

HEALTH CARE COVERAGE FOR CHILDREN

HEARING

BEFORE THE

COMMITTEE ON FINANCE

UNITED STATES SENATE

ONE HUNDRED FIRST CONGRESS

FIRST SESSION

JUNE 20, 1989



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HEALTH CARE COVERAGE FOR CHILDREN

TUESDAY, JUNE 20, 1989

U.S. SENATE,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 10:07 a.m. in room SD-215, Dirksen Senate Office Building, Hon. Lloyd Bentsen (chairman of the committee) presiding.

Also present: Senators Bradley, Rockefeller, Roth, Chafee, Heinz, and Durenberger.

[The press release announcing the hearing follows:]

[Press Release No H-35, June 12, 1989]

SENATOR BENTSEN ANNOUNCES HEARINGS ON CHILD HEALTH CARE

WASHINGTON, DC—Senator Lloyd Bentsen (D., Texas), Chairman, announced Monday that the Finance Committee will hold a hearing to consider proposals to improve health care coverage for children under the Medicaid and Maternal Child Health Services Block Grant programs.

The hearing will be held on Tuesday, June 20, 1989 at 10 a.m. in Room SD-215 of the Dirksen Senate Office Building.

"The health care problems facing our children are complex and we can no longer afford as a nation to ignore them. One of every five American children has no public or private health insurance. Of 37 million uninsured Americans, 12 million are children, 9 million of whom are the dependents of workers who lack insurance against any health care costs," Bentsen said.

"It is not an exaggeration to say that America's children are our future, and we must be prepared to invest in them," Bentsen said.

OPENING STATEMENT OF HON. LLOYD BENTSEN, A U.S. SENATOR FROM TEXAS, CHAIRMAN, SENATE FINANCE COMMITTEE

The CHAIRMAN. This hearing will come to order.

Today we are going to hear testimony about a wide variety of health proposals. We will hear from experts about Medicaid and MCH programs; we will hear about gaps in the current health care delivery system; we will hear recommendations about ways to remove barriers to health care.

Our witnesses have been asked to come because of their insight and their years of experience, and they will talk about an issue about which there is passionate concern of many of us on the Finance Committee.

There are a wide variety of bills that have been introduced by members of this committee to try to address these particular problems, particularly those that deal with the health of children and pregnant women.

Since the early 1980's, the committee has approved extensions of Medicaid and MCH coverage to pregnant women, infants, and chil-

dren; but there are still a lot of problems. In fact, the problems are so compelling that we have to solve them, even in an age when it is almost impossible to fund anything that has any expense at all.

White American babies now die at a greater rate than babies born in Singapore. Minority babies born here in Washington, within a few blocks of this hearing room, today have a greater chance of dying before the end of their first year than babies in Cuba.

Of the nearly 40 million Americans without health insurance, 13 million are children. Forty percent of children under 4 don't get their basic immunizations. Actually, immunizations declined in the 1980's, and that is when you saw this upsurge in the incidence of mumps, measles, and whooping cough—incredible. I don't know of any bigger payoff than on immunization shots; and yet, we are not fulfilling that need.

Meanwhile, we have seen those health insurance premiums go up, and up, and up; and, not surprisingly, some of the coverage is starting to go down.

Fifteen of the 20 members of this committee have sponsored and cosponsored child-related health care legislation. This week Senator Chafee and I have introduced the Maternal and Child Health Act. That is a bill that would increase the number of women and children eligible for medical care. And yesterday, Senator Riegle held a hearing on the larger issue of uninsured Americans.

One way to tackle at least a piece of that issue is to improve health care coverage for children, and to do it under the Medicaid and the Maternal Child Health Services Block Grant programs. That is why we hope our witnesses today will help us do that, and we will be welcoming them and looking forward to their testimony.

I yield to Senator Chafee, for any comment that you might have.

OPENING STATEMENT OF HON. JOHN H. CHAFEE, A U.S. SENATOR FROM RHODE ISLAND

Senator CHAFEE. Thank you very much, Mr. Chairman.

First I want to commend you for holding this hearing and also say how proud I am to join you in introducing the Maternal and Child Health Act of 1989.

There are several reasons why health care is unavailable to millions of children:

First, our health care system has changed dramatically over the past 20 years. Public and private efforts to protect families from catastrophic illnesses have contributed to the evolution of a sick-care system in our country instead of a health care system. We don't currently emphasize primary and preventive care as we once did and should now.

Second, many State Medicaid programs don't adequately reimburse the providers; so, more and more providers are turning away from serving Medicaid beneficiaries.

Third, malpractice premiums, especially for obstetricians and gynecologists, are increasing at alarming rates, thus leading to the expensive practice of defensive medicine, and thus an inefficient use of precious health care resources.

Now, the bill that Senator Bentsen and I have introduced would expand Medicaid eligibility to cover many of the poor and near-poor children who currently are without health care coverage. States who now have the option would be required to provide care to pregnant women, infants, and children under the age of 6 with incomes below 185 percent of the poverty level. In addition, States would be given the option to cover children under age 18 who were below poverty. This is all under Medicaid.

The Maternal Child Health Act of 1989 would establish four Medicaid buy-in demonstration projects targeted at low-income children and medically-uninsurable children. This is a spinoff from the Med-America legislation which I put in in the last Congress.

Med-America would cover all individuals below 100 percent of poverty, and allow people between 100 and 200 percent of poverty to purchase health care coverage on a sliding premium scale. That is, between 100 and 200 percent they could buy the coverage from Medicaid with an adjusted premium based on their incomes. All told, our bill would cover nearly 2½ million children by 1991, and I think this is good cost investment and efficient use of our funds.

In conclusion, Mr. Chairman, I would just say one thing that has troubled me about Medicaid and coverage for children, young children, and particularly pregnant mothers: I am disturbed over the fact that the services are available, but we cannot get the individuals to come forward.

I saw some shocking figures about Southeast Asians—Laotians, Vietnamese, and so forth—that x-percent, something like 40 percent, received no coverage, no medical attention, in the first trimester. It wasn't because the coverage wasn't available; it is that either they are not availing themselves of it or they don't know about it. Somehow we have got to perfect a greater outreach for these individuals if we are going to give them the services which in some instances aren't available, and under our legislation would become available. So, I believe the outreach has to be a part of any extension of this coverage for low-income pregnant women and their children.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you.

Senator Heinz, would you care to make a statement?

Senator HEINZ. Yes, Mr. Chairman, I would.

OPENING STATEMENT OF HON. JOHN HEINZ, A U.S. SENATOR FROM PENNSYLVANIA

Senator HEINZ. Mr. Chairman, I think that this committee, under your leadership, along with the Administration, are to be commended for making the health of America's children a top legislative priority.

The expert testimony we will hear today about gaps in our health care coverage of children, builds on Senator Chafee's earlier comments. The bipartisan legislation you introduced earlier this week, the Maternal and Child Health Act of 1989, Mr. Chairman, which I am pleased to cosponsor, addresses these gaps.

The truth is America ranks as one of the most dangerous places to be born in the industrialized world. Each day 100 American

babies die from preventable complications associated with low birth weight. Many of these babies would be saved if their mothers had received simple prenatal health care screening or nutrition counseling. The guarantee of a healthy baby may be nothing more than monthly vitamin supplements for the mother during pregnancy.

Part of the problem is that over one-fourth of the 56 million women of childbearing age in this country have no health insurance coverage for maternity care, and those women most likely to lack coverage are young and poor.

Another part of the problem lies in well-intentioned Federal programs that fall short when implemented by the States. For example, few States, and I am sorry to say even my home State of Pennsylvania, have taken full advantage of the 1987 Medicaid amendments to permit coverage of pregnant women, infants, and children living in poverty.

In 1980, the Surgeon General set a goal to reduce the tragedy of underweight newborns from some 6.8 percent to not more than 5 percent by the end of the decade. Our most recent statistics show that while 1990 is at hand, we are still far from achieving that goal. In Pennsylvania, for example, the rate of low birthweight infants continues at almost double the targeted percentage. From 1980 to 1986, the rate in Pittsburgh, my home town, remained at approximately 1 in every 10 babies born. In Philadelphia, the percent actually increased somewhat, from 10 to 10.8 percent, during the same period. As a result, a black child born in my State is less likely to live to age 1 than any baby born in either Cuba or Bulgaria.

Mr. Chairman, we have our work cut out for us. I think your legislation is an excellent start. It will help make good prenatal care every child's birthright. In the words of Frederick Douglas, it is a step toward giving every child in this country a fair start and an equal chance in the race of life.

We thank you for your leadership, Mr. Chairman.

**OPENING STATEMENT OF HON. WILLIAM V. ROTH, JR., A U.S.
SENATOR FROM DELAWARE**

Senator ROTH. Thank you, Mr. Chairman, for holding these hearings.

The health of the nation's children is of paramount importance to a successful next generation. Infants and children are the future, and we should not forget that they are particularly vulnerable to deficiencies in the health care system.

The hearing today will focus on a population that has never voted for any one of us yet, and reducing the rate of infant mortality is a goal we should continue to aim for.

I remember the hearing held last year when Senator Chiles testified before us. I was struck with his description of the child health care program in Japan. He told us that after World War II Japan made babies the national priority. Japan established a preventive health care system where pregnant women were given a passport which showed them what care was available to them. Today, Japan has one of the lowest infant mortality rates, still, almost half of ours.

While Japan may be ahead of us, we have made some improvement in recent years. I am pleased to say that in my home State we have reduced the black infant mortality by 37 percent and the total infant mortality by 17 percent. I have to say that part of this improvement has been accomplished through awareness campaigns and expansions in Medicaid. Governor Castle has made infants and pregnant women a State priority in stressing preventative care, but there is much improvement that yet remains.

Mr. Chairman, I would ask that my full statement be included in the record, and I congratulate you for holding these hearings.

The CHAIRMAN. That will be done. Thank you very much, Senator.

[The prepared statement of Senator Roth appears in the appendix.]

The CHAIRMAN. Our first witness will be Mr. Louis Hays, the Acting Administrator for the Health Care Financing Administration.

Mr. Hays, we are pleased to have you. If you would, proceed with your testimony.

We will try to keep everyone, if we can, within 5 minutes, and then take the full statements in the record. That will give us time to ask such questions as we want.

Mr. Hays?

**STATEMENT OF LOUIS B. HAYS, ACTING ADMINISTRATOR,
HEALTH CARE FINANCING ADMINISTRATION, DEPARTMENT OF
HEALTH AND HUMAN SERVICES**

Mr. HAYS. Thank you, Mr. Chairman.

Mr. Chairman and members of the committee, I am pleased to be here today to discuss the Administration's bill, S. 902, which would expand eligibility for pregnant women and infants under the Medicaid program.

This legislation would put into effect the President's strong commitment to improving the health of mothers and children, as expressed in his February 9th address to the Nation. To quote the President, "Infant and maternal health is an area where we must invest in the future, and where we must all be committed to improvement."

Secretary Sullivan has also made this issue a top priority at the Department of Health and Human Services. He, too, is deeply concerned for the well-being of this under-served population. And, Mr. Chairman, I am well aware of your personal commitment to better health care for children, as evidenced by the legislation you have sponsored in this area, as well as your other activities.

As this committee is well aware, the United States continues to lag behind other developed nations in measures of infant mortality. Even more disturbing, as noted already this morning, is the fact that the infant mortality rate for black infants is nearly twice that of whites.

The President recognizes the need to improve health care for lower income Americans and has chosen to focus first on the population's most at risk, pregnant women and infants. The Administration's bill is an important first step in carrying out that goal.

The Administration's proposal would require State Medicaid programs, by April 1, 1990, to cover pregnant women and infants with incomes up to 130 percent of the Federal poverty level. Under the President's proposals, a pregnant woman with an annual income of up to \$13,078 would be eligible, and, for a household of four, an annual income of \$18,382.

Because of the importance of early prenatal care, the President's proposal seeks to encourage eligible women to obtain services covered by Medicaid. Thus, all States would be required to offer presumptive eligibility determinations, so that qualified health care providers can make immediate Medicaid eligibility determinations.

States will have to demonstrate their efforts to make presumptive eligibility available to pregnant women in all parts of the State.

Finally, and perhaps equally notably, States will be required to conduct outreach and public education campaigns in areas with high rates of infant mortality.

One of the most cost-effective ways to ensure children's health, as noted by the chairman, is to protect them from the disabling and sometimes fatal diseases of childhood. To this end, the President's proposal would entitle all children under the age of 6 who receive food stamps to get Medicaid coverage for immunizations.

Medicaid alone, however, will not solve the problem of high infant mortality. For example, the Department of Agriculture operates the Women, Infants, and Children Nutrition Program, otherwise known as WIC, and in our Department, the Public Health Service, administers the Maternal and Child Health Block Grant Program.

The President's proposal also includes \$20 million for fiscal year 1990 and 1991 to test ways of coordinating these programs to maximize their effectiveness in combatting high infant mortality. The results will be used to develop future reforms of service delivery under the various programs affecting maternal and child health.

To make these important enhancements to the Medicaid program budget neutral, the President's budget has proposed offsets for Congress's consideration.

As the President noted, "At a time like today, when resources are tight, when we have more desires than funds, we must move resources from certain lower priorities to the higher priority of maternal and infant health."

The Administration proposes to fund these expansions by gradually decreasing the Federal match for all administrative services to 50 percent. We propose to phase down over a several year period enhanced matching rates that have outlived their purpose and to put that money into program enhancements. None of the Federal matching rates would go below 50 percent, which is the rate generally used for administrative costs, and there would be no cap on the amount of Federal funds matchable.

By phasing down over a period of years, States will be able to take necessary action to adjust to the reduction.

In closing, Mr. Chairman, the President has submitted a responsible proposal to address the national problem of children's health. It is a beginning. It is what we can afford right now. More needs to

be done, and we intend to do it in a thoughtful way that meets priority health care needs without violating budget agreements.

I note that you have several pieces of legislation pending before this committee which share the same goals as the Administration's proposal. Our objectives are the same, and we look forward to working with you on this important health policy.

I would be pleased to address any questions that you or the committee might have at this time.

[The prepared statement of Mr. Hays appears in the appendix.]

The CHAIRMAN. Thank you, Mr. Hays. Thank you for your testimony.

I note that the President's budget does have a modest increase in there for expansion for child health coverage, but the lack of adequate coverage for pregnant women and children in this country has to be, I think, one of this Nation's most pressing problems.

When you look at what we can spend in the first year, and if you are the most conservative on a budget process in trying to see that the taxpayer gets a real return for his money, and you spend \$1 on prenatal and neonatal health care, and you do that during the first year of that child's life, you will see that you get \$3.00 for every dollar you spend. It is a wonderful payoff.

Still, we find over 30 percent of the women receive no prenatal health care, which gets me to the point that Senator Chafee has made—the outreach is not being accomplished effectively.

Forty percent of children under 4 have not received a complete basic set of immunizations; and, as a result, the CDC has documented a substantial increase in the outbreak of infectious diseases such as mumps, measles, and whooping cough. One in five children have no private or public health insurance.

Now, those kinds of numbers document a failure, I think, to invest in America's future, and one that we have to work to try to turn around.

So, I have some questions about the program that you are presenting.

First, the budget proposes to fund expanded child health programs under Medicaid by cutting back on some of these administrative payments to the States, payments for administrative expenses. Do you think those States are going to be able to absorb those administrative costs? Or are they likely to just cut back on their oversight on nursing homes or family planning services?

Mr. HAYS. Well, Mr. Chairman, the changes that we are proposing to the so-called "enhanced" administrative matching rates would be phased in over a number of years. Let me clarify, of course, we are not talking about eliminating Federal reimbursement for these administrative costs.

The CHAIRMAN. I am not talking about that. I am talking about the reduction, and what happens, how do they respond to it.

Mr. HAYS. The States would continue to receive 50 percent Federal matching for those activities. We propose a rather lengthy phase-down from the higher rate to 50 percent.

The CHAIRMAN. How long is that?

Mr. HAYS. Well, the one that you mentioned, in particular, having to do with the new higher matching rates for nursing home

oversight would be phased down over a particularly lengthy period of time, so as to minimize the impact.

The CHAIRMAN. I keep asking you, tell me how long?

Mr. HAYS. With respect to nursing care oversight, it would not be until fiscal year 1995 that the 50 percent funding would occur.

The CHAIRMAN. That is one of the longer phase-outs, though. You have chosen to give that as an example.

Mr. HAYS. Yes. The others would be phased out by fiscal year 1992.

The CHAIRMAN. Next, then, is the mandating of Medicaid coverage for pregnant women and infants, up to 130 percent of the poverty line. When more than half of the insured infants reside in households with incomes above that level, why not use 185 percent, the threshold for the women, infants and children's nutrition program? That still wouldn't reach the 200 percent of the poverty level proposed by the Infant Mortality Commission. Would you comment on that?

