationist (June 1975).
It has become fashionable to be cynical about the achievements of big government programs during the 1960's and to discourage any new programs from starting. The social programs like the Great Society and the War on Poverty were described as massive experiments, which raised great expectations and failed to fulfill them. But the actual amount of resources devoted to these social programs was never massive—not in comparison to spending in other parts of the economy or to the actual needs of people. Nor was government intervention significant—in most cases, extra money was simply channeled through the same conduits, with few systemic or institutional changes made in the way that money was spent.

It is also not true that there have been no successful programs. There were some—that used the additional funds creatively to improve services. We simply cannot look at limited commitment, money and leverage at the federal level and become so discouraged that we throw up our hands in despair. Instead we must examine critically what has worked and what has not. Then we must proceed to build on past successes.

5. "Why not limit public support to those kinds of health services proven to be most cost-effective?"

When money is tight and priorities need to be set, one way of deciding what to support is to measure the pay-offs of various discrete services and fund only the most "successful." Under this "rational" management, immunizations are worth paying for since we can prove they prevent certain diseases. But paying for the time of health professionals to talk to mothers and listen to their concerns about pregnancy or their children's health or behavior may not be worth supporting, in cost-effectiveness terms, since the value of such a service has not been measured in clear-cut, quantifiable ways.

The trouble with this kind of thinking is that it fails to pay attention to the hard-to-measure components in health services that may be very important indeed, and it does not take into account the influences on whether parents will use health care appropriately or at all. Every few years there is a new consensus on what is really important, what is really cost-effective, without considering how parents use the health system and how they perceive their children's health needs, and without concern for services the effectiveness of which we simply don't know how to measure. A narrow view of cost-effectiveness—which isolates one aspect of health and pays for it separately, while sometimes achieving limited goals, will most likely create or preserve barriers to care—even that portion of care which is deemed cost-effective.

6. "The kind of support services and things you are asking for, like humane, personal care, are frills that doctors cannot afford. It is hard enough diagnosing and treating a person for his medical problems. We cannot possibly do more."

A professional cannot possibly diagnose and treat a patient who isn't in his or her office or clinic. That is, the obstacles that keep people from seeking health care—things like transportation, poverty, lack of education about the importance and availability of care, babysitters and so on—are just as important in being able to treat a patient as
is the eventual treatment. If they hinder a doctor's ability to heal, they become a health problem. Doctors can no longer ignore this fact.

Nor can the health system overlook the fact that if it permits doctors to deal with malnutrition or lead paint poisoning only after they become acute medical crises, it is wasting, not conserving, both human and economic resources. In medicine, prevention is a conventional wisdom. We need to recognize all the forms prevention may take and integrate them into good health care.

In addition, qualities like human warmth, communication with patients and their trust in a professional’s recommendations are an integral part of how successful the treatment will be. Brusque manners, hurried commands, overworked staff and unexplained messages will damage the quality of health care given. Support—both in services and understanding—are therefore a legitimate demand to make on the health system, and not at all a frill.

7. “Making health care available will not make any difference. Some people just don’t care. Immunizations have been provided free in public health departments for years and yet many children are not immunized. It’s not the health care system’s fault.”

It is true that many children are not fully immunized even though vaccinations can be obtained free of charge in most places. But the medical care offered to the poor has often been inaccessible and alienating. Health professionals are not helpless to affect this situation. In programs where outreach workers from the community explain the importance of immunization to parents, help them get to a health center, help care for other children, and so on, the numbers of children immunized increases markedly. This is true of other health services, including prenatal care and well-baby examinations. Health centers which offer comprehensive services and which include many of the features we have described are used at a rate that approaches that at which more advantaged people use medical services. It is the responsibility of health care professionals to bring their influence to bear on the system in the interests of their patients and of good medicine.

8. “People should pay something for health care. The poor should contribute a token share and those who can afford to should pay more.”

Two major arguments underlie this cost-sharing theory. One is that if people pay for something, they will use it more carefully. The second is that individual payments will reduce overall costs of the program. Neither has much merit.

First, there is simply no evidence that the poor who get free health services from public health programs inundate the system. The notion that people act irresponsibly unless they make out-of-pocket payments is not based in fact, and it does not address the fundamental problems of the health system which make care expensive.

Second, the benefits of money collected from individuals are surely not worth the costs entailed in collecting it. The paperwork and bureaucracy to figure out payments based on doctors’ prices and patients’ incomes simply are not worth the administrative costs, unless each person’s share is quite high. If it is, then we are back to the kind of system we have now, where ability to pay determines the amount and quality of services received. Rather than investing in moving millions of pieces of paper, the money would be better spent in providing health services with few administrative chores attached.

9. “The best way to improve people’s health is to get them to change their behavior. Neither access to or quality of medical services would make as much difference to health as would not smoking, eating properly and getting regular exercise.”

It is absolutely true that Americans could make enormous strides toward better health if they improved their individual health behaviors. It is also true, as the president of the American Public Health Association pointed out, that “for the vast majority of people in our society the life circumstances leading to poor health are not adopted as a matter of personal choice, but are thrust upon people by the social and economic circumstances into which they are born.” But one objective does not have to be sacrificed for the good of the other.

The fact remains that health care does make a difference and that many people are not receiving the professional attention they need. The rationale that health care won't solve all health problems does not mean that energy into reforming it is useless.

As a matter of fact, an efficient and supportive health care system could be the best source of education and advocacy to help people modify their personal health habits.

A Guide for Action: Principles of Good Health Care Delivery

Citizens must not be put off by arguments against change nor be so discouraged by the complexities of the problems that any action seems futile. In preparing this book we have found programs across the country boldly trying to change the way health care is delivered. It can and must be done. Monitoring the quality of services given to you, your family and others in the community is essential. We have included a list of questions which reflect the elements of good health care discussed at greater length in Chapters 3 and 4. An ideal system would incorporate all these elements.

In the real world of competing needs, each community should decide which elements are most important to introduce or improve immediately to increase access to or quality of care. When these are achieved, the others can be addressed, building a program over time that will be effective and responsive.

These elements should not be taken out of context: their content and specific form ought to be impeccably tailored to fit the needs and strengths of each community. But we offer them for citizens to have a capsule view of how health care services should be organized to be effective, and we urge those of you interested in pursuing action to refer back to the pages of the book where they are discussed in more detail.
More Effective Entry Into the System

Outreach
1. Is outreach made through personal contact? (p.28)
2. Is outreach performed by trained workers who share or are sensitive to the background of the people served? (p.29)
3. Is outreach conducted in a variety of places in the community? (p.30)
4. Are outreach efforts reinforced and supplemented by trained, nonhealth personnel in the community? (p.31)
5. Do outreach services link people to a system of care which provides continuing services? (p.31)

Location of Services and Transportation
1. In medically underserved areas, is there an organized setting which (a) offers combined practice with other professionals and expanded professional contact and activities beyond the immediate area; and (b) makes available support services which one professional on his own could not muster? (p.35)
2. Are primary care services located in the midst of the target population by (a) taking the needs of the target population into account in the decision about where to build a new facility, or (b) decentralizing the services of an existing program? Might it be appropriate to adopt a regional approach to the allocation of health resources? (p.38)
3. Where it is impossible to offer comprehensive primary health services in a conveniently located facility, are other approaches being used, such as the placement of health personnel in outlying areas, or the use of mobile clinics? (p.40)
4. Where health services exist within a reasonable distance, but parents do not have transportation available, are transportation services provided or arranged by (a) modifying existing public transportation systems to arrange schedules and routes that efficiently link users and health care facilities; (b) reimbursing families or patients for transportation they can find themselves but cannot afford; (c) contracting with other agencies to provide transportation to health services; or (d) developing a program-run transportation system? (p.42)

Telephone Access
1. Is there 24-hour, 7-day-a-week telephone access for emergencies, and day and evening telephone access to medical care for acute health needs? (p.45)
2. Is there some time during the day when families can consult with health professionals over the telephone concerning more general health questions? (p.45)
3. Is the person who responds to the telephone call able to communicate effectively with the caller and able to provide the caller with appropriate instructions? (p.45)

Hours of Service
1. Are hours when care is available designed so that they do not always conflict with school or work? (p.46)

Appointment Systems
1. Are there appointment systems? Are they designed to accommodate the habits and practical daily problems of consumers? (p.46)
2. Can parents make appointments in a number of different ways, such as through outreach workers, health aides in the home or hospital, by telephone, through other agencies, etc.? (p.48)
3. Are appointment systems designed to promote continuous care? (p.50)
4. Do appointment systems make possible the provision of related health services in an efficient manner? (p.51)

Care for Other Children
1. Where necessary, are there arrangements for the care of other children when a parent brings a child to the clinic or comes in for care herself? (p.51)

Reducing Cultural Barriers
1. Are there special provisions to assure that health services do not discriminate among patients by race and that services are responsive to the different cultural and socioeconomic backgrounds of the families they serve? Is there staff from or with knowledge about the communities being served? Are there language interpreters when needed?
Are there patient advocates from the communities to ease entry to health services and allay children's and parents' fears? Is there a procedure for hearing grievances and allowing consumers to participate in decision making? (p. 56)

Emergency Care
1. Are emergency services designed to introduce patients to a regular source of care when they do not have one? (p. 58)
2. Do parents in every location have a system of emergency care available which includes public information about how to get emergency help, emergency transportation and communication with a health center or hospital, health staff in the ambulance and emergency room who are trained in emergency care, high quality emergency room facilities, and provision for needed follow-up services? (p. 60)

Improving the Content of Care

Unifying Fragmented Services
1. Are most primary care services available in one place and under unified administrative auspices? (p. 67)
2. Does one person have the responsibility of coordinating the diverse services a child or family needs? (p. 68)
3. Are services that are now rendered in fragmented ways being reorganized toward comprehensive primary care? (p. 69)
4. Are services provided separately in those circumstances when providing services separately might be more effective (e.g. for adolescents)? (p. 70)

Providing Continuity of Care
1. Is the health program designed to allow each patient to have a continuous relationship with a physician, a nurse-practitioner, or other trained health worker? (p. 72)
2. Are medical record systems designed to promote continuity of care? (p. 73)

Humanizing Care
1. In planning how physicians use their time, is there leeway for the possibility of a leisurely consultation between health professionals and families either when the professional thinks it is crucial or when the child or family indicates a special need? Is the physical setting conducive to easy and private communication? (p. 78)
2. Are there educational efforts aimed at enabling parents and children to become active and knowledgeable partners with health professionals in the process of patient care and health maintenance? (p. 79)

Support and Advocacy from the Health Care System
1. Is a wide range of health support services (such as those listed in Appendix B) available as part of the health program? (p. 82)

The People Who Provide the Health Services
1. Do the criteria for selecting people to provide primary care include a high level of technical competence? Is equal attention given to the capacity to deal with children and parents in a compassionate, supportive, caring and respectful manner, and to work easily with others of different backgrounds and training? (p. 86)
2. Is the program designed in such a way as to provide a setting in which sensitivity, supportiveness and mutual respect can flourish? (p. 86)
3. Does the design of the health program make it possible for health workers to do those tasks for which they are particularly suited by their training, experience, skills, and personal qualities? (p. 86)
Appendix A

A Checklist of Standard Health Services for Children and Expectant Mothers

The following is a list of services comprising both preventive care and treatment for children and expectant mothers. According to the judgment of health experts these are considered essential to quality maternal and child health care. Primary pediatric care deals "with those medical, social and emotional factors that keep the child well, minimize the impact of inevitable infections, developmental problems and disturbances of behavior to which every child is subject and help the child and his parents adapt as successfully as possible to those handicaps and incurable diseases which fate has thrust upon them." Maternity care includes the physical care provided to mothers and babies; the educational and social supports provided the family, directed toward making pregnancy, labor, delivery and the postpartum recovery a safe and satisfying experience; and interconceptional care, including management of fertility.

In itemizing what constitutes preventive care, we rely primarily on the recommendations of the American Public Health Association; the list of services for illness care is adopted from recommendations by the American Academy of Pediatrics.

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2 American College of Obstetrics and Gynecology, in "Standards for Obstetric and Gynecologic Services," 1974 and Correspondence from Ruth Lubic, Director, Maternity Center.
Preventive Services for Mothers and Children

A. Care for Pregnant Mothers

1. Prenatal Services (Before Delivery)
   a. The first visit, irrespective of when it occurs, should include the following components:
      — Health history
      — Physical examination
      — Laboratory examinations:
         1) complete urinalysis
         2) complete blood count
         3) serological examination
         4) chest x-ray
         5) blood grouping and RH determination
         6) cytology screening for genital tract malignancy (cancer or Pap test)
         7) G.C. Culture (Gonorrhea test)
   b. Subsequent visits should occur:
      — Once each month, through 28th week of pregnancy.
      — Once each two weeks, 28–36 weeks of pregnancy.
      — Once each week after 36th week of pregnancy.