Mr. HAYS. A couple of observations, Mr. Chairman.

First of all, the States do have the authority to increase up to 185 percent of the poverty level. And in fact, we have been out working with the States, actively encouraging them to take advantage of all of the optional provisions that currently exist in the Medicaid program today.

With respect to making it mandatory up to 185 percent, I think you may hear later today from State representatives that suggest that there is a question as to whether it should be optional or mandatory.

From our perspective, it is a question of taking one step at a time. We do not envision the President's legislative proposal to be the ending point; we view it as the starting point, and we think it is a fiscally-prudent way to proceed.

The CHAIRMAN. All right.

Does the President still intend to send us a Medicaid buy-in program?

Mr. HAYS. We are now actively looking at how we could construct a Medicaid buy-in proposal. The President remains very interested in that. I note with interest the buy-in proposal referred to by Senator Chafee that is included in your bill, and I think particularly the idea of testing it in a demonstration mode in several States is a very interesting way to proceed. So, I hope that we will be able to work together on a Medicaid buy-in approach.

The CHAIRMAN. But no final decision has been made on that?

Mr. HAYS. No final decision.

The CHAIRMAN. Senator Chafee?

Senator CHAFEE. Thank you, Mr. Chairman.

Mr. Hays, several things.

One, on the outreach, we have run into great problems there, even in a very small, compact State like ours, where those who are most in need of this type of service are pretty well located in a certain section of our principal city. We just have great difficulties.

One of the things that has come to my attention is that by having these services delivered through the welfare department as opposed to through a health department, there is a certain stigma

attached to it, with the connotation of welfare. Have you had any experience with that?

Mr. HAYS. Well, I guess not directly, in quite the sense you are raising it. But I would note that many of the services that are provided for maternal and child health are actually provided at clinics that are under the Maternal and Child Health part of the activity, as opposed to the Medicaid and the welfare part of the activity. So, much of the actual service delivery to mothers and infants is provided outside of the welfare office or structure.

I think your point, though, is part of the reason we are proposing \$20 million for demonstration activities, that is, to see whether there are more creative ways of getting mothers into the program, that take into account those sorts of perceptions.

Senator CHAFEE. It is bad enough not to have the service available for these poor women, low-income women, pregnant women; but it is even worse that, when it is available, they don't know about it or, for some reason, they don't partake of it.

I think the chairman said 30 percent of all low-income women have no prenatal care. That is a shocking figure.

Mr. HAYS. It is shockingly high, and that is one of the reasons we have placed priority on working with the States over the last year in getting increased emphasis on outreach and education. It doesn't do any good to have the services available if we can't get the women and infants in to receive those services.

Senator CHAFEE. One of the factors that is upsetting this equation is malpractice insurance, and the expensive performance of defensive medicine. Has the Administration come up with any suggestions on malpractice insurance reform?

Mr. HAYS. It is an issue that we are looking at. As you may recall, the previous Administration was hoping that through State reform efforts the problem of malpractice could be addressed. That approach obviously has not been fully successful.

Senator CHAFEE. Well, it hasn't been fully successful in this Congress, either.

Mr. HAYS. We are looking at other options now.

Senator CHAFEE. I don't know why we don't seem to get very far on that. I suppose if you had an exemption from malpractice in connection with Medicaid, that would be looked on as a disservice to the poor in some way, that they were treated differently than the more well-to-do. So it would have to be an overall reform in the malpractice in the State, rather than solely the providers for Medicaid.

Mr. HAYS. Medicaid might be a place to start, though.

Senator CHAFEE. I can see you would get an awful row on that, people saying you were treating the poor differently than you are the better off—perhaps. I don't know.

Well, I am glad about your support for the Medicaid buy-in, which we have in this program.

The Administration's proposal would make the 130 percent mandatory?

Mr. HAYS. That is correct.

Senator CHAFEE. How many States have taken the 185 percent now, do you know?

Mr. HAYS. Our most recent data show that 11 States are voluntarily up to the 185 percent; 29 are at the 100-percent level.

Senator CHAFEE. We all believe this is true, but is there any indication statistically that by this expansion of Medicaid we are doing better, as far as reducing low birth-weight babies and infant mortality?

Mr. HAYS. I think it is too early to have outcome evidence of these recent expansions and stepped-up efforts to work with the States. We certainly hope that it is going to have that effect.

Senator CHAFEE. Well, I have to believe it is true.

Mr. HAYS. That is what it is all about.

Senator CHAFEE. Thank you, Mr. Chairman.

The CHAIRMAN. Senator Durenberger?

**OPENING STATEMENT OF HON. DAVID DURENBERGER, A U.S.
SENATOR FROM MINNESOTA**

Senator DURENBERGER. Mr. Hays, yesterday, I believe we had the first meeting of the Subcommittee on Family and the Uninsured, and I was structuring the 3 hours of this process by the fact that there are a lot of good ideas out there for improving access to health care.

But there was nobody there yesterday from the Administration, Mr. Chairman, to say, you know, "We sort of have a focus on the direction that this country ought to go." We do have a bipartisan commission working at it, and, even though during the course of 3 hours yesterday I was raising some questions about, "Well, isn't this approach better than the chairman's? Our chairman here has a little \$1.4 billion health insurance package," and I kept going through there for 3 hours saying, "Well, isn't this approach somewhat better than that, and that approach somewhat better than that?" I found that at the end of the day I was saying to myself that all of these are great ideas, including the proposal of the chairman.

If you sit down and start making comparisons, one against the other, we seem to have a lot of activity out here about how to provide access to more people, more kids, in particular, to the system, or their parents into the system, but no developing consensus. No developing consensus.

Some of us, particularly on this side, in the debate on ABC, are going to raise questions about the chairman's proposal; but at least the chairman has a proposal out there that I suspect will have a majority support from the Senate.

The CHAIRMAN. If you are not too disruptive, Senator. [Laughter.]

Senator DURENBERGER. Thank you, Mr. Chairman. I don't know how disruptive I am going to end up being.

I think the chairman's view is to prevent leakage from an existing part of our system. But the difficult thing for a lot of us is where the money comes from to provide this sort of basic access to care.

Here, when we do reconciliation on Medicare, we are going to hear from New York City hospitals and all of those big city hospitals, saying, "You can't cut us. You have got to give us more

money, because we have 100 percent occupancy, and we are trying to take care of all of these problems.”

I have a sense, and maybe you can tell us what is true, that to some substantial degree we are using Medicare money to provide basic access to services for a lot of people, particularly in our urban areas, and I suspect probably also, to some lesser degree, in some rural areas of this country. I mean, if in fact New York City is doing a poor job of catching people before they get to the emergency room, at least they are able to get to an emergency room, and at least they are able to get to hospital care, and it is at least in some part because Medicare is financing that access.

Now, do you have some feel—and I know this is sort of alongside this issue we are debating today—on the degree to which Medicare is currently facilitating access particularly for the poor to hospital and physician services?

Mr. HAYS. Well, I think it certainly provides a foundation, both directly and indirectly, and I think through the catastrophic health insurance program Congress has taken it a step further, through the program under which States actually help so-called “poor” Medicare beneficiaries directly by picking up the costs of the beneficiaries through the Medicaid program.

But certainly the payments to hospitals and physicians, including costs of uncompensated care that are included in Medicare payments to hospitals, does provide a certain base line or foundation.

Senator DURENBERGER. Yes. We have a specific adjuster to the DRG formula called “disproportionate share,” do we not?

Mr. HAYS. Yes.

Senator DURENBERGER. And that formula tries to deal with the adverse impact on a community with a substantial number of poor.

Mr. HAYS. Between bad debts and the disproportionate share, there are indirectly provisions in Medicare for that.

Senator DURENBERGER. Now, that may not be the most efficient way to get services to moms and kids and things like that, particularly because it doesn't get them primary care, and doesn't get them some of the ambulatory stuff they need; but at least there is a substantial amount of money going in that direction currently, is there not?

Mr. HAYS. Yes. As you point out, it is not exactly a systemic approach.

I think we all agree that the problem of the uninsured is a serious problem that needs to be addressed; the question is how best to go about it and how we can afford to do it.

Senator DURENBERGER. Thank you.

The CHAIRMAN. Thank you.

Senator Rockefeller?

Senator ROCKEFELLER. I have no question, Mr. Chairman. I just want to apologize to you. I represented the quorum at the Commerce Committee and had to hang on there for a while. I apologize for being late.

The CHAIRMAN. You particularly represented the quorum after I left, and almost broke it.

Thank you very much, Mr. Hays.

Mr. HAYS. Thank you, Mr. Chairman.

The CHAIRMAN. Mr. William Gadsby, the Director of Intergovernmental and Management Issues, Human Resources Division of the General Accounting Office.

Mr. Gadsby, if you would, come forward, please.

Mr. GADSBY. Thank you, Mr. chairman.

The CHAIRMAN. We are pleased to have you. If you would, proceed with your testimony.

STATEMENT OF J. WILLIAM GADSBY, DIRECTOR, INTERGOVERNMENTAL AND MANAGEMENT ISSUES, HUMAN RESOURCES DIVISION, GENERAL ACCOUNTING OFFICE, ACCOMPANIED BY ROBERT F. DERKITS, PROJECT MANAGER, AND DAVID BELLIS, PROJECT MANAGER

Mr. GADSBY. Mr. Chairman and members of the committee, I am pleased to be here today to discuss two GAO efforts relating to meeting the needs of children in a home-based setting. Both of these efforts are very relevant to the Maternal and Child Health Act of 1989, which you have introduced this week.

The first is our report, which is being released today, on the Home Care Experiences of Families with Chronically Ill Children. Mr. Robert Derkits, sitting on my right, is the project leader on that study.

The second is our study, which is still in progress, that deals with home visiting as a means to improve child health and well-being. Mr. Dave Bellis, sitting on my left, is the project leader on that study.

Nationally, about 1 million children have a severe chronic health condition. In the past these children were treated in hospitals, but in recent years advances in medical technology have made it possible to care for them at home. At your request, we reviewed the experiences of parents with chronically ill children in obtaining medical and support services at home.

What did we learn from this?

Families with chronically ill children at home need both medical and non-medical or support services. The need for medical services is great. Virtually all of the parents we surveyed said their children needed services such as physician office visits, medications or medical equipment and supplies. About three-fourths of the families needing these services said they had no difficulty obtaining them.

In contrast, although fewer families said they needed support services, obtaining them was more difficult. Three-fourths of the parents reported needing one or more support services, most commonly babysitting, counseling, day care, or transportation services. These support services sound like the typical needs of any family. But where they involve a chronically-ill child, providing them can become highly specialized. About one-half of the families said they had difficulty getting the support services that they needed.

Parents attributed their difficulties in obtaining both medical and support services primarily to three factors:

The first was high out-of-pocket costs;

The second, the lack of information about the availability of services and providers; and

The third, the lack of a focal point to contact when they needed help.

Comments directly from parents can perhaps best illustrate these points:

A Texas parent of a child with a heart condition and other complications told us: "Co-payments and uncovered or under-covered expenses have depleted our resources. We also fear preexisting condition clauses, and that has had a detrimental effect on my husband's career."

What are some possible solutions? Although many parents had difficulty in obtaining services for their children, especially the support services, not all of them did. The positive experiences of some parents form the basis for solutions.

We believe that the conditions we found can be improved by three things:

First, by consolidating and publicizing sources of information on services available for chronically ill children in a given community;

Second, by providing this information to parents at the time of hospital discharge or once they return to their own community; and

Third, by ensuring that a focal point, or a case manager, is available when needed.

We are recommending that the Secretary of Health and Human Services take a leadership role in developing the necessary policy guidance to accomplish this, and HHS has agreed with that recommendation in our report.

Now I would like to briefly discuss our ongoing work concerning home visiting programs in the United States and Europe. This assignment, which we are doing at the request of the Senate Appropriations Committee, and which also is an outgrowth of the work done by the National Commission to Prevent Infant Mortality, under Senator Chiles, should determine if such programs might be effectively used on a wider basis in the United States.

What do we mean by home visiting? Basically, we mean a service delivery approach that provides preventive health, social, or educational services directly to at-risk pregnant women and families with young children, in their home. Many researchers and practitioners believe that home visiting is a cost-effective and efficient way to improve health and decrease the risk of child abuse and developmental delay.

Our work has two components:

First, through extensive interviews and a literature search, we have identified key characteristics that seem to make home visitor programs effective. Second, we are testing, through case studies in five States and in two European countries whether these key characteristics have produced programs that meet their stated goals. Based on the field work we have done to date, it seems that there are at least three important characteristics to any successful home visiting program. These are: clearly defined objectives for those programs; providers' skills matched with service delivery objectives; and stable program funding.

When we have finished this review, Mr. Chairman, we will develop recommendations for the Congress and HHS to consider in

using home visiting to improve maternal and child health and well-being.

Also, Mr. Chairman, I would like to mention that we would very much like to supply comments on the Maternal and Child Health Act of 1989 when it is introduced. In addition to the two studies that I have just referred to, we have two other studies that we have done on block grant programs that deal with the use of set-asides in those block grants, as well as data collection strategies, that I think might be useful in working this bill through the committee and through the Congress.

The CHAIRMAN. Mr. Gadsby, I would think that would be helpful to us. We would be delighted to have that included, forward to seeing it.

[The information, and the prepared statement of Mr. Gadsby appear in the appendix.]

The CHAIRMAN. You recently sent us a report, a study, that we had directed on surveying the home care experiences of families with chronically ill children, and you referred to part of that.

You said part of the problem was, obviously, the expense, the lack of information, the lack of help in making the transition. What are the services that are least likely to be covered when we are talking about health insurance plans? And is there a difference between privately-held health insurance and public health insurance in that regard?

Mr. GADSBY. Well, if you look at the broad cut between medical services and support services, the least likely to be covered would be support-type services. The medical services would be the ones most likely to be covered.

The CHAIRMAN. What are the typical out-of-pocket expenses that a family would have in that kind of a situation?

Mr. GADSBY. The typical out-of-pocket expenses would represent basically any co-payments or deductibles that they would have to cover under their particular insurance policies, as well as any services that were not covered—be they medical services, or support services.

One of the things that was mentioned in the support area as being particularly difficult when we talked with parents was the transportation expenses for parents living in rural areas, having to travel considerable distances to get the care that they needed.

The CHAIRMAN. What changes would be made to the existing programs that would facilitate the transition from hospital to home care for the families of chronically ill children?

Mr. GADSBY. What we are recommending in our report, basically, is providing better information, to the parents of chronically ill children, either at the point of time they are discharged from the hospital or when they get back into their home community. And by "information" we are talking about what services are available in their home community, and who are the providers of those services.

We found, during our discussions with parents, that simply providing the information to some of the parents was quite enough, and they could deal with the logistics of getting those services themselves; but other parents needed help in getting the services. I

think that is where our recommendation for a case manager would provide help to parents who need it.

And the case manager isn't necessarily somebody new that has to be introduced into the process. People who can serve in that role are often available at public health clinics and at social welfare organizations. So it is really becoming aware of those individuals and using that resource where it is available.

The CHAIRMAN. When you were talking about improving the services for chronically ill children, you were discussing the fact that they needed some focal point to turn to for those services. Do you think that the Maternal and Child Health program is an appropriate place to create that kind of a focal point?

Mr. GADSBY. Yes, we do think that is an appropriate place.

The CHAIRMAN. Could you give me an example of any State that might be doing a particularly good job in that regard that we could study?

Mr. DERKITS. The State of Maryland has a demonstration program under the MCH block grant where they are going to place social workers or State employees in tertiary care centers—that is children's hospitals—to assist the parents of children who are being discharged into the home environment. Purportedly, that should overcome a problem that parents have regarding the lack of information and lack of a focal point. I am sure there are some other exemplary programs out there in other States, but that one comes to mind.

The CHAIRMAN. Thank you.

Senator Chafee?

Senator CHAFEE. Thank you, Mr. Chairman.

In Attachment 2 of your presentation, I notice the great difficulty the parents had in obtaining these support services—and I can believe that—whether it is day care or respite care. Of course, physician home visits under the medical services is very, very difficult for anyone.

Have you ever delved into the tendency to use emergency centers at hospitals in lieu of public health centers of some type?

Mr. GADSBY. Our office has done some work on that, yes.

Senator CHAFEE. It just seems that using the emergency centers at hospitals is probably the most expensive and least efficient way of taking care of these individuals, children.

Mr. GADSBY. It would be very expensive.

Senator CHAFEE. It entails waiting and getting the type of services that are far more expensive than the individual is seeking.

I don't have any more questions. Thank you, Mr. Gadsby.

Senator Durenberger?

Senator DURENBERGER. Yes, Mr. Chairman. I just wanted to indicate that Senator Bradley and I have, as you know, introduced the Healthy Birth Act, which is composed largely of amendments to Title V of the Maternal and Child Health Act. One of the areas that is accented in there is the Maternal and Child Health home visiting programs. Both of us are members of the National Commission to Prevent Infant Mortality, and I just want to say, Mr. Chairman, that I am pleased with the work that GAO did, at least this groundwork that GAO is doing, to examine the values both financially and health-wise to the home visiting program, and to compli-

ment the staff of GAO which always does very, very good work in this area.

Thank you.

Mr. GADSBY. Thank you, Senator Durenberger.

The CHAIRMAN. Senator Rockefeller?

Senator ROCKEFELLER. Mr. Gadsby, just a quick point: In your testimony you suggest that support services are very crucial. Of course, support services are often not seen as necessary medical services by some people. Currently, non-medical services are not allowed to be covered under the Medicaid program except under a special waiver. If you include them, you are going to have to expand—

Mr. GADSBY. Are you talking about Medicaid?

Senator ROCKEFELLER. Yes, you are going to have to expand Medicaid.

I am just thinking of my own State of West Virginia, a State with unbelievable financial problems. We go way beyond current mandates for prenatal care and some other things. When services and eligibility are optional in Medicaid, we try to do them. Where things are called for at 100 percent, we do them at 150 percent. The State is struggling but they are doing what they can.

What types of services do you think Medicaid should pay for?

Comments? [Laughter.]

Mr. GADSBY. We have observed this in work we have done in the Maternal and Child Health block grant, when it was first made a block grant. Areas like maternal and child health have been historically very strongly supported by States. When there were modifications to those programs or when the Federal Government has made cuts in those programs, the States have stepped in to stand in the shoes of the Federal Government and provide financial support.

I would suspect that in other locations like West Virginia, where there is a strong feeling that this is a very valuable service, the State would support some of these services. I don't know how you have them without paying for them.

Senator ROCKEFELLER. Thank you.

The CHAIRMAN. Senator Bradley?

Senator BRADLEY. Mr. Chairman, I will pass on questions at this time.

The CHAIRMAN. All right.

Mr. Gadsby, that will be helpful, and we are looking forward to the additional studies that you will be presenting. We have a lot of confidence in the General Accounting Office in this area, and we will be pleased to have it. Thank you.

Mr. GADSBY. Thank you, Mr. Chairman.

The CHAIRMAN. Would the members of our first panel please come forward? They are Mr. George Farr, who is president and chief executive officer of the Children's Medical Center of Dallas, testifying on behalf of the National Association of Children's Hospitals and Related Institutions; Dr. Donald Schiff, president of the American Academy of Pediatrics; Dr. Richard Schwarz, vice president of the American College of Obstetricians and Gynecologists, from New York; and Ms. Kay Johnson, who is the director of the health division of the Children's Defense Fund.

Mr. Farr, who is president and chief executive officer of the Children's Medical Center of Dallas, again, testifying on behalf of the National Association of Children's Hospitals. If you would proceed. We are pleased to have your testimony. It is good to have you.

STATEMENT OF GEORGE D. FARR, PRESIDENT AND CHIEF EXECUTIVE OFFICER, CHILDREN'S MEDICAL CENTER OF DALLAS, TESTIFYING ON BEHALF OF THE NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS AND RELATED INSTITUTIONS, INC., DALLAS, TX

Mr. FARR. Thank you, sir.

Mr. Chairman and members of the committee, I am honored to testify before you today. I am George Farr, president of the Children's Medical Center of Dallas, Texas. I am also the founding president of the Children's Hospital Association of Texas.

Before I go any further into my testimony, I want to take this opportunity to thank you, Mr. Chairman, on behalf of the children and families of Texas for your commitment to the quality of life of our children. We are proud of you, and we stand committed to you in this regard. Thank you very much, sir.

The CHAIRMAN. Well, you are very generous in your statement, Mr. Farr. I appreciate that. I served on the board of the Texas Children's Hospital in Houston for a number of years, before, so it is a long-standing interest. If you would, proceed, sir.

Mr. FARR. Thank you.

Today I am representing NACHRI, the National Association of Children's Hospitals and Related Institutions. I will submit my written statement for the record and summarize it for you.

I want to emphasize three points:

First, NACHRI believes improvements in child health coverage must include changes in both public programs and private insurance, because each affects the other. We are very encouraged to see the committee acting on tax credits for children's health insurance at the same time you are exploring changes in Medicaid and the MCH Block Grants.

A second point is: Children's hospitals are major providers of care to low-income children, so we know that there are four primary barriers to access for children under Medicaid—(1) restrictions on eligibility; (2) burdensome application processes; (3) uncovered services; and (4) limits on reimbursement.

My third point is: We believe effective Medicaid reform for children must address all four barriers to children's access, and our testimony offers specific recommendations on each. We also believe these reforms must be coordinated with changes in the tax law and the MCH Block Grants.

I think the stories of two children from our hospital in Dallas will make clear why we believe improvements in public and private coverage go hand in hand:

Maria was a 3-year-old Medicaid patient admitted for congestive heart failure who required more than 4 months of care in our hospital. The total charges for Maria's care amounted to more than \$234,000. Our hospital was reimbursed the State's cap on hospital care at that time—\$50,000.

Sean was a 16-month-old with severe respiratory problems requiring 24-hour ventilation. He spent more than 6 months in Children's in late 1987 and early 1988, followed by another 4-month stay in late 1988. Sean's charges totaled more than \$655,000. However, because he had spent the first 16 months of his life in another hospital, most of his private insurance coverage had already been exhausted; and in addition, Sean required more than \$140,000 in home health care which his insurance did not cover. Our hospital's total uncompensated care for Sean was more than \$500,000.

These stories are about miracles of health care. We know that we can provide care that significantly affects the morbidity and mortality rates for children with severe, life-threatening illnesses. We know children with cancer can be cured; a child whose liver does not function can be transplanted; and that extremely premature babies can be saved. These children who spend 70 to 100 or more days in pediatric ICUs do not represent poor management or a willful disregard of financial incentives; they represent a reality. A premature child can show an amazing will to survive, but this fight takes time.

This committee has led Congress to begin to unlink Medicaid from welfare in order to open up eligibility for pregnant women and children. We support such efforts. Without them, nearly half of all poor children are denied Medicaid eligibility.

Children's hospitals have learned that eligibility alone does not determine access to care under Medicaid. The process of applying for Medicaid enrollment can be so burdensome that many eligible families do not complete it. Likewise, enrollment does not guarantee that Medicaid will cover all of the services a child may need. And even if the services are covered, reimbursement may not come close to matching the cost of them.

For example, in States where there are dollar and length-of-stay limits on coverage, the baby who dies would be virtually covered. The baby who survives would do so without the provider having any means of recovering the total cost of treatment. In reality, the better the survival rates for children in our hospitals, the greater the financial risk.

Based on a survey of children's hospitals' experience with Medicaid in 1987, NACHRI estimates that on average Medicaid reimburses a children's hospital only 75 cents for every dollar of expense it incurs for a child. Of this 25-cent loss on cost dollars, not charged dollars, 3 cents are due to failed enrollment, 6 cents are due to uncovered services, and 16 cents are due to inadequate reimbursement.

If a 25-cent shortfall seems large, consider the fact that in Texas children's hospitals had an average loss in 1987 of 40 cents on the cost dollar.

Mr. Chairman, Medicaid was enacted in 1965 to provide a particular service. Today, the people who in that timeframe agreed to support indigent care no longer feel compelled to do that. We must make changes.

You, Senator Bradley, and other members of the committee have various proposals that will enable our children to have greater access to care. We salute the 185 percent of the Federal poverty guideline as the entry level for pregnant women and children.

A number of Senators have proposed different ways to improve enrollment. We suggest that these enrollment centers be taken away from the welfare department and centered in other areas, primarily the hospitals.

The CHAIRMAN. Mr. Farr, you will have to summarize and finish.

Mr. FARR. Sure. Thank you.

[The prepared statement of Mr. Farr appears in the appendix.]

The CHAIRMAN. Thank you. And we will take your entire statement for the record. That is true for each of you. We have a number of people yet to be heard this morning, so we want the time to be able to ask each of you questions.

Our next witness is Dr. Schiff, who is president of the American Academy of Pediatrics. Dr. Schiff, we are pleased to have you again.

**STATEMENT OF DONALD SCHIFF, M.D., PRESIDENT, AMERICAN
ACADEMY OF PEDIATRICS, WASHINGTON, DC**

Dr. SCHIFF. Thank you very much.

Good morning, Senator Bentsen and members of the Senate Finance Committee. I am Don Schiff, President of the American Academy of Pediatrics and Professor of Pediatrics in Denver, Colorado.

I am particularly pleased to be here today, Mr. Chairman, because I believe that we are making headway—evidenced by new relationships being forged by State, MCH, and Medicaid programs and by the potential roles for these programs suggested in your legislation, cosponsored by many members of this committee.

The Academy, along with a number of other child advocacy organizations, has worked closely with this committee to improve and enhance maternal and child health services. The component parts of your legislation represent many elements needed to craft an effective child health system at the State level. Indeed, the single most important point I will make today is the need to fashion a comprehensive, integrated system to meet the needs of children and pregnant women. Your proposals are clearly a strong step in that direction.

In the time I have today I would like to comment on five recommendations of particular importance, and let me begin with a statewide assessment of maternal and child health needs:

A clear definition of the needs of pregnant women and children is essential to the future effectiveness of the MCH Block Grant.

The Academy also strongly supports requirements for State annual reports through the Block. The information included in these reports should reflect the data collected as part of a statewide needs assessment.

In addition to identifying unmet needs and available resources, we believe these reports should set specific and measurable goals for improving services and health outcomes, define steps to be undertaken to attain these goals, and specify ways to coordinate efforts among providers and relevant federally-supported programs.

We further applaud requirements for developing a statewide system for the planning and development of care-coordination services for children with special health care needs and the creation of

a State maternal and child health advisory board. In addition to assisting with the development and review of the State plan, this advisory board should be used to improve the coordination of this program with all other State child health programs, such as Title X, WIC, and the lead agency under Public Law 99-457.

While the incremental enhancements in allowable Medicaid benefits and eligibility over the past years have certainly helped, the enormous variations and limitations in State coverage have resulted in an ineffective or, for many children, a nonexistent program. The present system, by offering different health care coverage to a child based on where he lives rather than what he needs, is inequitable and discriminatory.

A number of proposals are pending before this committee which would mandate extending Medicaid eligibility. While the Academy supports mandating the phase-in of all children up to age 21, and pregnant women up to 185 percent of the Federal poverty level, we do realize the economic implications of such a recommendation. Implicit in each of these proposals is the recognition that the variation in State programs is intolerable, and we support this committee's efforts to mandate improved, uniform eligibility.

In this same light, we encourage you to address the variations in the State benefits packages. While the Medicaid package may appear ample, children are clearly being discriminated against by being ineligible to receive necessary benefits. All children should and must have access to a comprehensive range of benefits.

No comprehensive report currently exists on the health of children, either on their unmet needs or on the deficiencies of the current health care delivery system. At a minimum, such information would give us a clearer picture of the state of our Nation's children's health, and hopefully help us to plan more effective ways to address their needs.

We recommend the Secretary provide a summary of all efforts taken by the Administration to address areas covered by the report and the priority areas for future initiatives, including budget requests, and they should be based on this information. Each year the Secretary should set specific and measurable goals for improving services and outcomes and steps to attain these goals.

The Academy strongly endorses the requirement that the Secretary develop a model health benefit package for pregnant women and children through age 21.

As you know, a crucial shortcoming of our current health insurance system for children is the inadequacy of coverage. Primary care, preventive services, and services for children with special health care needs are either completely uncovered or subject to inappropriate limits.

The Academy has developed such a package, including a catastrophic provision, as part of our objective to develop an access proposal for children and pregnant women.

In conclusion, the Academy's main priority for the next several years is to ensure access to quality health care for all children and pregnant women. To that end, we are in the process of drafting a proposal to restructure the current financing system for these populations. We would be happy to share that with you and work with you to that end.

Thank you.

[The prepared statement of Dr. Schiff appears in the appendix.]

The CHAIRMAN. Dr. Schiff, that is why we keep asking you back here. Your comments are always helpful and thoughtful, and we are pleased to have you.

Dr. SCHIFF. Thank you.

The CHAIRMAN. Our next witness is Dr. Richard Schwarz, who is the vice president of the American College of Obstetricians and Gynecologists.

Dr. Schwarz?

STATEMENT OF RICHARD H. SCHWARZ, M.D., ACOG, VICE PRESIDENT, AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, NEW YORK, NY

Dr. SCHWARZ. Thank you, Mr. Chairman.

In addition to the ACOG office, I am professor and chairman of obstetrics and gynecology, and provost, at the State University of New York Health Science Center of Brooklyn.

One of the best ways to get children off to a healthy start is to assure that all pregnant women have access to prenatal care. In these days when we are forced to make difficult budget decisions, the choice is an easy one; it is simply a question of whether to invest now or to pay later.

Medicaid is the single most important source of maternity care for low-income pregnant women and their children; yet, a major problem is that far too few qualify.

During the past several years, the Congress has taken significant steps to address the infant mortality problem by expanding Medicaid eligibility for maternity care to low-income women. Fully 15 percent of the 3.7 million women who give birth each year have no insurance, either private or public, to pay for their care. Raising the Medicaid ceiling further could greatly reduce the number of women who are without maternity services.

Since only a few States have raised eligibility, we strongly support the proposal included in the fiscal year 1990 budget agreement to require States to expand Medicaid eligibility to low-income women, and their children, with incomes up to 185 percent of the poverty level.

ACOG also supports requiring continuous eligibility throughout pregnancy and the post-partum period, as well as presumptive eligibility.

Changes in the law expanding eligibility, while positive, have not addressed the problems created when there are not enough providers in the Medicaid system. In a 1987 survey, ACOG obstetricians reported low reimbursement, slow payment, denial of eligibility after the patient has been in care, and a belief that Medicaid patients are more likely to sue as the main reasons for non-participation.

ACOG believes that States should be encouraged to try innovative approaches to increasing provider participation through such Medicaid demonstrations as proposed in Senate Bill 339.

Research does indicate that there is a positive response by physicians when States have increased reimbursement and improved claims processing, eligibility determinations, and scope of services.

The problems of professional liability affect access to care by all women, not just those insured through public programs. Increasingly, obstetricians and gynecologists, as well as family physicians, are no longer providing maternity services. To address access for the Medicaid population, we must encourage all physicians to continue the practice of obstetrics.

One proposal that could affect the willingness of physicians to provide obstetric care will soon come before this committee, and that is the inclusion of liability costs in the new Medicare reimbursement rates under the resource-based relative value scale. If not done properly, this could actually lead more physicians to stop providing care.

Congress should increase funding for the Maternal and Child Health Block Grant. Clinics funded through MCH block grants are a critically important source of prenatal care for low-income women.

Finally, we urge the committee to support an increase in the cigarette excise tax. Smoking during pregnancy increases the risk of miscarriage, of pre-term delivery, and of stillbirth. Smoking is thus an important preventable contributor to adverse pregnancy outcomes.

As one of the members of this committee, Senator Moynihan, will recall from the visit he paid us at the Health Science Center at Brooklyn, we also cannot ignore the major impact of this country's drug abuse and AIDS problems on having good pregnancy outcomes.

ACOG commends this committee, and particularly its chairman, for all of the efforts you have made on behalf of pregnant women and their children. Much progress has been made. Much remains to be done. And we at ACOG look forward to working with you, Mr. Chairman, in that regard.

[The prepared statement of Dr. Schwarz appears in the appendix.]

The CHAIRMAN. Thank you very much.

Our next witness is Ms. Kay Johnson, director of the health division, Children's Defense Fund.

Ms. Johnson, we are pleased to have you.

**STATEMENT OF KAY A. JOHNSON, DIRECTOR, HEALTH DIVISION,
CHILDREN'S DEFENSE FUND, WASHINGTON, DC**

Ms. JOHNSON. Thank you.

Mr. Chairman and members of the Finance Committee, I am Kay Johnson, director of the health division of the Children's Defense Fund, and on behalf of CDF I would like to thank you for this opportunity to testify today regarding programs that promote the health of children.

For more than 15 years our efforts to improve programs and policies for children have included extensive work on ensuring access to care for low-income children and their families.