   Laboratory tests for subsequent visits should include:
   — Urinalysis
   — Hemoglobin or hematocrit (for anemia) as needed.
   c. Vitamin and iron supplements and medication as needed.
   d. Group or individual instruction on nutrition, family planning, self care, delivery, and parenthood.
   e. Home visit by a public health nurse, or other qualified health provider, for purposes of preparing the home and family for the absence of the mother during confinement, and for the care of the infant afterwards.

2. Care Surrounding Childbirth
   a. Necessary services associated with giving birth in an accredited hospital or other accredited institution, including:
      — managing labor
      — delivery
      — immediate post-partum care of the mother and newborn
      — including infantile resuscitation if necessary
      — routine care of the eyes and cord
      — testing for congenital diseases such as P.K.U.
      — infantile serological testing
      — care of the mother and baby in the hospital or other institution
   b. Group or individual supervised bedside instruction to the mother on self care and infant care.
   c. Family planning counseling and services

3. Postpartum Care (After Delivery)
   a. Home visit by a public health nurse, or other qualified health provider, within the first two weeks after discharge from the hospital in order:
      — to assist with implementation of home care.
      — to provide additional education for parenthood.
      — to assess the service needs and make referrals as appropriate.
   b. One office or clinic visit each for the mother and infant to their respective physicians during the first 8 weeks of the infant’s life for routine examination and for:
      — advice
      — laboratory procedures to include hemoglobin and urinalysis if they are indicated
      — follow-up family planning services

B. Child Care

1. 1st year of life—7 visits
2nd year of life—3 visits
3–6 years—1 visit each year

5 There are differences of opinion about the appropriate frequency of pediatric visits. The numbers given are suggested norms. Some children may require fewer visits and some may need more.
Included in these visits would be:
- Physical examination and appropriate laboratory tests
- Developmental assessment
- Counseling and anticipatory guidance regarding nutrition, accidents, hygiene, and child development
- Immunizations according to the following schedule:

**Schedule for Active Immunization and Tuberculin Testing of Normal Infants and Children in the United States**

<table>
<thead>
<tr>
<th>Age</th>
<th>DTP</th>
<th>TOPV</th>
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</thead>
<tbody>
<tr>
<td>2 mo</td>
<td>DTP(^1)</td>
<td>TOPV(^2)</td>
</tr>
<tr>
<td>4 mo</td>
<td>DPT</td>
<td>TOPV</td>
</tr>
<tr>
<td>6 mo</td>
<td>DTP</td>
<td>TOPV</td>
</tr>
<tr>
<td>1 yr</td>
<td>Tuberculin test(^4)</td>
<td>Measles(^3)</td>
</tr>
<tr>
<td>1-12 yr</td>
<td>Rubella(^5)</td>
<td>Mumps(^3)</td>
</tr>
<tr>
<td>1½ yr</td>
<td>DTP</td>
<td>TOPV</td>
</tr>
<tr>
<td>4-6 yr</td>
<td>DTP</td>
<td>TOPV</td>
</tr>
<tr>
<td>14-16 yr</td>
<td>Td(^6)</td>
<td>TOPV</td>
</tr>
<tr>
<td>Thereafter</td>
<td>Td every 10 years</td>
<td></td>
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</tbody>
</table>

Note:
- DTP—diphtheria and toxoids combined with pertussis vaccine.
- TOPV—trivalent oral polio virus vaccine. The above recommendation is suitable for breast-fed as well as bottle-fed infants.
- Measles—measles-rubella (or measles-mumps-rubella) combined vaccines [see rubella (page 127) and mumps (page 88) for discussion of age of administration].
- Frequency of repeated tuberculin tests depends on risk of exposure of the child and on the prevalence of tuberculosis in the population group.
- Td—combined tetanus and diphtheria antigen.

3. Other Services

a. Routine dental services beginning at age 3, at least once annually, including:
- Oral examination, prophylaxis, counseling and education
- X-ray, topical fluoride application, restorations including fillings, space maintenance
- Extractions of deciduous teeth as necessary.

b. Vision Care Services
- Routine eye examinations
- Provision of eyeglasses or therapy as indicated.

c. Hearing:
- Audiometry
- Provision of hearing aids or therapy as needed

C. Female Reproductive Care\(^6\)

In addition to the above preventive services, all women within the reproductive ages should receive, on an annual basis:
- Breast and pelvic examinations
- A Papanicolau smear (for cervical cancer) and a G.C. culture (test for gonorrhea)

The annual visit may also include:
- Health education
- Family planning counseling
- Provision of contraception

\(^{6}\) We include female reproductive care (including breast and pelvic exams, tests for cancer and gonorrhea, and family planning services) because by preventing disease of the reproductive system and by allowing women to have the desired number of children when they want them, these services improve the health of children.
Illness Care for Children

A. Diagnosis and treatment of:
   1. Disorders of growth and development
   2. Acute illness
   3. Chronic illness including rehabilitation and management of physical, mental, congenital and acquired abnormalities.

B. X-ray and laboratory services.
C. Consultations and concurrent services by more than one physician or surgeon where needed.
D. Diagnostic and therapeutic psychiatric and psychological services.
The following health support services are suggested for inclusion in organized programs of comprehensive health care:

1. Outreach and community education
2. Transportation as needed
3. Provision for child care as needed
4. Nutrition counseling and services
   - Planning and advising on formula preparation, routine dietary needs, special diets, purchase and preparation of food;
   - Assistance in obtaining food supplements through WIC programs housed in health centers and through referrals to other food assistance agencies (such as a food stamp office).
5. Environmental education and services
   - Education on rectifying housing and sanitary conditions which can lead to accidents, acute infections, and chronic diseases like lead paint poisoning;
   - Assistance in using other community resources to improve the conditions.
6. Other health education services\(^1\) on an individual and group basis to:
   - Develop the appropriate health habits and the assurance that an individual is complying with a prescribed regimen;
   - Assist the health consumer to utilize services appropriately;
   - Lessen risks leading to health problems, minimize the effects of an illness, and avoid its recurrence.

These health education efforts would be aimed both at entire population groups (e.g. smoking reduction, weight control, exercise, nutrition, V.D. education, etc.) as well as at highly targeted groups who are either at risk for, or who already have a disease condition (e.g. hypertension, high risk pregnancy, diabetes, etc.)

7. Genetic counseling and referral as needed for sickle cell anemia, RH incompatibility, and other genetic diseases or conditions
8. Social and mental health counseling and treatment and necessary referral
   - Counseling for children and their parents around specific health problems like handicapping and other chronic conditions, learning disabilities, acute illness like venereal disease;
   - Personal counseling and treatment for individuals; couples and family groups to assist them in dealing with stress and

\(^1\) As adapted from recommendations by the American Public Health Association in “Proposed Benefits to be Covered on a First Dollar Basis Under National Health Insurance,” July 16, 1974.
cresses, and with other problems of living for which they seek help and support.