I would like to commend you, Mr. Chairman, for holding this hearing to focus attention on key publicly funded maternal and child health programs. As you know, for millions of low-income families, lack of access to needed health care has become a serious threat. Erosions in income, family health insurance, health status, have led to widening cracks in our health care system.

While my written testimony discusses at greater length the size of this problem and the barriers to health care services which exist, in the interest of time I would like to summarize my recommendations and submit my complete statement for the record.

The CHAIRMAN. That will be done.

Ms. JOHNSON. Today I will discuss reforms in the two key programs, Medicaid and Title V, which are of particular relevance to the work of this committee.

Before I move to the discussion of these key publicly-funded health programs, I would like to begin by restating our position in support of the dependent care tax credit proposal.

Last week, CDF testified before this committee regarding this initiative. We view the expansion of the dependent care tax credit, designed to help low-income families with children offset the cost of health insurance coverage, as one important component of an overall effort by the members of this committee to ensure access to health care for children. Specifically, we view the tax credit initiative as a complement to, although in no way a substitute for, your efforts to expand Medicaid.

For low-income children and women, Medicaid is the primary source of health care financing. In 1987 more than 11 million children under age 18 received services paid for by Medicaid. Children comprised about 50 percent of all recipients, and they accounted for only about 15 percent of all expenditures. Medicaid paid for maternity care for approximately one-half million births that year, nearly one in every six United States births.

The recent reforms in Medicaid have the potential to dramatically affect access to care for low-income pregnant women, infants, and the youngest children; however, if we are to ensure health care access, even for all poor children and pregnant women, Congress and the States must take additional steps to improve Medicaid in a number of ways. Among these are the following eligibility expansions:

Medicaid coverage should be provided to all pregnant women and infants with family incomes below 185 percent of the Federal poverty level, and I am pleased to note that nine members of this committee support such an expansion.

Second, the Medicaid program should be expanded to cover all poor children. Currently, we have millions of school-age children who are without coverage and who are forced to go without needed medical and dental care. Provisions for such coverage have been introduced by Senator Bradley and supported by many members of the committee.

In addition, Medicaid eligibility for near-poor children over age 1 should be phased in over the coming years.

In addition to eligibility reforms, Federal support should be available to States to allow them to make structural improvements in their Medicaid programs. For example, policies should be en-

acted which improve and simplify enrollment procedures through modifications to resource tests, eliminations of unnecessary distinctions between groups of children, requirements that States review and redetermine eligibility before benefits are terminated, guaranteed annual enrollment periods, and improvements to presumptive eligibility programs.

Reforms also are needed to enhance provider participation. CDF supports protections for disproportionate-share hospital providers, improvements to Medicaid reimbursement for community health centers, efforts to ensure the provision of primary and outpatient treatment services for children with mental health conditions, and the study of provider reimbursement rates to allow us to plan for further reforms in that area.

All of these reforms are included in legislation now pending before Congress and have the support of one or more members of this committee. In addition, as we know, President Bush has made Medicaid a priority in the area of low-income pregnant women and children expansions, and has worked with Senator Dole to introduce legislation which would expand such coverage.

CDF also supports the proposed reforms in the preventive health component of Medicaid, the Early and Periodic Screening, Diagnosis, and Treatment Program, also known as EPSDT. EPSDT is the most important publicly-financed preventive child health program ever enacted by Congress, and the benefits that it offers are unparalleled.

We appreciate the interest that the chairman has shown in improving the EPSDT program through the Maternal and Child Health Act of 1989. There also should be improvements to the Title V Maternal and Child Health Block Grant Program, particularly in the areas of increased accountability, priority to all of the three target groups within the program's mission, and increased flexibility to demonstrate and replicate new models of care.

We are very pleased that so many members of this committee have made a commitment to improving the health of mothers and children. We know that you believe, as we do, that we must make preventive investments now to ensure the health and security of our population in the future.

Thank you.

[The prepared statement of Ms. Johnson appears in the appendix.]

Senator ROCKEFELLER. Thank you very much, Ms. Johnson.

OPENING STATEMENT OF HON. JOHN D. ROCKEFELLER IV, A U.S. SENATOR FROM WEST VIRGINIA

I will start with a question for Dr. Schwarz.

On page 4 of your testimony you talk about low reimbursement rates as one of the reasons why physicians don't participate in the Medicaid program, and you specifically mention West Virginia's reimbursement rate. I want to tell you there has been an update on that; we are doing better than you indicate in your testimony. We are up to \$600, and I think that ought to be reflected.

This goes back to the question I was asking the GAO person. I have been torn in my mind, because I was Governor of West Vir-

ginia for 8 years and we really have tried to push hard on expanding Medicaid benefits and doing more than is required by the law. When services or income eligibility are optional, we go beyond that, and we need to, because we are a poor State.

It just seems to me, on balance—and I am not asking you a question so much, Dr. Schwarz, as I am talking to myself—that the child health initiatives contained in Senator Bentsen's bill and also, of course, in Senator Bradley's bill, are so compelling that even States like West Virginia, that have massive financial problems and too many poor children have to do better. We have to do better. I am not sure how we can afford to do better, but we have got to find a way to do better.

So, I want to cosponsor this bill, and I am very proud to do it, even as I am proud of what West Virginia, against unbelievable financial odds, has been doing. But still, we have to do better.

Nevertheless, I want to set the record straight in terms of your own testimony.

I do have a question. There have been a lot of articles about the scarcity of doctors delivering babies, and there has been a lot of talk about malpractice. Would you clarify something for me? Is it more a matter of where it is that those doctors are practicing, that there is a shortage in some areas? Are there, in fact, fewer OB-GYNs in this country practicing today than there were 10 years ago? Or is that they are practicing in certain areas and not practicing in others? It relates not only to malpractice and the effect of that, but also simply the substance of the argument that there aren't enough OB-GYNs.

Dr. SCHWARZ. Senator, in my own State of New York where we have surveyed obstetricians and gynecologists, it is not that they are dropping the practice entirely, although some are retiring earlier than they had anticipated, but many are dropping obstetric practice as a part of their practice of medicine, and others are limiting the number of high-risk pregnant women that they take care of in their practices.

All of that leads to a reduced number of providers available. That is most acute for the Medicaid population, but in the Upstate rural areas of New York, there are counties with no obstetrician-gynecologists, or at least no obstetrician-gynecologists who are providing obstetric services. So, I think the data is real.

Senator ROCKEFELLER. You have spoken of New York. I am asking on a national basis.

Dr. SCHWARZ. I think surveys would indicate, also, on a national basis similar trends—that is, to retire early, for those physicians approaching retirement; to give up obstetric practice but continue gynecologic practice. In our testimony we have shown the differential insurance rates. For example, in States like Florida the differential is just enormous for those who provide obstetric care and those who don't.

So I think these trends are national by our survey information.

Senator ROCKEFELLER. Thank you.

[The prepared statement of Senator Rockefeller appears in the appendix.]

Senator ROCKEFELLER. Senator Chafee?

Senator CHAFEE. Thank you, Mr. Chairman.

Dr. Schiff, can you give us some idea of the trends among pediatricians in terms of serving Medicaid beneficiaries? It is a downward trend, isn't it?

Dr. SCHIFF. Yes, Senator, you are quite accurate about that. The numbers are in this order:

In 1979 we did a survey which suggested that 85 percent of all of the pediatricians in this country were taking Medicaid patients. In a more recent survey—we have one going on now, and we don't have the data on that yet, but the last one was done in 1983—there had been a significant decline.

What we are hearing is that, although pediatricians continue to take Medicaid patients in substantial numbers, they have found that, because of the poor reimbursement, they have had to limit the numbers of patients coming from the Medicaid program.

Senator CHAFEE. Dr. Schwarz, I was fascinated with your comparison between the liability insurance cost per birth and the payment that Medicaid makes. As I understand it, in New Hampshire Medicaid pays \$214 a birth, and the liability insurance works out to \$154 a birth; so the physician nets \$60 for all of his expenses and his own reimbursement, as well—that is, his office coverage, all of the assistants, and everything, he must pay for, and to pay himself. He has got \$60 for that.

Dr. SCHWARZ. That is correct, Senator.

Senator CHAFEE. What are "high-risk patients"? I am not sure I know what the term means.

Dr. SCHWARZ. Well, I am speaking about medically high-risk patients, patients who might be at high risk because of some medical or obstetric complications that they may have.

Senator CHAFEE. That they foresee in advance of the delivery?

Dr. SCHWARZ. That is correct, sir.

Senator CHAFEE. On page 7 of your testimony you get into this, and you point out that "less than 2 percent of our members devoted a nominal 10 percent or less of their practice to high-risk care. But in 1987, 45 percent restricted their high-risk practice." In other words, they see some trouble coming down the line, so what do they do with the patient?

Dr. SCHWARZ. They will refer those patients either to tertiary care institutions or to sub-specialists who devote their entire practice to high-risk cases.

Senator CHAFEE. Now, do I understand from what you are saying on page 7, that for one insurance company in Florida, a doctor who is an obstetrician and a gynecologist, in some parts of Florida, would have to pay \$217,000 a year for liability insurance?

Dr. SCHWARZ. That is correct, Senator.

Senator CHAFEE. Suppose he is a real hard worker: He works 50 hours a week for 50 weeks—you give him 2 weeks vacation—that is 2,500 chargeable hours a year, and of that he has to pay \$217,000. That is a pretty good slug per hour that he has to pay for liability insurance.

I believe in this committee—and not necessarily solely in this committee but in the whole Senate—we waltz around this malpractice situation and wrestle with the high cost of medical care, but no one wants to get into malpractice problems, and I appreciate what you have done in pinpointing this.

In West Virginia, even though—what is it you said, Senator Rockefeller? They are up to reimbursing \$300?

Senator ROCKEFELLER. Six hundred.

Senator CHAFEE. Oh, \$600. Okay.

Also, Dr. Schwarz, I want to appreciate the plug you put in about not smoking. That struck a sympathetic cord. I am for increasing the tax by 22 cents a pack. Does that have your endorsement?

Dr. SCHWARZ. Yes, sir.

Senator CHAFEE. Well, I am glad it got yours, because it is not getting many other people's. [Laughter.]

Also, I think this is all wonderful testimony. I want to thank you, Ms. Johnson, because of where you point out the decline in the immunization in some of your charts there.

Thank you very much, Mr. Chairman.

Senator ROCKEFELLER. Senator Bradley?

OPENING STATEMENT OF HON. BILL BRADLEY, A U.S. SENATOR FROM NEW JERSEY

Senator BRADLEY. Thank you very much, Mr. Chairman.

I would like to ask each member of the panel, although I think you have stated such in your testimony, are each of you in favor of raising Medicaid eligibility for pregnant women and infants to 185 percent of poverty, and also, coverage on a phased-in basis up to 18 years of age for children from families with incomes below the poverty level?

Mr. Farr?

Mr. FARR. Yes, sir.

Senator BRADLEY. Ms. Johnson?

Ms. JOHNSON. We are very concerned about the health status of older children, Senator Bradley. We have all been focusing a great deal of attention on infant mortality, and it is a very serious problem; but it is only the grossest indicator of the health status of our children. It is the most dramatic, but it is only one indicator, and we know that children of school age need a great deal of health care that they are not able to have access to right now.

Senator BRADLEY. So, the answer?

Ms. JOHNSON. Absolutely, yes.

Senator BRADLEY. Dr. Schiff?

Dr. SCHIFF. Yes, indeed. In fact, we would prefer to raise it to age 21.

Senator BRADLEY. Okay.

Dr. Schwarz?

Dr. SCHWARZ. And we would prefer to 200 percent, Senator Bradley. [Laughter.]

Senator BRADLEY. Well, thank you very much. You have given us the next goal here.

Let me ask Mr. Farr: Will mandating States to cover poor children up to the age of 18 lighten the uncompensated care load that, say, the children's hospitals are now carrying?

Mr. FARR. Increasing the eligibility to 185 percent will certainly make much—

Senator BRADLEY. No, no, having coverage up to age 18.

Mr. FARR. Significantly. Yes, sir, especially in Texas. If you look at Texas, we haven't done a very good job.

Senator BRADLEY. Could you describe how that would help your hospital?

Mr. FARR. Yes, sir. A significant part of our uncompensated care falls between Medicaid and, the term that is often used, the "working poor." They can't pay. It would take these people into account and would provide coverage for them. It would have a significant impact not only on the Children's Medical Center but on all of the children's hospitals in Texas.

Senator BRADLEY. And would covering the children of the working poor up to age 18 have the same impact?

Mr. FARR. Yes.

Senator BRADLEY. Okay.

Now, Dr. Schiff, do you have any thoughts on payment to providers? In the bill that was introduced, we seek data from States. Do you have any suggestion as to what data would be most useful in terms of payment rates?

Dr. SCHIFF. One suggestion that we have made has to do with the current work on the RBRVS. As you know, at this moment that is confined to Medicare. I have suggested in testimony before the Physician Payment Review Commission that the responsibility of that group also be given for Medicaid. Our understanding of that would be, if the pediatric Medicaid payment reimbursement levels were comparable to Medicare, that that would go a great distance toward improving the response of pediatricians and the ability of pediatricians to serve the Medicaid population.

Senator BRADLEY. Picking up on Ms. Johnson's point: You know, the focus has been on infant mortality. That is a very important focus and a primary focus, but what about the need to deal with the wellness of children from 5 to 18 or 20?

Dr. SCHIFF. We certainly feel that that is an enormously important part of our population that do not currently receive the preventive health care that they deserve and need.

I would also like to state even in the first year of life; you know, infant mortality is up to 1 year of age. Part of the reason that we have significant infant mortality variability has to do with the kind of care that patients get not only in the immediate newborn period but up to a year. But then, even beyond that, certainly the level of care available declines, and it is very important that that be improved. That is why you heard me say "up to 21."

Senator BRADLEY. Yes.

Dr. Schwarz, what reason do you have in the way of explanation for why OB-GYNs sometimes are reluctant to take pregnant women?

Dr. SCHWARZ. Well, I listed a number of reasons.

Senator BRADLEY. If we take the reasons that you listed in your testimony, would it be helpful if we mandated that coverage be continuous through 2 months after delivery?

Dr. SCHWARZ. Yes, I think that it would be. I think that the model programs or projects that are being contemplated could look at a number of innovations, perhaps that had to do with establishing eligibility, that had to do with some of the complicating factors in reimbursement—for example, kicking out every request for re-

imbursement that involves a caesarian section, no matter what the reason for doing it might be, and prolonging it; with every line in the application, rejecting it on the basis of that line, and having it come back and then being rejected on the basis of the next line. There are many, many pieces of red tape that I think could be streamlined that would make it easier and more attractive for obstetricians to participate.

Senator BRADLEY. Thank you.

Senator ROCKEFELLER. It sounds to me like the Senior Senator from New Jersey is in need of a special health care program, himself.

I would ask Dr. Schiff my final question:

If the EPSDT services are now only—and that is from birth to 21, right?

Dr. SCHIFF. That is right.

Senator ROCKEFELLER. It's my understanding that EPSDT services are being used at only a 25- to 30-percent rate, so that approximately 70 to 75 percent of young people who are eligible for care not getting that care.

Part of that could be that parents don't take them in, and another part could be that pediatricians are declining to see these children. How do you interpret that?

Dr. SCHIFF. I think, for the most part, that portion of the Medicaid program is little understood. It comes back, again, to a very important need that we have in this country, and that is to help people understand the value of preventive health care. This is a critical part of preventive health care for children. Again, as with other portions of preventive health care, this is not understood.

We have an enormous task in front of us to do outreach and to help our population understand the value received from EPSDT and similar programs in both the private and the public sector. And I think we have that responsibility.

The Academy of Pediatrics is taking that on as part of its goal, and we hope that others will join us.

Senator ROCKEFELLER. That is the answer to the first part of my question. The second part of the question: To what extent are pediatricians not participating in the EPSDT program?

Dr. SCHIFF. I think most pediatricians will participate in the EPSDT program. I think, of all of the portions of the Medicaid program, this is the one which pediatricians place high value on and really work hard at encouraging folks to come in and receive this service.

So, I think you would find an analysis of the figures would indicate there is a higher proportion interested in and more supportive of this portion than any other.

Senator ROCKEFELLER. Would you have a ball-park figure, like 85 percent of pediatricians participate?

Dr. SCHIFF. I would say in excess of 50 percent, but I don't have a more accurate figure. The data is being collected right now.

Senator ROCKEFELLER. It would be interesting to have that.

Senator Chafee?

Senator CHAFEE. Mr. Chairman, I don't have a calculator, but I did work it out successfully: Your friend from Florida who is practicing obstetrics and gynecology, to pay his liability insurance, he

would have to start off by charging \$87 an hour solely for the insurance coverage. That is for starters.