9. Provision or referral for problems which are not medical but which may have serious health implications

—Help or referrals with follow-up for a range of non-medical health related problems which might otherwise not receive attention, including unmet housing, employment, welfare, child care and legal needs.

10. Home health care

—Medical, nursing, dietary, rehabilitative, educational services in the home to mothers and children who are recently discharged from the hospital, ill or disabled.

11. Homemaker services

—Assistance in routine household responsibilities like cooking, shopping, cleaning and taking care of the children for families in which there is illness or disability.
## Major Federal Programs Which Finance or Provide Health Services for Children and Expectant Mothers

<table>
<thead>
<tr>
<th>Program and Authorizing Legislation</th>
<th>Purpose</th>
<th>Population Eligible for Services</th>
<th>Activities</th>
<th>Financing</th>
<th>State Contact</th>
<th>Federal Agency*</th>
</tr>
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<tbody>
<tr>
<td><strong>Maternal and Child Health Services (MCH)</strong></td>
<td>To reduce infant mortality and improve the health of mothers and children by providing financial support to states to extend and improve related health services, especially in rural and low-income areas.</td>
<td>Determined by states. In general, any mother or child who comes to the clinic may receive services.</td>
<td>Grants to states to support maternal-infant, public health nurse home visits, well-child clinics, pediatric clinics, school health and vision-hearing screening, dental care for children and pregnant women, immunizations, mental retardation clinics and screening programs.</td>
<td>Federal/State matched formula grants</td>
<td>Division of Maternal and Child Health in the State Health Department</td>
<td>Office of Maternal and Child Health (In the Bureau of Community Health Services, Health Services Administration, Public Health Service, U.S. Department of Health, Education and Welfare) 5600 Fishers Lane, Rockville, Md. 20852 Tel. 301-443-6600</td>
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<tr>
<td><strong>Maternal and Child Health Program of Projects Social Security Act, Title V Maternal and Infant Care (MIC)</strong></td>
<td>To reduce the incidence of mental retardation and other handicaps caused by complications associated with childbearing, and to reduce infant and maternal mortality.</td>
<td>Diagnostic and preventive services to all women and infants within the target area. Treatment of women and infants who would not otherwise receive services because they are from low-income families or other circumstances beyond their control.</td>
<td>Grants to specific projects serving particular target populations (or areas) to identify high-risk mothers and provide full prenatal care, including hospitalization as needed, care for delivery, post-natal care and infant care.</td>
<td>Federal/State matched formula grants</td>
<td>Division of Maternal and Child Health in the State Health Department</td>
<td>Office of Maternal and Child Health (In the Bureau of Community Health Services, Health Services Administration, Public Health Service, U.S. Department of Health, Education and Welfare) 5600 Fishers Lane, Rockville, Md. 20852 Tel. 301-443-6600</td>
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<tr>
<td><strong>Children and Youth (C &amp; Y)</strong></td>
<td>To provide comprehensive health services to children living in areas with high concentrations of low-income families.</td>
<td>Screening, diagnostic and preventive services available to all children and youth within the target area. Treatment, correction of defects, aftercare available only to children and youth who otherwise would not receive such services because of low income or circumstances beyond their control.</td>
<td>Grants to specific projects serving particular target populations (or areas) to provide comprehensive health care services to children and youth.</td>
<td>same as above</td>
<td>same as above</td>
<td>same as above</td>
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<tr>
<td><strong>Intensive Infant Care</strong></td>
<td>To provide necessary health care to infants during their first year of life when they have conditions, that may prevent them from achieving normal development.</td>
<td>Available only to infants in the area served by the program who would otherwise not receive such services because they are from low-income families or for other reasons beyond their control.</td>
<td>Grants to specific Projects serving particular target populations (or areas) to provide appropriate services for intensive care of infants, including surgical and specialized consultative services, and for follow-up care of the infant during the first year of life.</td>
<td>same as above</td>
<td>same as above</td>
<td>same as above</td>
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<tr>
<td><strong>Dental Care</strong></td>
<td>To promote the dental health of children and youth of school and pre-school age, particularly in areas with concentrations of low-income families.</td>
<td>Diagnostic, screening and preventive services to all children in the area served by the program. Treatment, correction and aftercare to children in the area who would not otherwise receive services because of low income or some other reasons beyond their control.</td>
<td>Grants to specific projects serving particular target populations (or areas) to provide comprehensive care and prevention services, treatment and correction of dental problems with aftercare as well.</td>
<td>Federal/State matched formula grants</td>
<td>Division of Maternal and Child Health in the State Health Department</td>
<td>Office of Maternal and Child Health (In the Bureau of Community Health Services, Health Services Administration, Public Health Service, U.S. Department of Health, Education and Welfare) 5600 Fishers Lane, Rockville, Md. 20852 Tel. 301-443-6600</td>
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<td><strong>Family Planning</strong></td>
<td>To develop projects with special attention to family planning services for mothers in needy areas and among groups with special needs.</td>
<td>Primarily for low-income women living within the area served by the program. Treatment only for women who would not otherwise receive such services because of low-income or for other reasons beyond their control.</td>
<td>Grants to specific projects among particular target populations (or areas) to provide comprehensive family planning services, including those medical, educational and social services related to family planning and contraception.</td>
<td>same as above</td>
<td>same as above</td>
<td>same as above</td>
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<td>Program and Authorizing Legislation</td>
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<td>Crippled Children's Services (CCS)</td>
<td>To assist states, especially in rural areas, in locating children with crippling conditions or suffering from conditions leading to lifelong handicap and providing a full range of diagnostic and corrective services.</td>
<td>All children under age 21 with a handicapping condition, as defined by the state, are eligible for diagnostic and corrective services. Flexible income standards applied for treatment services.</td>
<td>Grants to state crippled children's agencies to pay cost of medical, hospital, diagnostic and corrective care, to locate children and see that the child gets needed care and follow-up.</td>
<td>Federal/State matched formula grants</td>
<td>Division of Maternal and Child Health or Division of Crippled Children in the State Health Department</td>
<td>Office of Maternal and Child Health (in the Bureau of Community Health Services, Health Services Administration, U.S. Department of Health, Education and Welfare) 5600 Fishers Lane, Rockville, Md. 20852 Tel. 301-443-6600</td>
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<td>Social Security Act, Title V, Sections 301, 304</td>
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<tr>
<td>Family Planning Services Public Health Service Act, Title X, Section 314(e)</td>
<td>To provide families full opportunity to exercise freedom of choice to determine the number and spacing of their children through access to information and medical services, particularly for low-income families and to those who would not receive such help or other reasons beyond their control.</td>
<td>Available to all persons desiring such services, with payment requested from individuals able to pay for all or part of their services.</td>
<td>Comprehensive family planning services including family planning education, medical, educational and social services related to family planning and contraception.</td>
<td>Federal/State matched formula grants</td>
<td>State Health Department</td>
<td>Office for Family Planning (in the Bureau of Community Health Services, Health Services Administration, Public Health Service, U.S. Dept. of Health, Education and Welfare) 5600 Fishers Lane, Rockville, Md. 20852 Tel. 301-443-2430</td>
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<tr>
<td>Indian Health Service Snyder Act of 1924 Indian Health Transfer Act of 1954</td>
<td>To improve the health of all Indians and Alaskan natives living on or near reservations.</td>
<td>All Indians and Alaskan natives living on or near reservations.</td>
<td>Funds to provide a full range of comprehensive health care programs, including dental and nutrition care, psychiatric care, sanitation, health education.</td>
<td>Federal funding of direct services.</td>
<td>Eleven area offices throughout the U.S.</td>
<td>Indian Health Service (in the Health Services Administration, Public Health Service, U.S. Department of Health, Education and Welfare) 5600 Fishers Lane, Rockville, Md. 20852 Tel. 301-443-1083</td>
</tr>
<tr>
<td>Migrant Health Public Health Service Act, Title IV, Section 319, as amended.</td>
<td>To increase the availability of high-quality comprehensive health services to migrant and seasonal agricultural workers and their families through the establishment of family health services and payment for the cost of other necessary care.</td>
<td>Migrant and seasonal agricultural workers and their families.</td>
<td>Funds to provide acute and preventive medical care, maternity care, hospitalization, dental care and rehabilitation through family clinics and purchase-of-care arrangements.</td>
<td>Federal grants to non-profit agencies.</td>
<td>State Health Department</td>