I see you have some recommendations as to what we should do on that insurance in your legislation. I will take a look at that, the Medical Offer and Recovery Act, and where you point out that "only 28 percent of the premium dollars paid by physicians are used to compensate injured patients." A lot of lawyers must be getting rich under that bill.

Having now antagonized the lawyers, Mr. Chairman, I will cease. Thank you. [Laughter.]

Senator ROCKEFELLER. Are there any other questions?

The CHAIRMAN. If I might make a comment here, Mr. Farr, you were talking about some of the problems in the outreach insofar as enrollment of people for AFDC. That is a real concern to me.

I have seen a situation in one of our major cities in Texas where a woman was getting information on prenatal health care. She had to fill out a long, involved application, difficult to understand. After she had accomplished that and had the prenatal health care, then she had to go to another hospital for the delivery of the baby and had to go through the same process again. They finally have been able to take care of that with a computer link-up between the two hospitals.

But when you are talking about enrollment there, and many of the counties and States do not allow the onsite enrollment in AFDC, it seems to me that we really have to do some things on outreach, to try to see that where we do have these funds available, do have the money available, these people understand it is there, that the service is available, and that we make it so that they can utilize it much more effectively and efficiently than they have up to now.

Dr. Schiff, as I read your testimony and listened to you, it is obvious also that, as we expand this service away from Medicaid for pregnant women and for children, we are going to have to have more providers, and we are going to have to see that it is attractive to them, or they are not going to be servicing those clients. I have a deep concern there because, as I understand it, we are also seeing a diminishing situation there and quite a serious problem.

Dr. SCHIFF. I think you have pointed out something quite accurately, and important, Mr. Chairman. We, too, are concerned about that, but we believe that if our proposal is phased in, as most proposals are, we will be able to arrange service for the children who need that service. We believe it is possible to do that.

The CHAIRMAN. I apologize to the witnesses for having to leave during part of the testimony, but we have some matters on the floor, and they have had me involved in some decisions on that.

Thank you, Mr. Chairman.

Senator ROCKEFELLER. Thank you very, very much. We appreciate it.

Mr. Chairman, I notice that Senator Chiles is here.

Senator Chiles, we welcome your testimony, sir.

The CHAIRMAN. Well, I am very pleased to see my very good friend Senator Chiles before us, a man who has had a great interest in this subject, is committed to it, dedicated to it. Although he has chosen to retire from public service, still he is very much ex-

pressing his concern—just not paid as well, but in the public service. But he is a man who has had a long-time interest and concern here and has made a very major contribution. We are pleased to have him back.

Yes, Senator Bradley.

Senator BRADLEY. Mr. Chairman, Senator Chiles is here also in the capacity of chairman of the National Commission to Prevent Infant Mortality, which I am fortunate to serve on with him. I think that his voice on these matters not only has the credibility of his years of service in the Senate but also of his continued commitment to issues that relate to children, particularly infant mortality.

Senator DURENBERGER. Mr. Chairman, briefly, if I might claim some credit—not for his commitment to infant mortality but for sitting over on that side of the table, when at Senator Chiles' suggestion we created the Commission on Infant Mortality. It gave him the opportunity to do all of the things he had been longing to do for so long. And then to see him quit on us was sort of a disappointment, but a great honor to continue to serve with my colleague from New Jersey and our former colleague on the commission.

The CHAIRMAN. Well, he just quit being paid for it, that was all. [Laughter.]

STATEMENT OF HON. LAWTON CHILES, A U.S. SENATOR (RETIRED), AND CHAIRMAN, NATIONAL COMMISSION TO PREVENT INFANT MORTALITY, TALLAHASSEE, FL

Senator CHILES. Mr. Chairman, it has been a long time since I have been so lathered up. [Laughter.]

I am delighted to see old friends and colleagues and to have a chance to talk to you about these particular programs.

Mr. Chairman, your interest in this issue goes back so many years I can't sort of remember when. I know of your great and continuing interest, your creation of the Children's Commission, and I certainly applaud you for that. I am delighted to see two of my colleagues that serve on the Infant Mortality Commission with me, as well as Senator Chafee, who has long had an interest.

Many years ago, Mr. Chairman, largely through the work of this committee, we made a commitment to our older citizens that, regardless of their wherewithal, we would give them medical care. That is now just sort of a given. We all accept that they have access to care. Now this committee wrestles with how far we go with that care—catastrophic coverage, coverage on nursing homes, prescriptions, and many of the other things that we are looking at; but the fact that they are given care and access to that care is something we made as a commitment.

We have not yet made that commitment to our children, nor to our pregnant women, that all are entitled to access to care. I think that really is what we are talking about now, beginning to do that. I applaud the committee and its legislation, and I think that is what we really have to do.

The reasons for doing so are compelling:

The first is certainly a moral obligation that we don't deny the most vulnerable citizens of our society, those without representation, the ability to have care.

But in addition to that, certainly from a fiscal point of view and a good-government point of view, investing in our children early in their lives, even before birth, we now know results in long-term economic benefits to society as a whole.

We wrestle with problems of how many prisons we can build and how many mandatory sentences we can pass. But we have not gotten around to the front end of that question: how to prevent some of these problems from ever occurring.

The voices that speak on behalf of children are growing stronger every day. Certainly we see it with the President and the members of this committee, and many others in the Congress.

Our Commission was formed a couple of years ago to examine the policies affecting women and children. We attempted to do that. We made a report, and the number-one recommendation of that report was to provide everyone with access to care.

I am here today to urge the committee to pass into law some of the other legislation we proposed, as well.

We know that infant mortality has slowed in this country. We know that we rank nineteenth among the industrialized world. We know there has been no increase in the early utilization of prenatal care and well child care by pregnant women and children.

We know that the low birthweight rate has stalled since the 1970's. We see the same percentage of the low birthweight that we have seen for many, many years.

The problem of infant mortality is easily stated. Too many babies are born too soon and born too small, and low birthweight can be prevented in most of the cases with comprehensive, coordinated prenatal care, care that our health care system knows how to deliver. By delivering the care early on, we can avoid that special care.

We need, then, to target our efforts at prevention. Our medical technology has focused on keeping babies alive that we didn't keep alive before, but that is an after-the-crisis approach.

It is interesting to note that Japan, with half the infant mortality rate that we have in this country, does not have the extensive neonatal facilities that we have. They deliver a healthy baby to start with, so they don't need the high-tech sort of keep-them-alive-after-you-have-the-crisis care.

Infant mortality now costs our Nation over \$2.4 billion annually, and those costs occur from caring for that low birthweight or critically ill infant. Those costs really do not include many of the lifetime costs because they are handicapped as well.

We know that the Institute of Medicine has reported that every one dollar invested in prenatal care for high-risk women saves more than three dollars in later health care costs. So, the real problem of infant mortality centers around this access to care and the barriers to that care.

Most of the talk in the committee today has been about the financial barriers, and those are real. I am delighted to see that the committee is talking about doing something. I applaud the legislation to go to 185 percent, that Senator Bradley and others have introduced. That is tremendously important.

But, Mr. Chairman, there are barriers other than the financial barrier, and I think we have to recognize them. You touched on one of the barriers in your question about the paperwork maze which faces women seeking care.

So, the problem amounts to implementing programs and policies that help pregnant women and children overcome these barriers to care. The financial barrier certainly has got to be the biggest one.

The Medicaid legislation of Senator Bradley includes other changes in the Medicaid program, and one of those that would keep a woman from losing her coverage in the middle of a pregnancy is tremendously important.

Considering these program changes in the proposed legislation, I applaud the committee and you, Mr. Chairman. The number-one recommendation to the committee, as I say, on infant mortality, was to provide this access to care.

Under consideration by Congress this year is reauthorization of the Maternal and Child Health Block Grants. Everyone agrees that this program needs additional funding. The committee certainly is to be praised for considering an increase of \$150 million in additional funds.

I support many proposals under the committee's consideration which coincide with the Commission's recommendations. Increasing participation and enhancing use of early and periodic screening, diagnostic, and treatment programs is critical. In the Commission we certainly lend our support to the additional reporting requirements for the MCH Block Grants as well as other proposals under consideration.

I learned with interest of the proposed statewide block grant needs assessment, which is intended to identify unmet maternity and infant care needs, including prenatal care in the prevention of low birthweight and infant mortality. That is great, and it calls for a plan to meet these needs.

The Commission, and Senator Bradley and Senator Durenberger as members, have introduced some legislation that would also provide some changes to specific programs for the block grant. These four programs grew out of work of the Commission and are part of our recommendations.

As I might point out, what we attempted to do during our existence is similar to a needs assessment: we tried to examine prenatal care, low birthweight, and infant mortality and then come up with a plan of action. And part of the recommendations I want to talk about now were part of that plan of action.

One of the programs that the bill recommends is home visiting. Some people refer to this as "resource mothers." I think the chairman is interested in looking at part of that in some of the legislation he is proposing.

What we found in our hearings is that, even where you have clinics and where you have some doctors, where you are dealing with an at-risk population, where you are dealing with a child who is having a child, a 13-year-old whose mother maybe had her when she was 15 years old, and you are in this cycle, well these women are scared of doctors. They are scared to go see a nurse. When they show up is when they are in labor, and they go to the emergency room in labor.

How do you reach those people? How do you break that cycle, even when some care is out there? The best way we found is through the use of "resource mothers." These are people who are in the community, who have successfully raised their children. They are persons who have some peer status in the community.

You get those people, you train them, you pay them a minimum wage—they do it as a calling—and they go out. They have a certain number of cases, and they work one-on-one to intervene with these unmarried women, in many instances, that are not very well educated. They say, "We are going to take you to the doctor today," or they say, "I heard you were drinking a beer the other day, and I'd better not hear about that," or, "I heard you were smoking. You had better cut that out." And they tell them why. They care about them, and the people know they care about them.

We have seen more success, I think, in some of these poverty areas in breaking the cycle by using that kind of method than any other one. They don't have to be professionally trained. In fact, it is better if they are not. As I say, it has to be someone that the pregnant women can relate to. We think that is one of the most important recommendations the Commission has made.

The second program of great importance, we think, is what we call "one-stop shopping." I think it gets to what the chairman was talking about with the paperwork maze.

In many instances now, we are talking about the uneducated child trying to access maybe four different programs. That means four different stops, and it means four different sets of forms. I would ask you to look at one of those sets of forms that your State has come up with. It is designed to frustrate, literally. I mean it is almost impossible to try to fill out. And when you realize that many times they have to pay Uncle John \$10 to take what is his "taxi," the ride, to each one of those trips, and they get there and they can't fill out their form, they get frustrated. Then you wonder why they don't show up until their delivery.

Of course, WIC is through the Department of Agriculture, so it has a different bureaucracy. There is some way, as the policymakers, you need to try to coordinate that. I mean there ought to be one simple set of questions and once the mother answers those, then we can tell her whether she is eligible, for how many programs, what she is eligible for. We ought to try to do that so there is one stop, and they don't have to go to all of these places.

We are not talking about something now that costs a world of money, but we are talking about something that is very hard to change in the bureaucracy that we are dealing with. Changing the way these programs are set up would be tremendously important.

Another recommendation is the development of a health handbook, or a "passport," we call it. Over 100 nations have a health passport which the mother gets when she becomes pregnant. It tells her, basically, what some of her rights are and where she can get services, but it is also an immunization record and a health record of each of her children.

Many of our problems are with migrant children, as the chairman knows, in his State and my State, where they are passing through the agricultural system. They go to one place, and they don't remember, maybe, where their child has problems, is allergic

to certain drugs, whether they have had measles or whooping cough, or what they have had. This passport would give them that record, as well as some information on the rights that they have.

It is interesting—in Japan the women carry this handbook like a little badge. It gives them transportation, literally, during the time they are pregnant. It is something, as I say, that over 100 nations have adopted. Again, the cost of this is minimal, but it is something we can do that we think helps spread the word.

Finally, the establishment of a toll-free information number—which, again, I think is partially proposed in some of the legislation—we think would be helpful.

I applaud very much the committee going into these hearings and the work that you are doing. I think there is an opportunity now that we haven't seen before of really trying to do something about the health of women and children. I think the States are more ready now, as well. Senator Rockefeller was talking about how his State has raised the rates; I see that happening in a lot of places. It is a timely subject, and one in which I think we could move on now.

[The prepared statement of Senator Chiles appears in the appendix.]

The CHAIRMAN. Senator, you have made a number of suggestions. You were talking about home visiting; Senator Chafee and I have made that as an option for medically fragile infants. And you talked about a health handbook, which I think could be very helpful.

But a number of these things that were tried in Europe and in some other countries, none of those systems, or very few of them, are as privatized as ours. Do you feel that they would be effective in ours?

Senator CHILES. Well, you know, the one-stop shopping has nothing to do with the difference in the systems.

The CHAIRMAN. No, that is bureaucratic.

Senator CHILES. That is right. That is where we have got to control our bureaucracy, and make it simple for them to do. I think many of the other countries have a health visitors program. England has what they call their "flying nurses," you know. They drive around on their little motorbikes and visit everyone, including Princess Anne, and they make certain visits to check on the baby and how she is doing.

So I think, again, that can work, and I urge that it be included as a preventive method of prenatal care, and not just to infants that are high-risk to start with, because it is a way I see of trying to break this cycle that we have, of children having children.

And for the health passport, Mr. Chairman, it is my guess to how that will work; but these people care about their kids, and I think they will carry that kind of a document. I think it will be of some help to them. I think it helps pass information around. You could put basic information in there of where they could get help. And again, as I say, it is something that could be done with very little cost.

The CHAIRMAN. One of the things Senator Chafee and I have in our bill is to mandate that the Secretary give us a simplified Medicaid application form.

Senator CHILES. That is tremendously important. But really, we ought to look at the WIC forms, the AFDC, each of these, and there ought to be some way that, when you go through a set of questions, they will tell you the answers as to whether you are eligible for maternal and child care for each of these programs.

The CHAIRMAN. Well, in part, it seems that you ought to be able to have a computerized hookup, where you could have all that information coordinated, pulled together for whatever the identification number of that patient happened to be.

Senator CHILES. Absolutely. And there are some test programs out there on that now.

We know that can be done now, when we see everything else that we are doing with computerized information.

The CHAIRMAN. Senator, if you will forgive me, I am going to go back and try to take care of some of these situations on the floor. Senator Chafee?

Senator CHAFEE. Why don't you, Senator Bradley, go ahead? I want to talk to the chairman before he leaves.

Senator BRADLEY. Senator Chiles, let me thank you for your testimony, particularly the points you made on the information barrier.

In responding to some of the questions, you could almost imagine the home health visitors out there encouraging women who are pregnant to go to the doctor, which is what we want them to do.

They could arrive at the doctor—the visiting nurse or the doctor could have the passbook—to give to the pregnant women. This would be the first contact, right?

Senator CHILES. Right.

Senator BRADLEY. Then if you had a reasonable computer program, you could, in coordination with the States, work out a “one-stop shopping” type of source. Then for any questions you could have an 800-number, which could be attached to the passbook, if need be.

Senator CHILES. Yes, sir.

Senator BRADLEY. It seems to me that that makes eminent sense and that it all ties together; in other words, this is not one thing but really four things that are usually supportive of each other.

Senator CHILES. I think that is right. And if you couple that with the legislation that you have introduced, of trying to up the amount of funding, then you try to break down and get into some of these other barriers that are set there—that is why I think the four parts are important to trying to do that.

Senator BRADLEY. I think that people don't appreciate the information barrier, or the “fact barrier,” really.

Senator CHILES. Right.

Senator BRADLEY. You know, the application form is bewildering, and you do need us to simplify that.

Senator CHILES. Yes, sir.

Senator BRADLEY. But it is getting people to the application point that you are addressing in your testimony.

Senator CHILES. Right.

Senator BRADLEY. Getting them there, with follow-up, and with some guidance for not only what to do for the remaining months of

their pregnancy but what to do in the first year or two of the life of their child, in terms of the immunization records, et cetera.

Senator CHILES. That is right.

Senator BRADLEY. Well, I thank you very much for your testimony, and I also thank you for your leadership as the head of the Commission.

Senator CHILES. I am delighted that you are there to try to get these things implemented, as you know.

Senator BRADLEY. Senator Chafee?

Senator CHAFEE. Well, Senator, we welcome you back and appreciate so much what you are doing.

On page 5 you touch on the high medical malpractice rates, and that is something I am going to wrestle with as we struggle with this. I hope we can get some support across the country.

Have you seen any area or State where this resource-mother system—I have forgotten how you phrased it—where it has worked?

Senator CHILES. Yes, sir. We can show you some information and studies on that. Lynda Robb, who is a member of the Commission, is very acquainted with some programs that work in the Appalachians and also around Norfolk, and at one of our hearings she brought up a number of the resource-mothers from the Norfolk area. Their testimony was very, very moving. These are very dedicated women. They have successfully raised their children, and they believe that the job they have is very important. As I say, they are normally paid sort of a minimum wage. They have 10 or 12 cases that they work on. But they go out into the homes and see that these people have the transportation and the information necessary.

Again, very good programs have worked in some of the poorest areas in Louisiana, and we have some programs that we are beginning to do in Florida. And if what I have seen so far is trying to barrier, this is one of the best ways.

I want to give you an example that a resource-mother just told us about who came out of a rural country in Florida. She now has a client, a 15-year-old. The 15-year-old has three children—the first one was born when she was 11. She is also taking care of two of her mother's children. The mother is 30, and the mother's children are age 1 and a newborn baby; so the 15-year-old is taking care of five children all under the age of 3.

This 15-year-old, remember, was born to her mother when the mother was 15, because she is 30 now. So what you see is the cycle. To make it a little worse, the mother is on cocaine, and they are both prostitutes for a living.

This is the cycle that you see of children having children, and then it repeating itself. And now perhaps we have an opportunity, with this resource-mother, to try to deal with this 15-year-old and tell her what she can do about a day care situation, try to get her back into school so she can complete her education—all of these kinds of things—at least trying to get in and break that kind of a terrible cycle.

Senator CHAFEE. Well, thank you. That is an idea I hadn't known of, and we will certainly try to convey that to our folks. I will check with the Commission on some suggestions.

Senator CHILES. I will get you some more information.

Senator CHAFEE. Good.

Well, thank you very much. I am so glad you came and for the time and energy you are giving to this Commission.

Thank you, Mr. Chairman.

Senator CHILES. Thank you.

Senator BRADLEY. Thank you very much, Senator Chafee and Senator Chiles.

Our last panel is Mr. Raymond Scheppach, executive director of the National Governors Association; Richard Nelson, director of the Child Health Specialty Clinic, University of Iowa; and Mr. Aaron Johnson, chairman of the Health Care Committee of the National Council of State Human Service Administrators and commissioner of the Georgia Department of Medical Assistance.

Let me welcome all three of you. Your full testimony will be submitted to the record. Would you please summarize your comments, briefly? Time is running out, unfortunately.

Mr. Scheppach?

STATEMENT OF RAYMOND C. SCHEPPACH, EXECUTIVE DIRECTOR, NATIONAL GOVERNORS ASSOCIATION, WASHINGTON, DC

Mr. SCHEPPACH. Thank you, Senator.

I appreciate the opportunity to appear before you today on behalf of the Nation's Governors. I would like to submit my full statement for the record and summarize it very briefly.

First, the Governors are committed to reducing infant mortality and improving children's health in the United States. To date, 44 States have taken advantage of the option to provide Medicaid eligibility to pregnant women and infants with family incomes below the poverty level. Fifteen of these States have elected to cover pregnant women and infants with incomes up to 185 percent of poverty. Twenty-three States are providing coverage to all children below the poverty level up to age 3, and 20 States are using presumptive eligibility.

The Governors are very proud of the progress that they have made in helping these populations over the last few years. Beyond expanding Medicaid eligibility, States have been working to streamline the eligibility process, improve outreach, and increase participation of physicians.

While States have been moving forward rapidly in this area over the last several years, we are opposed to any further mandated eligibility requirements in the Medicaid program. Individual States are in the best position to decide how Medicaid funds should be spent.

This is not to say that these populations are not in need; however, we must recognize the fiscal condition of States.

Medicaid will be 11 percent of State budgets in 1989; in 1981 it was only 7 percent. By 1995, it is projected that Medicaid will represent 15 percent of State budgets.

Projected State surpluses for next year are expected to be only 1.5 percent of total spending, which is essentially the lowest level that we have seen in the last 12 years that we have been surveying States.

The continued mandated increases will force States to both raise taxes and/or cut other programs. Over the last year and a half, Congress has mandated huge increases in State spending for nursing home reform and catastrophic insurance, as well as for Medicaid. The State are just beginning to feel the fiscal impact of these changes.

For these reasons, we ask the committee to forego any new mandates of Medicaid eligibility at this time. We do, however, support proposals that would allow States to provide Medicaid eligibility to children below the poverty level, up to the age of 18.

Mr. Chairman, I also want to express concern with the proposal to mandate presumptive eligibility. Some States have taken action to streamline the standard eligibility process so that it is as effective or even more effective than presumptive eligibility.

Finally, I am very concerned with the proposal that Medicaid must reimburse physicians a fee that will provide Medicaid recipients with the same access as the general population. It is not realistic to try to achieve a goal through reimbursement alone. In a recent survey that we have done in increasing provider participation, we found that the reasons obstetricians and gynecologists give us for not participating in the Medicaid program include not only the fee but a growing concern about malpractice, reasons with respect to the high-risk nature of these individuals, and the burden of administrative procedures. Many of these issues are in fact beyond the control of the Medicaid program.

In summary, Mr. Chairman, States have not had time to bear the costs of the recent changes, coupled with those for catastrophic and nursing home, and therefore we would rather not see the committee move forward on mandates at this time.

Thank you.

[The prepared statement of Mr. Scheppach appears in the appendix.]

Senator BRADLEY. Thank you very much, Mr. Scheppach.

Dr. Nelson?

STATEMENT OF RICHARD NELSON, M.D., DIRECTOR, CHILD HEALTH SPECIALTY CLINICS, UNIVERSITY OF IOWA, TESTIFYING ON BEHALF OF THE ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS, IOWA CITY, IA

Dr. NELSON. Mr. Chairman, I am Richard Nelson. I direct Iowa's Title V program for Children with Special Needs, which is funded under the Maternal and Child Health Block Grant, and I am here today to speak on behalf of the association of the State programs that administer the Block Grants throughout the Nation.

The Association of Maternal and Child Health programs strongly supports Congressional action to improve and to expand the health care of mothers and children in the United States.

In my brief verbal remarks this morning, I want to concentrate on the expansions of Title V and Title XIX that this committee will be considering in subsequent weeks.

We strongly support your efforts to expand these Titles of the Social Security Act. Until there is a national consensus for more fundamental reform in our nation's fragmented system of health

care delivery and financing, these two Federal-State programs continue to be the major vehicles to assure health care for pregnant women and children in the United States. We certainly are interested in more universal attempts to improve the health care of America's women and children, but we feel we must continue to improve the existing legislation that provides the basis for current activities.

For Title V, the Maternal and Child Health Block Grant, we support:

Strengthening the requirements for accountability to the States.

We support increasing resources to the States so that they can further work on developing a coordinated system of care. We have heard a great deal this morning about the fact that not only having a source of health care financing is important but also that there is a system to deliver the services that women and children need.

We support legislation that continues to strengthen State efforts to assure access to primary and preventive services, and we certainly support legislative intent to support the development of services for children with special health care needs, and their families, through a series of initiatives that the United States Surgeon General has emphasized during recent years.

We realize, though, that our Maternal and Child Health programs don't function in isolation, and we do support the strengthening of mandates for our programs to work with other Federal programs, especially Title XIX, or Medicaid; although we have not heard yet this morning about the early intervention legislation that is being implemented in the States under Public Law 99-457, it is also a key program in meeting child health needs, and also, of course, other programs for women and children, including WIC, family planning, community health centers, and migrant health centers.

In terms of Title XIX:

We do support expansion of eligibility to the age of 21 for women and infants under 185 percent of poverty;

We support reforms to facilitate early and continuous participation of pregnant women and children in Medicaid. A problem that has not been highlighted this morning is that many times eligibility, once established, is soon lost; but the needs of women and children continue.

We support reforms to increase provider participation; and

Greater consistency throughout the country in what Medicaid will provide for women and children.

We would like you to look at ways to require Title V and Title XIX programs in the States to work in a more coordinated fashion, to make the best uses of the resources available.

We have had a chance to review proposals coming from the committee, including your own proposal and that of Senator Bentsen, and we certainly applaud all efforts to generate legislation that will improve access to care, including the recommendations of the Commission to Prevent Infant Mortality and to strengthen States' ability to improve outcomes for women and children.

Thank you.

[The prepared statement of Dr. Nelson appears in the appendix.]

Senator BRADLEY. Thank you very much, Dr. Nelson.
Mr. Johnson?

STATEMENT OF AARON J. JOHNSON, CHAIRMAN, HEALTH CARE COMMITTEE OF THE NATIONAL COUNCIL OF STATE HUMAN SERVICE ADMINISTRATORS, AND COMMISSIONER, GEORGIA DEPARTMENT OF MEDICAL ASSISTANCE, ATLANTA, GA

Mr. JOHNSON. Mr. Chairman, I am Aaron Johnson. I am Medicaid commissioner for the State of Georgia, and I speak to you today as both the chairman of the National Council of State Human Service Administrators' Health Care Committee and as chairman of the State Medicaid Directors Association. Both of these organizations are integral parts of the American Public Welfare Association.

Let me begin by thanking the chairman and members of the committee for providing this opportunity to day to discuss children's health. I also want to commend the committee's leadership in the area of infant and child health indigent care and long-term care.

Members of this committee have worked long and hard to bring attention to and resolution of the plight of those who have inadequate access to the health care system. Those efforts are starting to come to fruition. The American people are becoming more aware of the problems and, for that reason, are more willing to accept changes in the system.

I would like now to turn my attention to the issue before us, children's health care under the Medicaid program, and to address what I believe to be key aspects of the various bills. A full copy of my testimony is available to you, so I will just highlight here.

Senator BRADLEY. I would appreciate it if you would. Your full statement will be in the record.

Mr. JOHNSON. Thank you, sir.

Innovation: With regard to innovation, State agencies strongly support funding demonstration projects aimed at both greater coordination among various agencies that serve pregnant women, infants, and children, and increasing provider participation in the EPSDT program.

Eligibility: States have long advocated breaking the tie between Medicaid eligibility and eligibility for cash assistance programs. This is because health care is a very different market good than food, shelter, or housing. However, State agencies believe that mandating coverage of pregnant women and infants up to 185 percent of poverty is not appropriate at this time, when State budgets are fixed, and when States are implementing costly nursing home reform and qualified Medicare beneficiary legislation. States support an option to cover children through income-related eligibility.

Presumptive eligibility: States continue to pursue a variety of innovative ways to provide expedited eligibility to pregnant women. These methods do not necessarily follow the presumptive model. Therefore, a mandate to implement a presumptive process would be inappropriate. State agencies would also like to see changes to the presumptive program which would facilitate program goals.

Provider reimbursement: Many States are increasing provider rates and analyzing the effect of these increases. There are many unresolved issues that bear on provider participation, only one of which is payment rates. States are concerned about the feasibility of obtaining certain data and the accuracy of that data in support of rates.

Outreach: State agencies believe that providing an enhanced Federal match for outreach activities, including out-stationing eligibility workers at a variety of sites, would provide incentives for States to develop new outreach strategies and build on a variety of State initiatives already in place.

In summary, I would say that States in general are equally cognizant of the problems and need for change. States have been making good-faith efforts to expand and expedite eligibility, increase outreach, and educate about wellness to combat increased infant mortality. We remain unconvinced, however, that mandating further incremental expansions and reporting requirements at this time constitutes a realistic solution. Further mandates at this time will have significant implications for the whole of the Medicaid population in different States.

The APWA has given the issue of access to health care serious consideration over the past 2 years and has published a set of proposals for broader reform. We are aware that our proposals do not constitute the ultimate solution to all the health care problems, but we believe they are a substantive place to start.

I would like to stress that States want to work together with Congressional leaders and their staffs to develop a set of viable proposals, based on what we, together, know at this point. It is clear that something needs to be done.

Our system of governance is based on Federal-State partnership. That partnership must be evaluated in the context of the Medicaid program, which is designed to be operated by the States. We should build on that concept in order to turn our nation's health care situation around.

Thank you for this opportunity to testify. I will be happy to receive any questions.

[The prepared statement of Mr. Johnson appears in the appendix.]

Senator BRADLEY. Thank you very much, Mr. Johnson.

The 185-percent mandate: As I heard your testimony, the Governors don't support it, the Medicaid directors don't support it; but you do support it, Dr. Nelson, right?

Dr. NELSON. Yes.

Senator BRADLEY. Now, could you give me three sentences as to why you don't support it? Why don't you support it, Mr. Schepach, and why don't you support it, Mr. Johnson?

Mr. JOHNSON. It is a good idea. The concept is great. The problem is the dollars. I would support it, and I am sure a number of Governors would support it, if the Federal match was increased along with the increase in the level of eligibility.

Senator BRADLEY. Okay. And Mr. Schepach?

Mr. SCHEPPACH. I think it is also a cause. I spent yesterday in the State of Mississippi and spent 2 hours with the Governor, at which time he told me that he is closing three charity hospitals within

the next 6 months to pay for the Medicaid expansion. Now, that may well be good policy.

Senator BRADLEY. He has already gone to 185 percent, right?

Mr. SCHEPPACH. I think that is true.

Senator BRADLEY. Right. So, he is at the mandated point.

Mr. SCHEPPACH. Okay. But, as you know, the Federal Government pays probably 80 percent of the State of Mississippi's Medicaid. But I am saying that is the kind of trade-off and tough decisions that some of the States are going to have to make.

The second thing, I think, is that you have to be careful, when you go to 185 percent, of what kind of disincentives are you sending to private employers in terms of decreasing the insurance coverage they are providing. So, I think you have to be careful. It may not happen in all States, but it is clearly going to happen in a number of States, that you are going to see basic shifts from employer and individual insurance, essentially to government insurance.

Senator BRADLEY. But the people we are after don't have any health insurance here, right?

Mr. SCHEPPACH. That is who you are after, but can you target that without creating disincentives in the other industry? I don't believe you can.

Senator BRADLEY. Yes.

Dr. Nelson?

Dr. NELSON. I think there is a great political tendency here to take the woes of Medicaid and place it fully on the shoulders of pregnant women and children.

We have heard testimony this morning that in fact preventive prenatal care and appropriate care of infants really will save Medicaid. I think if there were more careful analyses of some of the Medicaid expenditures for low birth-weight infants as well as older infants—and, for that matter, women, due to complications of pregnancy, preventable complications—we would see that the real outcomes of expanding eligibility to 185 percent would not have the disastrous effects on State Medicaid budgets that many people suppose.

You only need to walk into any neonatal intensive care unit in a major hospital now and obtain social histories of the infants to realize that they probably, to a great extent, should not be there if their mothers had had more appropriate care.

Senator BRADLEY. Mr. Johnson, do you want to respond on behalf of the State Medicaid Directors to that comment?

Mr. JOHNSON. The only thing I would say, sir, would be that States are interested in taking care of pregnant women and children, no question about it. However, there are many other concerns which States have, and they work with fixed budgets in a way in which the Federal Government does not.

If the match-rates for some of the mandated services could be elevated, along with the elevated requirements, the incentives would be greater for the States to go along with them.

Senator BRADLEY. I understand that, but do you have any specific response to Dr. Nelson? In other words, what do we say to the mothers in States who don't have adequate prenatal care? If the Federal Government says, "We want to mandate it," but the State

says, "No, we are not going to do it," what do we say to these women?

Mr. JOHNSON. It is a tough call, and it is a political call. The politics of the situation is something that I can't speak to. I can't speak for the politicians. I am an appointed official of the State, but I imagine the politicians know how they wish to respond in those situations, and they have responded accordingly. They would rather trade off something else for increasing Medicaid.

Senator BRADLEY. Right.

Let me thank all three of you very much for your testimony. I think it was very helpful. I will have some written questions that I would like for you to answer for the record, if I could.

Thank you very much for being a part of today's hearing.

[Whereupon, at 12:31 p.m., the hearing was concluded.]

APPENDIX

ALPHABETICAL LISTING AND MATERIAL SUBMITTED

PREPARED STATEMENT OF SENATOR LAWTON CHILES (RET.)

Thank you Mr. Chairman and Members of the Committee. It is always a pleasure to see old friends and colleagues, especially when I have the chance to speak about the policies and programs which affect our nation's women and children.

We politicians are famous for kissing babies before election day; now it is time to pass some laws which guarantee that the children of America have the greatest opportunity to be born healthy and grow up to reach their full potential.

Many years ago, our nation made a commitment to its elderly citizens to provide them the care and assistance that they need. We need to make the same commitment to our children.

The reasons for doing so are tremendously compelling. First of all, we have a moral obligation. We should not deny the most vulnerable citizens of our society—those without any representation—the help they deserve. Second, from a good government standpoint, investing in our children early in their lives—even before birth—results in long term economic savings and benefits to government and society.