<td>Office for Migrant Health (in the Bureau of Community Health Services, Health Services Administration, Public Health Service, U.S. Dept. of Health, Education and Welfare) 5600 Fishers Lane, Rockville, Md. 20852 Tel. 301-443-1153</td>
</tr>
<tr>
<td>Community Health Centers Comprehensive Health Planning and Public Health Service Act, Section 314(e)</td>
<td>To provide comprehensive services to urban or rural areas where there is a shortage of medical personnel and services, through neighborhood health centers, family health centers or community health networks.</td>
<td>Anyone residing in the target area.</td>
<td>A broad range of outpatient, medical care referral and environmental health services.</td>
<td>Federal grants to non-profit private or public organizations or agencies.</td>
<td>State Health Department</td>
<td>Office for Community Health Centers (in the Bureau of Community Health Services, Health Services Administration, Public Health Service, U.S. Dept. of Health, Education and Welfare) 5600 Fishers Lane, Rockville, Md. 20852 Tel. 301-443-2270</td>
</tr>
<tr>
<td>Health Maintenance Organizations Health Maintenance Organization Act of 1973</td>
<td>To provide encouragement for the establishment and expansion of health maintenance organizations.</td>
<td>Anyone enrolled in the HMO.</td>
<td>Provision of comprehensive health services on a prepaid capitation basis with emphasis on primary care and preventive services.</td>
<td>Federal grants for feasibility studies, planning and initial development. Once established, loans or loan guarantees to meet operational deficits for the first three years.</td>
<td>State Health Department</td>
<td>Office for Health Maintenance Organizations (in the Bureau of Community Health Services, Health Services Administration, Public Health Service, U.S. Dept. of Health, Education and Welfare) 5600 Fishers Lane, Rockville, Md. 20852 Tel. 301-443-4936</td>
</tr>
<tr>
<td>Community Mental Health Centers Community Mental Health Centers Amendments of 1975</td>
<td>To continue and expand community mental health services.</td>
<td>Anyone residing in the catchment area.</td>
<td>Provision of comprehensive mental health services.</td>
<td>Federal grants to non-profit public or private organizations or agencies.</td>
<td>State Health Department, State Mental Health Department or State Department of Human Resources</td>
<td>Community Mental Health Support Branch, National Institute of Mental Health (in the Alcohol, Drug Abuse and Mental Health Administration, Public Health Service, U.S. Dept. of Health, Education and Welfare) 5600 Fishers Lane, Rockville, Md. 20852 Tel. 301-443-3623</td>
</tr>
<tr>
<td>Comprehensive Health Service Grants Comprehensive Health Planning and Public Health Service Act, Section 314(g)</td>
<td>To assist states in establishing and maintaining adequate public health services in accordance with priorities and goals established by states.</td>
<td>Varies with service.</td>
<td>Provision of communicable disease programs, environmental health services, chronic disease prevention programs, laboratory services, home health, public health nursing services and community mental health services.</td>
<td>Formula grants to states.</td>
<td>State Health Department or State Mental Health Department</td>
<td>Bureau of Community Health Services (in the Bureau of Community Health Services, Health Services Administration, Public Health Service, U.S. Dept. of Health, Education and Welfare) 5600 Fishers Lane, Rockville, Md. 20852 Tel. 301-443-6350</td>
</tr>
<tr>
<td>Program and Authorizing Legislation</td>
<td>Purpose</td>
<td>Population eligible for services</td>
<td>Activities</td>
<td>Financing</td>
<td>State Contact</td>
<td>Federal Agency*</td>
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<td>Medicaid</td>
<td>To provide financial assistance for medical services to families certified as eligible by state welfare or Medicaid agency.</td>
<td>Those certified eligible by the state Welfare or Medicaid Agency including families with dependent children (AFDC), and in some states other medically needy individuals.</td>
<td>Varies with the state. Includes payment for inpatient hospital care, outpatient hospital care, nursing home care, physicians care, laboratory and x-ray services, home health services, family planning, Early and Periodic Screening, Diagnosis and Treatment, and other services as the opinion of the state.</td>
<td>Federal-state matched reimbursement for services provided.</td>
<td>State Medicaid Agency (Usually State Department of Health or Welfare)</td>
<td>Medical Services Administration (in the Social and Rehabilitation Services, U.S. Dept. of Health, Education and Welfare) Room 5118, Switzer Bldg., 330 C St., N.W., Washington, D.C. 20201 Tel. 202-425-0377</td>
</tr>
<tr>
<td>Social Services, Title XX</td>
<td>To provide preventative health care to children in low-income families by identifying, diagnosing and treating medical, dental and developmental problems.</td>
<td>Varies state to state-Medicaid eligible population.</td>
<td>Varies with the state. Assessment of an individual’s physical and mental health, diagnostic services for those found to need them, treatment within the amount, duration and scope of the State plan as always including eyeglasses, hearing aids, other treatment for visual and hearing defects and dental services.</td>
<td>Federal-state matched reimbursement for services provided.</td>
<td>State Medicaid Agency (Usually State Department of Health or Welfare)</td>
<td>Early and Periodic Screening, Diagnosis and Treatment (in the Medical Services Administration, Social and Rehabilitation Services, U.S. Dept. of Health, Education and Welfare) Switzer Bldg., 330 C St., N.W., Washington, D.C. 20201 Tel. 202-245-0055</td>
</tr>
<tr>
<td>Title XIX, Social Security Act, Title XX (Social Service Amendments of 1974) (replaces IV-A)</td>
<td>To furnish services to families directed at achieving or maintaining self-sufficiency by preventing or remediating neglect, abuse or exploitation of children and adults unable to protect their own interests.</td>
<td>Determined by states (only limitation is on income level).</td>
<td>Grants to states to support services which include but are not limited to child care services, protective services for children and adults, family planning services for all AFDC recipients, services related to the management and maintenance of the home, transportation services, information, referral, and counseling services. May include medical care if it is an integral but subordinate part of a service, provided funds are not available to the individual under Title XIX (Medicaid).</td>
<td>State matched federal reimbursement, possibly supplemented by fees</td>
<td>Social Services Administration (in the Social and Rehabilitation Services, U.S. Dept. of Health, Education and Welfare) Room 5129, Switzer Building, 330 C Street, S.W., Washington, D.C. 20201 Tel. 202-245-8717</td>
<td></td>
</tr>
<tr>
<td>Title XX</td>
<td>To find and remedy health defects of each child enrolled in a Headstart Program by introducing the child and family to continuing sources of health care, nutritious meals, and health education.</td>
<td>Children enrolled in Headstart</td>
<td>Funds to facilitate and sometimes provide medical, dental and developmental assessment, referral, treatment for children enrolled in Head Start, health and education for staff, parents, and children enrolled in Headstart.</td>
<td>Federal project grants with some local matching funds.</td>
<td>Community Services Administration (in the Social and Rehabilitation Services, U.S. Dept. of Health, Education and Welfare) Room 5129, 330 C Street, S.W., Washington, D.C. 20201 Tel. 202-245-8717</td>
<td></td>
</tr>
<tr>
<td>Special Supplemental Food Program for Women, Infants and Children (WIC) National School Lunch Act of 1966, as amended</td>
<td>To provide special nutritious food supplements to pregnant and lactating women, and to children up to 4 years old at nutritional risk because of inadequate nutrition and income.</td>
<td>Pregnant or lactating mothers, and non-nursing mothers to 6 months after delivery, and children up to 5 years who reside in approved project area if they are eligible for care at a reduced cost from local agency serving project area, if they have nutritional needs.</td>
<td>Provision of specific supplemental foods.</td>
<td>Federal grants to states</td>
<td>WIC Coordinator, State Department of Health, or comparable state agency, Indian tribes, bands or groups</td>
<td></td>
</tr>
<tr>
<td>National School Lunch Program</td>
<td>To provide nutritious lunches in schools to children, particularly need children.</td>
<td>All children in a participating school. Reduced price or free lunches to those who have need as determined by local school officials in accordance with national income standards.</td>
<td>Provision of food and cash assistance.</td>
<td>Federal funds and federally donated foods to participating schools.</td>
<td>State Department of Education</td>
<td>Food and Nutrition Service (in the Dep. of Agriculture) 12th St., N.W., Washington, D.C. 20250 Tel. 202-424-3700</td>
</tr>
<tr>
<td>Title XIX, Social Security Act, Title XX National School Lunch Act and Child Nutrition Act of 1966, as amended</td>
<td>To provide nutritious breakfasts in schools to children, particularly need children.</td>
<td>All children participating in participating school. Reduced price or free breakfasts to those who have need as determined by local school officials in accordance with national income standards.</td>
<td>Provision of food and cash assistance.</td>
<td>Federal funds and federally donated foods to participating schools.</td>
<td>State Department of Education</td>
<td>same as above</td>
</tr>
<tr>
<td>School Breakfast Program</td>
<td>To provide nutritious breakfasts in schools to children, particularly need children and children who travel long distances to school.</td>
<td>All children participating in school.</td>
<td>Provision of food and cash assistance.</td>
<td>Federal funds and federally donated foods to participating schools.</td>
<td>State Department of Education</td>
<td>same as above</td>
</tr>
<tr>
<td>Child Care Food Program</td>
<td>To provide nutritious meals for preschool and school-age children in public and private nonprofit institutions (day care centers, camps, settlement houses), particularly need children.</td>
<td>All children participating in participating institutions. Reduced price or free meals to those who have need.</td>
<td>Provision of food and cash assistance.</td>
<td>Federal funds and federally donated foods to participating institutions.</td>
<td>State Department of Education</td>
<td>same as above</td>
</tr>
</tbody>
</table>

*Federal Agency: The agency responsible for managing and providing services.
For many programs more detailed information is available through Regional Offices than through the Central/Washington office.

Region I (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont)
John F. Kennedy Federal Bldg.
Government Center
Boston, Mass. 02203
617-223-7291

Region II (New York, New Jersey, Puerto Rico, Virgin Islands)
Federal Building
26 Federal Plaza
New York, N.Y. 10007
212-204-3620

Region III (Delaware, Maryland, Pennsylvania, Virginia, West Virginia, District of Columbia)
3333 Market Street
Philadelphia, Pa. 19101
215-597-6482

Region IV (Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee)
50 Seventh Street, NE
Atlanta, Georgia 30323
404-526-5001

Region V (Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin)
300 South Wacker Drive
Chicago, Illinois 60606
312-353-5122

Region VI (Arkansas, Louisiana, New Mexico, Oklahoma, Texas)
1114 Commerce Street
Dallas, Texas 75202
214-749-2436

Region VII (Iowa, Kansas, Missouri, Nebraska)
601 East 12th Street
Kansas City, Missouri 64106
816-374-3438

Region VIII (Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming)
945 South 33rd Street
Denver, Colorado 80202
303-837-3700

Region IX (Arizona, California, Hawaii, Nevada, Guam, Trust Territory of Pacific Island, American Samoa)
Federal Office Building
50 Fulton Street
San Francisco, Calif. 94102
415-524-3066

Region X (Alaska, Idaho, Oregon, Washington)
Arcade Plaza
1321 Second Avenue
Seattle, Washington 98101
206-442-0486
People and Groups to Contact on Health Record Keeping Issues

Mental Health Law Project (MHLP)
1220 19th Street, N.W.
Suite 300
Washington, D.C. 20036
(202) 467-5730

Contact Person: Robert Plotkin

MHLP is a foundation-funded, public interest organization composed of lawyers and mental health professionals. It has been developing a model legislative guide covering a wide range of issues concerning the delivery of mental health services. One chapter in this guide contains a model code on the confidentiality of records, along with a detailed discussion of client access, third-party access, security and related problems. A separate chapter discusses certain access issues relating to children, adolescents and parents. This guide is presently in draft form, but copies of individual chapters are available upon request. MHLP is especially concerned with computerization of data, access to client records by government auditors and the availability of health records to insurance companies and employers. MHLP is available to answer specific inquiries about the legality and adequacy of particular health record systems, from a privacy point of view and to provide legal assistance on individual patient access problems.