The voices that speak on behalf of children are growing stronger every day. They include the President's, the Chairman's, that of many of the members of this Committee, and that of many other Members of Congress. Two of the members of the Committee, Senators Durenberger and Bradley, also serve as members of the National Commission to Prevent Infant Mortality, which I chair.

The Commission was formed two years ago to examine the policies and programs affecting our infants and make recommendations on ways to improve maternal and child health. Our Commission's current activities focus on publicizing these recommendations and assisting others in their implementation. Many of these recommendations, in different forms, have been included in legislation introduced this session. I am here today to urge this Committee to pass into law much of the proposed legislation as well as all of the remaining recommendations contained in the Commission's report. It's no small agenda, Mr. Chairman.

As the Committee knows, the infant mortality rate is one of the leading indicators of a nation's health. During this decade, the rate of decline in infant mortality has slowed, and our nation now ranks 19th in the industrialized world. The proportion of infants and toddlers who receive immunizations has declined, and there has been no increase in the early utilization of prenatal care and well child care by pregnant women and children. In 1986, almost a third of all American infants were born to women whose care could not be considered adequate.

The problem of infant mortality is easily stated. It is most often the result of low birthweight. Too many babies are born too small and too soon. Low birthweight can be prevented in most cases with comprehensive, coordinated prenatal care—care that our health care system knows how to deliver. By delivering that care early on, we can avoid the special health care needs of many infants born early and low birthweight. To have the greatest impact, we've got to target our efforts at prevention—not at high technology, high cost care delivered after the crisis has already occurred.

Infant mortality now costs our nation over \$2.4 billion annually. The cost arises from caring for low birthweight or critically ill infants in neonatal intensive care units, as well as from the cost of numerous other life long disabilities that result from low birthweight births. The lifetime costs of a low birthweight infant can reach \$400,000. The costs of prenatal care, on the other hand, can be provided for as

little as \$400. By investing in prevention, we save on the high tech crisis care that might be required later. As the Institute of Medicine reported, every \$1.00 invested in prenatal care for high risk women saves more than \$3.00 in later health care costs.

The real problem with infant mortality centers around access to care and the barriers to that care—whether financial, institutional, geographic, educational, cultural, or behavioral. As Marsden Wagner of the World Health Organization said and I often quote, "Infant mortality is not a health problem. It is a social problem with health consequences." The problem, as I see it, is in bringing health care providers and those in need of care together earlier and more often. The problem amounts to implementing programs and policies which help pregnant women and children overcome the many barriers to care.

One of the greatest barriers is financial. In 1985, 9.5 million women of childbearing age had no health insurance. An additional 5 million women of childbearing age had health insurance that did not cover maternity care. This Committee's proposals for tax credits to families to help them get and retain coverage are needed. Government must help provide the incentives to individuals and the private sector to do their part in helping women and children.

But government must also take direct responsibility for those who cannot afford care. Legislation affecting the Medicaid program as introduced by Senator Bradley of this committee and other Senators and Members of Congress directly addresses this concern, proposing to raise the eligibility threshold for participation by pregnant women and children in the Medicaid program to 185 percent of the poverty level. Our government must do this to help reach our ultimate goal of universal access to care for all pregnant women and children.

Senator Bradley's Medicaid legislation also includes other changes in the Medicaid program which are of great importance to our women and children. Because in many states a pregnant woman can lose her coverage in the middle of a pregnancy, states will be required to provide continuous coverage to pregnant women until at least sixty days after birth. Because many pregnant women must wait many weeks to become eligible for Medicaid, states will be required to provide "presumptive eligibility" so that women can get proper prenatal care immediately. Coverage for children up to age 19 would also be expanded.

For considering these program changes in proposed legislation, I applaud this Committee and its Chairman. The number one recommendation of the Commission is for universal access to care for all pregnant women and children. We have added our voice to the many other organizations and individuals who want to break down the financial and administrative barriers to care, and we are pleased that they are being heard.

I also applaud the proposals being considered to ensure the adequacy of provider participation in the Medicaid program. Rates of participation in Medicaid by obstetricians and pediatricians continue to remain inadequate due to high medical malpractice rates across the country, unstable eligibility, the changing benefits that are covered, claims processing problems, as well as the level of reimbursement.

The Committee must also be lauded for other proposals in its legislation that would reduce barriers to care. A significant barrier for many women who often lack extensive education or speak English only as a second language is all the paperwork. Under consideration is a proposal to develop a uniform eligibility application for Medicaid. The forms must be streamlined, the asset tests simplified, and they should be uniform between the Medicaid and WIC programs.

Also under consideration by the Congress this year is a reauthorization of the Maternal and Child Health Block Grant. Nearly everyone agrees the Block Grant needs additional funding. This Committee must again be praised for considering an increase of \$150 million in additional funds. This money is greatly needed to support the health care services provided to mothers and children in the states.

I support the many proposals under this Committee's consideration which coincide with the Commission's recommendations. Increasing participation and enhancing use of the Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT) is critical to the general physical and mental health of this nation's children. Like WIC and the immunization programs, it has proven its effectiveness as an investment in our children.

The Commission also lends its support for the additional reporting requirements for the MCH Block Grant as well as for some of the newer proposals under consideration. A demonstration project within SPRANS focusing on public/private partnerships to evaluate and extend health coverage is an innovative concept, and I am happy it includes a requirement for preventive care.

I also learned with interest of the proposed statewide Block Grant Needs Assessment which is intended to identify unmet maternity and infant care needs including prenatal care and the prevention of low birthweight and infant mortality. It also calls for a plan to meet these needs.

Two of the members of this Committee, Senators Durenberger and Bradley, have proposed additional programs for the MCH Block Grant. Earlier this year, they introduced legislation entitled the "Healthy Birth Act of 1989," proposing at least four specific programs for the block grant. These four programs grew out of their work with the National Commission to Prevent Infant Mortality and are part of the recommendations contained in the Commission's report, "Death Before Life: The Tragedy of Infant Mortality." I urge the Committee to consider seriously and to adopt their proposed programs.

As I might point out, what the Infant Mortality Commission has done during its existence is very similar to a needs assessment. We examined prenatal care, low birthweight, and infant mortality, and we came up with a plan of action. "The Healthy Birth Act" which Senator Durenberger and Senator Bradley introduced is a product of that plan.

One of the programs which the bill recommends is home visiting. The Commission found that too many women never enter the health care system because of various barriers. Home visiting is an outreach mechanism that can serve as a liaison to the health care system. We've got to try to serve women where they are. That's where prevention begins. That's where women can be motivated to seek care, to stop smoking or abusing drugs, and to take better care of themselves and their children. These programs are proving effective, and the Commission will soon publish a report on home visiting programs which I will certainly provide to Members of this Committee.

The second program of great importance to our women and children is called "one-stop shopping." It is an extension of our concern with achieving better coordination between the different programs serving women and children, like Medicaid and WIC. Just as it makes no sense to have multiple application forms for these programs, it makes no sense that they be located in different places, requiring pregnant women without money or means of transportation to seek care at multiple sites. We need to implement this program and see the results it will produce. I can guarantee that it will increase utilization of services, and utilization directly corresponds with improved birth outcomes.

Third is the development of a Health Handbook. Over 100 nations around the world currently have some form of health handbook. It serves as a permanent record for women to track their own health as well as that of their children. It helps to educate women about health care needs and risks, and it also tracks care such as immunizations. The idea is simple, the cost is minimal, and it is time to implement the handbook soon.

Finally, the Healthy Birth Act proposes the establishment of a toll-free information and referral telephone number for pregnant women and children. I have noted that the Committee is considering telephone information numbers for children with special health care needs. Doesn't it make sense to provide information to women so that unnecessary health problems can be prevented and the need for special health care treatment avoided?

Infant mortality can be reduced. We know how to do it, and we know it is a good investment. We can stop the dying and we can stop so many children from suffering permanent disabilities. We need to commit the resources now, and I urge the Committee to continue taking the largest and boldest steps forward to achieve that goal.

Thank you.

PREPARED STATEMENT OF GEORGE D. FARR

Mr. Chairman and members of the Committee, I am George Farr, President and Chief Executive Officer of Children's Medical Center of Dallas. Children's is a 168 bed, not-for-profit pediatric hospital treating diseases and disorders of children from birth to age 18, with approximately 9,000 inpatient admissions and more than 90,000 outpatient visits per year. We are the primary pediatric teaching facility for The University of Texas Southwestern Medical Center at Dallas and a major pediatric referral center for North Texas. I also had served as the founding President of the Children's Hospital Association of Texas.

I appreciate the opportunity to appear before you today on behalf of NACHRI—the National Association of Children's Hospitals and Related Institutions. I am a member of NACHRI's Board of Trustees and its Council on Public Policy. NACHRI

is the only national, voluntary association of children's hospitals. It represents 100 institutions, including six hospitals in Texas. Children's hospitals have missions of serving children who are very sick, children who have special health care needs, and children whose families often have very low incomes, particularly those eligible for Medicaid and those for whom no public or private coverage is available. Virtually all of NACHRI's members are teaching hospitals. Most are regional medical centers receiving referrals from larger geographic regions in the United States and around the world.

NACHRI applauds Chairman Bentsen and members of the Committee for the significant efforts you have made this year to develop legislation to reform health care coverage for children of low income families. NACHRI also is deeply appreciative of the opportunities the Chairman and members of the Committee have given children's hospitals to provide input on draft legislation. In my testimony this morning, I will make three points:

- First, as NACHRI testified before this Committee last week, we support the development of a package of child health coverage reforms which together build a public-private partnership of responsibility for extending access to health care for children of low income families.
- Second, the preliminary results of NACHRI's year-long study of Medicaid coverage for children strongly indicate the need for reforms that address the four key obstacles to access to care under Medicaid: eligibility restrictions, burdensome enrollment processes, uncovered services, and limits on reimbursement.
- Third, offer four sets of recommendations on: Medicaid reforms, coordination of Medicaid reforms with Title V, coordination of Medicaid reforms with child health insurance credits, and new reporting requirements.

PUBLIC-PRIVATE PARTNERSHIP

Health coverage in the United States is a complex system of public and private financing. As NACHRI explained in its June 12 testimony, children's hospitals are especially sensitive to the interaction between private insurance and public programs, because our hospitals are major providers of care to children of low income families who are uninsured or by Medicaid. We know from first-hand experience that declines in employer-paid dependent coverage increase the numbers of uninsured and the need for publicly funded access to care. Growing numbers of uninsured patients, coupled with inadequate Medicaid financing for care, increase the costs of operation for which hospitals must charge private payers and raise non-operating revenues.

We are convinced that changes in either private health insurance or public programs can have significant implications for coverage of all children. NACHRI believes it is essential to develop child health coverage reforms that strengthen public coverage to guarantee access to care but do not erode further private coverage. We are especially encouraged by the decision of this Committee to endorse a child health insurance credit as it turns its attention to reform of Medicaid and reauthorization of Title V.

CHILDREN'S HOSPITALS' EXPERIENCE WITH MEDICAID

During the past year, NACHRI has undertaken a study of Medicaid coverage of poor and near-poor children. The association will issue a final report in October. It will be based on two efforts. The first is an assessment of children's eligibility and coverage prepared for NACHRI by George Washington University's Intergovernmental Health Policy Project. The second effort is an analysis of children's hospitals' 1987 experience Medicaid reimbursement, derived from a NACHRI survey of its member hospitals last fall.

The preliminary findings of NACHRI's study make clear to us that access to care for children of low income families under Medicaid is a function of four aspects of a state's program:

- the state's *eligibility standards* for determining who qualifies to receive care under Medicaid;
- the state's *enrollment process* which determines how many eligible individuals actually enroll;
- the state's restrictions on the duration and scope of *covered services* under Medicaid; and
- the state's limits on *reimbursement* for covered services.

Eligibility Restrictions.—In recent years, this Committee has given particular attention to the barriers to access to care for children and pregnant women under

Medicaid posed by states' restrictions on eligibility. Historically, Medicaid eligibility has been linked to a family's eligibility for AFDC—Aid to Families with Dependent Children. In 1988, according to the National Governors' Association, a family with an annual income of more than 48 percent of the Federal poverty level—about \$4,350 for a family of three—would be ineligible for AFDC in the average state. In Alabama, a family with annual income of \$1,380 would be ineligible; or \$3,300 in Missouri; or \$2,150 in Texas.

In short, when linked to states' Medicaid eligibility standards have denied coverage to nearly half the nation's children living in poverty. These facts have led Congress to begin to reform Medicaid eligibility standards for pregnant women and infants by gradually breaking the link to welfare.

Enrollment Difficulties.—According to a study sponsored by the Southern Governor's Association, an average of one third of the people who apply for AFDC or Medicaid assistance were disqualified—not because they were ineligible, but because they are unable to complete the application process.

Because children's hospitals have missions of caring for children of low income families, enrollment failures can be a source of significant financial shortfalls and without question limit children's access to care. According to our survey, nearly 30 percent of responding hospitals cited non-enrollment as a major reimbursement problem resulting in substantial uncompensated care. The hospitals attributed those enrollment problems to:

- burdensome application forms—sometimes dozens of pages in length which discourage their completion;
- overworked, undertrained, and in some cases, under-motivated caseworkers who do not provide needed assistance; and
- comply and lengthy Medicaid application processing.

Although more than one-third of the responding children's hospitals have sought to expedite enrollment for inpatients by providing application processing at the hospital—often at their own expense—others have been denied state or county permission for on-site enrollment.

Uncovered Services.—States limit their coverage of services in two ways—(1) by denying coverage for specific services or (2) by limiting the volume, duration, or total payment for covered services. More than half of responding children's hospitals reported non-coverage or extremely restrictive medical criteria for inpatient services—most often in the areas of rehabilitation, psychiatric care, eating disorders, organ transplants, or transportation. Almost 50 percent of the hospitals reported denial of coverage for outpatient services, including durable medical equipment for home care use and home care services.

Even when services are covered, limits on duration of coverage or total payment can be significant. More than 30 percent of the responding hospitals cited inpatient limits such as the Texas 30 day length of stay limit. More than 50 percent cited limits on outpatient services, such as Ohio's cap of four outpatient visits per month for a patient. Based on its survey, NACHRI estimates that for affected hospitals Medicaid day limits may result in 10 or more percent of Medicaid pediatric inpatient days being uncovered. With children's hospitals averaging more than 25 percent of their care devoted to Medicaid patients, and more than a third of their care to low income patients, day limits, volume caps and dollar caps can have serious consequences. Last year, this Committee led Congress in beginning to address this problem as it affects infants receiving care in hospitals with a disproportionate share of their states' Medicaid patients.

Reimbursement Restrictions.—Mr. Chairman, Medicaid was enacted in 1965 to provide financial assistance to the cost of caring for the poor. Other payers in that era were tolerant of sharing in the cost of the medically indigent. That era is gone now, and Medicaid really must more fully the cost of care of the patients it sponsors. States impose a variety of different restrictions on reimbursement, all of which can affect a children's hospital's ability to fulfill its mission of caring for children with special health care needs as well as low income children. These include restrictions not only on reimbursement rates for inpatient and outpatient services but also on promptness of payment and interstate payments. In addition, restrictions on reimbursement for physician care can have a double impact on children's hospitals which often are located in low income communities short of physicians. The hospitals must provide increased primary care in outpatient services, and low physician payment rates make recruitment of hospital-based physicians are difficult.

In terms of inpatient reimbursement, more than 80 percent of responding hospitals reported that Medicaid paid them using fully prospective rates. Yet, such payment systems can pose special challenges to children's hospitals, because they may not

reflect the uniqueness of the care such hospitals provide or they may under-estimate seriously the costs of caring for children, particularly infants. Again this Committee led Congress in beginning to address this complex set of payment issues by amending Title XIX to require states to provide outlier payment adjustments under prospective payment for the care of infants with exceptionally long or costly stays in disproportionate share hospitals.

The combined effects of restrictions on enrollment, covered services, and reimbursement on a children's hospital's ability to provide care for children are substantial. NACHRI estimates that on average in 1987 children's hospitals received only 75 cents in Medicaid reimbursement for every dollar—in costs, not charges—it incurred to care for a Medicaid-eligible child. In other words, the hospital spent 25 cents for which it was not reimbursed—16 cents due to reimbursement restrictions, 6 cents due to coverage limitations, and 3 cents due to incomplete enrollment. On average, a children's hospital's Medicaid shortfall accounted for more than 30 percent of its uncompensated care. Nearly one out of three hospitals reported that they either postponed expansion of services or curtailed services as a result of Medicaid shortfalls.