H.E.W. Task Force on Health and Medical Records
U.S. Dept. of Health, Education and Welfare
17A13
Parklawn Building
5660 Fisher's Lane
Rockville, Maryland 28052
(202) 443-2563

Contact Person: John P. Fanning

This permanent committee was established to deal with policy issues concerning health and medical records within the Department. While not a technical assistance center, this committee can provide aid in understanding federal privacy laws and regulations governing health records.

Public Citizen Health Research Group (HRG)
7th Floor
2000 P Street, N.W.
Washington, D.C. 20036
(202) 872-0320

Contact Person: Sidney Wolfe

HRG is a citizen-supported, consumer advocacy group composed of lawyers and health professionals. They are particularly concerned with the privacy implications of the PSRO’s and with public
access to data generated by the peer review process. While interested in patient access to health records, they do not have the staff to handle individual access problems. They are available as a resource for those establishing and evaluating particular health records systems.

**U.S. Privacy Protection Study Commission**
2120 L Street, N.W.
Washington, D.C.
(202) 634-1477
Contact Person: Carole Parsons

The Privacy Commission was established by Congress in 1975 to investigate a variety of records/privacy problems including those relating to medical records. In addition to its research function, this group "may ... upon request, prepare model legislation for use by state and local governments in establishing procedures for handling, maintaining, and disseminating personal information. . . ." In January, 1976, the Privacy Commission started a preliminary investigation on medical and social service records. Hearings on these records may be held later in the year. Information inquiries should be put in writing and sent to Ms. Parsons' attention.

**National Commission on Confidentiality of Health Records**
% American Psychiatric Association
1700 18th Street, N.W.
Washington, D.C. 20009
(202) 232-7878
Contact Person: Robert L. Robinson

The National Commission on Confidentiality of Health Records was established on an interim basis in 1975 and is presently seeking to incorporate itself. This group is composed of 17 national health associations including the American Academy of Pediatrics, the Blue Cross Association, the National Association of Clinical Social Workers, the American Academy of Child Psychiatry, American Hospital Association, and the American Psychological Association. Formed as a result of a national conference on confidentiality and health records held in November 1974, the objectives of the Commission are:

—To promote and preserve the confidentiality of health care records and to establish guidelines and recommendations for appropriate access to them.
—To propose legislation and regulations, to study and analyze legislation and regulations in formation or already introduced, and to make recommendations for action and implementation by sponsoring organizations.
—To engage in public education on confidentiality and the access of records.
—To develop methods for improved handling of health care information.

**Children's Defense Fund (CDF)**
1520 New Hampshire Avenue, N.W.
Washington, D.C. 20036
(202) 483-1470
Contact person: Linda Lipton

CDF has concentrated its efforts in the privacy area on problems surrounding access to and correction of school records. They are particularly concerned with implementation of the Family Educational Rights and Privacy Act and the privacy provisions governing special education records as contained in the Education of the Handicapped Act. CDF is also beginning to explore the difficulties in assuring the confidentiality of records on children generated by federally-funded programs such as EPSDT and Title XX. Pamphlets on parent and youth rights concerning their own records can be obtained from CDF.

**Domestic Council Committee on the Right of Privacy**
Room 709
1800 G Street, N.W.
Washington, D.C. 20504
(202) 395-3254
Contact Person: Bob Belair

The Domestic Council is an arm of the federal executive administration. Its committee on the right to privacy deals with national policy issues concerning the collection, dissemination and use of
personally identifiable information. This group can be a useful source of information on current governmental projects and activities in the privacy area.

**Materials on Health Record Keeping**

In addition to the groups and materials discussed above, there are several publications which explore the problems of organizing health data systems to assure the confidentiality of patient records:

   
   This is a special issue on the privacy and confidentiality of health records. Articles cover the operation of the nationwide computerized medical data bank serving 700 insurance companies (Medical Insurance Bureau), different approaches to patient access to their medical records, and the duties of physicians in protecting patient privacy.

   
   Using a question and answer format, this patient rights guide focuses on patient access to hospital records and on the storage of hospital data under present law.

   
   Lister, Baker and Milhous focus on the problems of exceptional children and the particularly sensitive information collected on them. The authors lay out some specifications for fairness in record keeping on such children.

   
   Kelley and Weston review the record keeping practices of mental health authorities using computerized collection and maintenance procedures. Recommendations are made for assuring patient confidentiality.

   
   Eight record-keeping principles for health service providers are set out and several suggestions for immediate action are proposed.

   
   The authors argue in favor of giving patients copies of their medical records and review the anticipated positive results and expected objections to such a proposal.

   
   Spingarn provides an overview of the problem of confidentiality and health records with some possible solutions. The report is based on the proceedings of the Conference on Confidentiality of Health Records in Key Biscayne, Florida, November, 1974. A brief discussion of children’s records can be found on pages 12–13. (Further discussion of children’s records is set forth in the Report of the Topic 8 participants at the Conference.)

   
   The items published in this pamphlet are reprints of documents and position statements submitted to H.E.W. by several consumer advocacy groups, including the Health Research Group and the University of Pennsylvania Health Law Project. Provisions necessary to assure patient privacy and recommendations for public disclosure of certain data gathered by P.S.R.O.’s and participating doctors and health institutions are made.

The committee report discusses the conflict between the need to know and an individual's rights to privacy. While this book does not focus specifically on health records, it does offer some useful background material on confidentiality issues and lays out a general framework for analyzing the problems involved.


Westin and Baker review the impact of computers on record keeping and the implications this has for an individual's rights to privacy. One section deals specifically with the record-keeping system of the Kaiser-Permanente Medical Care Program.
APPENDIX E

List of Programs Included in this Report

Adolescent Program of the University of California Medical Center 400 Parnassus San Francisco, California 94143 Tel. 415-666-9000

Anthony Jordan Health Center 82 Holland Street P.O. Box 876 Rochester, New York 14603 Tel. 716-454-2400

Barrio Comprehensive Child Health Care Center 1102 Barclay San Antonio, Texas 78207 Tel. 512-434-2368

Beaufort-Jasper Comprehensive Health Services Post Office Box 357 Richland, South Carolina 29936 Tel. 803-726-8171

Charles R. Drew Postgraduate Medical School 1621 East 120th Street Los Angeles, California 90059 Tel. 213-639-8550

Child Development Center Rhode Island Hospital Providence, Rhode Island 02903 Tel. 401-277-5681

Child Health Advocacy Project Children’s Hospital 2125 13th Street, N.W. Washington, D.C. 20009 Tel. 202-835-4152

Child Health Services Department of Pediatrics Cambridge City Hospital 1493 Cambridge Street Cambridge, Massachusetts 02139 Tel. 617-354-2020

Children and Youth Project Department of Pediatrics University of Texas Medical Branch Sealy-Smith Professional Building, Suite 728 Galveston, Texas 77550 Tel. 713-765-2431

Children and Youth Project University of Texas Health Science Center Suite 802 Stemmons Tower North 2710 Stemmons Dallas, Texas 75232 Tel. 214-637-0405

1 The material for this report was collected during 1974 and 1975. This was a period of cut-backs and changes in funding patterns, particularly in regard to project grants under Title V, which supported Children and Youth and Maternal and Infant Care Projects. For this reason, some aspects of the programs we have described may have changed.
Children and Youth Project
Las Animas-Huerfano District Health Department
723 Arizona Avenue
Trinidad, Colorado 81082
Tel. 303-846-2213

Children and Youth Project
Provident-Druid Comprehensive Pediatric Center
1515 West North Avenue
Baltimore, Maryland 21217
Tel. 301-728-0500

Children and Youth Project
Roosevelt Hospital
430 West 59th Street
New York, New York 10019
Tel. 212-554-7475

Clinica de La Raza
1501 Fruitvale Avenue
Oakland, California 94601
Tel. 415-261-4773

Community Health Education Program
Duke University Medical Center
Box 15159
Durham, North Carolina 27706
Tel. 919-477-7391

Community-University Health Care Center
2016 16th Avenue South
Minneapolis, Minnesota 55404
Tel. 612-376-4774

Comprehensive Health Care Program for Children and Youth
University of Miami
Division of Comprehensive Health Care
P.O. Box 520875
Biscayne Annex
Miami, Florida
Tel. 305-324-1551

Cuba Checkerboard Rural Health Project
Presbyterian Medical Services
P.O. Box 2384
207 Shelby Street
Santa Fe, New Mexico 87501
Tel. 505-982-5560

Early and Periodic Screening, Diagnosis and Treatment Program
Florence County Department of Social Services
710 South Irby Street
Florence, South Carolina 29501
Tel. 803-669-3354

East Coast Migrant Health Project
1330 Massachusetts Avenue, N.W.
Washington, D.C. 20005
Tel. 202-347-7377

Family Planning Services
Louisiana State Department of Health
P.O. Box 60560
New Orleans, Louisiana 70160
Tel. 504-581-6613

Genesee Hospital Department of Ambulatory Services
224 Alexander Street
Rochester, New York 14607
Tel. 716-263-5250

Given Health Care Center
University of Vermont
Burlington, Vermont 05401
Tel. 802-864-0316

Guilford County Family Planning Program
208 South Spring Street
Greensboro, North Carolina 27401
Tel. 919-373-3245

Health Insurance Plan of Greater New York
Central Office
625 Madison Avenue
New York, New York 10022
Tel. 212-754-1144

Home Culture Program
Pediatric Department
Columbia Medical Plan
Columbia, Maryland 21044
Tel. 301-730-5000
hot springs health program
p.o. box 68
hot springs, north carolina 28743
tel. 704-622-3245

kaiser foundation medical care program
kaiser foundation hospitals
4610 s.e. belmont street
portland, oregon 97215
tel. 503-233-5631, ext. 405

lee county cooperative clinic
530 west atkins boulevard
marianna, arkansas 72360
tel. 501-295-5225

los angeles county-university of southern california medical center
1200 north state street
los angeles, california 90033
tel. 213-226-2622

lowndes county-women and infant care project
lowndes county health services association
p.o. box 735
hayneville, alabama 36040
tel. 205-548-2517

martin luther king, jr. health center
3674 third avenue
bronx, new york 10456
tel. 212-992-9100

maternal & infant care project
new york department of health
377 broadway
new york, new york 10013
tel. 212-966-3828

minneapolis maternal and infant care and children and youth programs
city of minneapolis: division of public health
250 south fourth street
room 401
minneapolis, minnesota 55415
tel. 612-348-2963

neighborhood health program
denver department of health and hospitals
west eighth avenue & cherotree street
denver, colorado 80204
tel. 303-893-7666

north carolina memorial hospital
combined clinic program
chapel hill, north carolina 27514
tel. 919-966-1085

o’bleness memorial hospital
hospital drive
athens, ohio 45701
tel. 614-593-5551

office of emergency medical services
1375 pacific highway
san diego, california 92101
tel. 714-236-3663

pediatric clinics
baltimore city hospital
4940 eastern avenue
baltimore, maryland 21224
tel. 301-396-3100

project help
school of community and allied health resources
scahr building
room 220
1917 5th avenue s.
birmingham, alabama 35294
tel. 205-934-3262

rural health associates
north main street
farmington, maine 04938
tel. 207-778-6521

seven areas council for health: emergency services
rockforge neighborhood house
p.o. box 3042 sabraton station
rockforge, west virginia 26505
tel. 304-292-3286
Southeast Ohio Emergency Medical Services (SEOEEMS)
Box 805
415 Vinton Pike
Gallipolis, Ohio  45631
Tel.  614-592-4457

Tri-City Citizen's Union
675–681 South 19th Street
Newark, New Jersey  07103
Tel.  201-374-5254

United Health Services of Kentucky and Tennessee, Inc.
General Delivery
Clairfield, Tennessee  37715
Tel.  615-424-8492

Watts Health Foundation
2051 E. 103 Street
Los Angeles, California  90002
Tel.  213-564-4331
This is not a complete bibliography of all the references used in writing this book. We have listed here those references and guides which we think will (a) give you an overview of the important issues in child health; (b) give you some ideas for approaching the problem of finding out about and organizing child health services locally.