RECOMMENDATIONS

Congress has demonstrated its support for Medicaid reform by including funding for Medicaid expansions in its FY 1990 budget resolution. Several Members of Congress have developed major legislative proposals to reform Medicaid on behalf of pregnant women and children. NACHRI has endorsed specific bills drafted by Senators Bentsen, Bradley, Riegle, and Biden. As the Committee anticipates acting on these initiatives, we offer four sets of recommendations.

(1) *Medicaid Reform.*—NACHRI believes that Medicaid reform should address problems with eligibility, enrollment, coverage, and reimbursement. We believe that at a minimum, new legislation enacted this year should:

- Mandate eligibility for pregnant women and infants with incomes less than 185 percent of the Federal poverty standers, and at least phase-in mandatory eligibility for children born after Sept. 1, 1983, with incomes less than 100 percent of poverty.
- Mandate application processing outside the welfare office.
- Authorize states to cover home and community-based services for children under age 18 who depend on mechanical ventilation for survival or have AID.
- Prohibit states' use of day limits or prospective payment without outlier adjustments for inpatient care of children up to age 18 in disproportionate share hospitals; require payment adjustments for children receiving care in outpatient services with a disproportionate number of low income patients; and codify HCFA regulations on sufficient payment for obstetricians and pediatricians.

(2) *Coordination with Title V.*—NACHRI supports a substantial increase in the authorization for a more accountable MCH Block Grants program. As providers of care to children with special health care needs, children's hospitals are encouraged by draft legislation that would highlight such needs in the use of Title V funding. NACHRI also supports proposals to increase coordination between Title V and Title XIX, including:

- Require states to establish a state MCH advisory board, with Medicaid agency representation, to oversee the state's MCH program.
- Authorize demonstration grants to fund models of improved coordination among Title XIX, Title V, and other programs serving children.
- Direct DHHS to coordinate the use of data from Title V, Title XIX, and other programs in annual child health reports to Congress.

(3) *Coordination with Tax Credits.*—In NACHRI's June 12 testimony on the child health insurance tax credit we recommended specific measures to ensure that Medicaid reforms and tax credits complement one another:

- Enable Medicaid eligible families to purchase private coverage so that Medicaid remains the secondary payer.
- Authorize states' use of Medicaid funds to assist families with incomes up to the Medicaid eligibility limit to meet the cost of private insurance premiums not covered by the credit.
- Authorize states' use of Medicaid as a "wrap around" for private insurance for Medicaid eligible pregnant women and children, to meet the costs of co-payments, deductibles, and coverage maximums.

(4) *Reporting.*—The child health care reforms under consideration by the Committee represent major improvements in access to care that believe are politically feasible today. But realize that the Committee recognizes that these changes do not represent the sum of the needs for health care of all of America's children. Consequently, NACHRI supports and endorses legislative proposals that enable Congress to

take a more comprehensive look annually at the status of child health and access to care. Congress should:

- Require DHHS to report annually to Congress on the status of children's health, health care coverage, utilization and cost of services.
- Require DHHS to report to Congress on definitions of medically at risk and un-insurable pregnant women and children, as well as model benefit packages, including children's catastrophic insurance.
- Authorize an independent study comparing reimbursement for care to cost of service delivery and changes in utilization patterns.

Mr. Chairman, thank you for the opportunity to present NACHRI's views.

PREPARED STATEMENT OF J. WILLIAM GADSBY

Mr. Chairman and Members of the Committee: I am pleased to be here today to discuss two GAO efforts relating to meeting the needs of children in a home-based setting. The first is our report, which is being released today, on the home care experiences of families with chronically ill children. The second is our study, which is still in progress, on home visiting as a means to improve child health and well-being.

HOME HEALTH CARE FOR CHRONICALLY ILL CHILDREN

Nationally, about 1 million children have a severe chronic health condition. In the past, these children were treated in hospitals. But in recent years, advances in medical technology have made it possible to care for them at home. At your request, we reviewed the experiences of parents with chronically ill children in obtaining medical and support services at home.

To do this, we focused on children who had the more severe forms of 10 medical conditions, such as spina bifida, congenital heart disease, or cystic fibrosis (see att. I for complete list). Working in 11 states and the District of Columbia, we contacted 14 hospitals that care primarily for children, surveyed 892 parents, and had group discussions with 96 of these parents about their experiences. We also contacted 60 local service providers and organizations for information about services they offered in the communities where we conducted family interviews. What did we learn?

Families' Needs for Services and Difficulties in Obtaining Care Varied

Families with chronically ill children at home need both medical and nonmedical (or support) services. The need for medical services is great: virtually all of the parents we surveyed (98 percent) said their children needed services such as physician office visits, medications, or medical equipment and supplies (see att. II). About three-fourths of families needing these services (73 percent) said they had no difficulty obtaining them.

In contrast, although fewer families said they needed support services, obtaining them was more difficult. Three-fourths of the parents reported needing one or more support services, most commonly baby sitting, counseling, day care, or transportation. These support services sound like the typical needs of any family. But, where they involve a chronically ill child, providing them can become highly specialized. About one-half (56 percent) of the families said they had difficulty getting the support services they needed.

Lack of Financing and Information Create Difficulties in Obtaining Some Services

Parents attributed their difficulties in obtaining both medical and support services primarily to three factors: (1) high out-of-pocket costs, (2) a lack of information about service availability and providers, and (3) the lack of a focal point to contact when they needed help. Comments directly from parents can perhaps best illustrate these points.

A Texas parent of a child with a heart condition and other complications told us:

... [C]opayments and uncovered or under-covered expenses have depleted our resources. We also fear "pre-existing condition" clauses and that has had a detrimental effect on [my husband's] career (he is in a field where upward mobility is achieved by changing companies).

A Maine parent of a child with muscular dystrophy said:

... [T]rying to get information concerning grants, funds, special schools or programs is difficult at best. It's like a secret society—no one wants to share information that should be public knowledge.

And a Minnesota parent of a child with a cleft lip/palate remarked that:
 Support groups and contact persons were not available and it would have been such a relief to talk to a person who had gone through [what we have] after the birth of our daughter.

Possible Solutions

Although many parents had difficulty obtaining services for their children, especially support services, not all did. The positive experiences of some parents form the basis for possible solutions.

We believe that the conditions we found can be improved (1) by consolidating and publicizing sources of information on services available for chronically ill children in a given community, (2) by providing this information to parents at the time of hospital discharge or once they return to their own home community, and (3) by ensuring that a focal point (case manager) is available when needed. We are recommending that the Secretary of Health and Human Services take a strong leadership role in developing the necessary policy and program guidance to accomplish this. HHS has agreed with our recommendation.

HOME VISITING AS A PREVENTIVE STRATEGY

Now, I would like to briefly discuss our ongoing work concerning home visiting programs in the United States and Europe. This job, which we are doing at the request of the Senate Appropriations Committee, should determine if such programs might be effectively used on a wider basis in the United States.

What do we mean by "home visiting?" Basically, we mean a service delivery approach that provides preventive health, social, or educational services directly to at-risk pregnant women and families with young children in their home. Many researchers and practitioners believe that home visiting is a cost-effective and efficient way to improve health and decrease the risk of child abuse and developmental delay.

Our work has two components. First, through extensive interviews and a literature search, we have identified key characteristics that seem to make home visitor programs effective. Second, we are testing, through case studies in five states (Illinois, Michigan, Rhode Island, South Carolina, and Texas) and in two European countries (the United Kingdom and Denmark), whether these key characteristics have produced programs that meet their stated goals. Based on the field work we have done to date, it seems there are at least three important characteristics to any successful home visiting program. These are:

- clearly defined objectives,
- providers' skills matched with service delivery objectives, and
- stable program funding.

I'd like to talk for a moment about why each of these is important.

Clearly Defined Objectives

Clearly defined objectives are important because they provide the framework for deciding who to serve and with what services, monitoring program progress, and evaluating outcomes. One place with such clearly defined objectives is the Roseland Adolescent Parent Project in Chicago. This project serves teenage mothers with first-born children who lack a family or other "support systems." By routinely monitoring program activities, such as seeing whether infants get a minimum number of pediatric visits, program managers are evaluating their progress in reaching stated goals and desired outcomes.

Providers' Skills Matched With Service Delivery Objectives

Matching the skills of the provider to service delivery objectives is a key to success for home visitor programs. Programs focusing primarily on preventive health objectives often use highly skilled public health nurses. Trained lay workers, on the other hand, are often used to provide social support and referrals to other existing services.

The United Kingdom's program, for example, uses health visitors who are highly skilled and highly trained nurses functioning as part of a primary medical team. Among other things, they provide preventive health services, such as immunizations and well-baby check-ups, in the home. In contrast, the Resource Mothers Program in South Carolina uses lay workers to provide social support, health education, and referral information to pregnant teens in rural areas. In each case, program managers believe their program's objectives—whether primarily medical or social—are best met by the type of home visitors they are using.

Stable Funding Sources

Another vital contributor to success seems to be stable funding. Effective home visiting programs need providers who can develop rapport with program participants and maintain a relationship over time with the families they visit. Experience shows it can take 2 to 3 years to develop a program, put it in place, and begin to show results. Yet, in the past, much of the Federal support for home visiting has been for research and demonstration projects. While this Federal support has been valuable in demonstrating that home visiting works, such programs need stable sources of funding to continue or to be replicated in other locations. Without such funding, programs often lapse or become less effective.

A home visiting program in Elmira, New York, was particularly effective in its initial phase when it received Federal and private research and demonstration funding. When these funds ran out, the local health department continued to support the program, but in a different and diluted form. Because of funding constraints, the home visitors found they had to shorten their visits and drop families earlier (when the baby was 4 months old, as compared to 2 years under the demonstration program). County officials told us that the current project is no longer having the same impact as the original demonstration project because the same level of intensive services is no longer provided.

When we have finished this review, Mr. Chairman, we will develop recommendations for the Congress and HHS to consider in using home visiting to improve maternal and child health and well-being.

Mr. Chairman, this concludes my statement. I would be pleased to respond to any questions you or other members of the Committee may have regarding our work.

ATTACHMENT I.—10 CHRONIC HEALTH CONDITIONS COVERED IN GAO REVIEW

Juvenile-onset diabetes
Asthma
Spina bifida
Cleft palate and other craniofacial anomalies
Congenital heart disease
Leukemia
End-stage renal disease (kidney failure)
Sickle cell anemia
Cystic fibrosis
Muscular dystrophy

Some of these conditions are long-term (such as diabetes, spina bifida, and cystic fibrosis), while others (such as heart conditions and cleft palates) can often be corrected early in life.

These 10 conditions are among those included in a 1985 Vanderbilt University study (Nicholas Hobbs, James M. Perrin, and Henry T. Ireys, *Chronically Ill Children and Their Families: Problems, Prospects, and Proposals From the Vanderbilt Study*, Josey-Bass, Inc., 1985) and are considered to be representative of the problems and costs parents faced in obtaining care for a wide variety of chronic illnesses.

ATTACHMENT II.—FAMILIES' NEEDS FOR SPECIFIC SERVICES AND DIFFICULTIES IN OBTAINING THEM

	Families who had a need for services		Families with a need who had difficulty obtaining services (Percent)
	No.	Percent	
Medical services ¹			
Physician office visits	823	97	6
Medications	759	90	9
Medical equipment	470	55	16
Medical supplies for equipment	464	55	15
Rehabilitative and other therapies	273	32	30
Skilled nursing visits	208	25	27
Physician home visits	162	12	58
Support services ²			
Baby sitting	412	65	58
Counseling	368	58	32

ATTACHMENT II.—FAMILIES' NEEDS FOR SPECIFIC SERVICES AND DIFFICULTIES IN OBTAINING THEM—Continued

	Families who had a need for services		Families with a need who had difficulty obtaining services (Percent)
	No	Percent	
Day care	336	53	57
Transportation	320	51	32
Case management	266	42	31
Respite care	152	24	53
Homemaker	129	20	50

¹ Of 865 valid responses to GAO's question about medical service needs, 848 (98 percent) said they needed one or more of these services

² Of 840 valid responses to GAO's question about support service needs, 634 (75 percent) said they needed one or more of these services

BLOCK GRANTS

FEDERAL-STATE COOPERATION IN DEVELOPING NATIONAL DATA COLLECTION
STRATEGIES

GAO

United States
General Accounting Office
Washington, D.C. 20548

Human Resources Division

B-217560

November 29, 1988

The Honorable Augustus F. Hawkins
Chairman, Subcommittee on Elementary,
Secondary, and Vocational Education
Committee on Education and Labor
House of Representatives

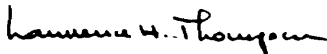
The Honorable William F. Goodling
Ranking Minority Member
Subcommittee on Elementary, Secondary,
and Vocational Education
Committee on Education and Labor
House of Representatives

The Honorable David R. Obey
House of Representatives

You asked us to compare the data collection and reporting provisions of the education block grant (chapter 2 of the Education Consolidation and Improvement Act of 1981) with those of other block grants and to assess the viability of federal and state cooperation in the collection of national block grant data. This report assesses the viability of this approach to obtaining national data without resorting to prescriptive federal regulation.

As agreed with your offices, we are sending copies of this report to other interested congressional committees and members; the appropriate executive department heads; the Director, Office of Management and Budget; state and local governmental agencies; and national associations representing state block grant officials. We will also make copies available to other interested parties upon request.

This report was prepared under the direction of J. William Gadsby, Associate Director. Other major contributors are listed in appendix IX.



Lawrence H. Thompson
Assistant Comptroller General

Executive Summary

Purpose

One goal of the 1981 block grants was to expand states' authority to administer federal programs. The states' current flexibility in collecting data on block grant programs contrasts markedly with data collection requirements under prior categorical programs, which compelled states to adhere to federal standards. As a result, block grant data first reported to the federal government were not comparable across states.

In 1984, the Congress responded to this situation by legislating the development of model criteria and standardized forms for some block grants to facilitate uniform data collection through a process that relied heavily on voluntary state cooperation. This report, requested by several Members of Congress, assesses the viability of this approach to collecting national data on block grant programs.

Background

For some block grants, mandatory data collection standards set forth in federal regulations were replaced by a cooperative approach in which data were voluntarily submitted to the federal government using reporting forms, standard definitions, and data elements and categories developed by national associations in cooperation with federal agencies. This approach attempts to minimize differences between state data collection systems by using generic data elements and broad categories of information to describe the types of data to be collected without resorting to prescriptive federal data collection requirements. GAO assessed the viability of this approach for four block grants: alcohol, drug abuse, and mental health services; energy assistance; community services; and education. GAO used three criteria: data must be (1) available in a timely fashion, (2) available without undue burden, and (3) technically adequate to draw proper conclusions and to provide confidence in the results. The review was made at the Departments of Health and Human Services and Education and in six states. GAO also visited eight national associations and organizations that were involved in the development of model criteria and standardized forms to provide national data on block grant programs. (See p. 30.)

Results in Brief

Although the cooperative approach is voluntary and allows deviation from the model format, GAO believes that it can be a viable way for federal policymakers to obtain national block grant data for program oversight purposes without imposing rigid, burdensome federal reporting requirements on states. Generally, the data were timely, and most officials in the six states perceived the collection efforts to be less burdensome than reporting under categorical programs. However, data

Executive Summary

collected through this approach for the four block grants were not always comparable across states. Limited data comparability, however, would be a consequence of any voluntary effort. Nonetheless, several factors, primarily national leadership in developing standard forms and definitions, can improve data comparability.

Because of limitations in data comparability, the voluntary approach cannot equitably serve other potential congressional and federal agency needs that require comparable data, such as to allocate funds or compare the cost per client served among states. To increase data comparability to meet such needs would probably require mandatory federal data collection standards, which would result in additional costs and increased state and local administrative burdens. Even then, some states might have difficulty in regrouping data to meet federal reporting requirements.

Principal Findings

Burden Reduced but Data Were Not Always Comparable

The collection of data through the cooperative approach for the four block grants reduced administrative burdens on state and local governments. It also promoted broad state cooperation in the development of national data systems by involving state officials in the systems' design. Further, it allowed states flexibility to accommodate national reporting requests by making maximum use of their own information systems. However, limited data comparability reduces the usefulness of data collected under this approach for other purposes where fully comparable data are needed, such as allocating federal funds or determining the magnitude of needs among individual states.

Several Conditions Contribute to Increased Data Comparability

Where policymakers have concluded that the cooperative approach can meet federal data needs, several conditions, primarily the existence of national leadership, appear to have contributed to the success of the approach. When a federal agency or a national association took the lead in developing model criteria and standardized forms, it was easier to collect comparable data through the cooperative approach. Under the energy assistance and the alcohol, drug abuse, and mental health services block grants, where legislation requires federal agencies to work with appropriate national associations representing state officials to develop national data systems, states fully supported the cooperative

efforts. For example, under the leadership of a national association with guidance from the federal agency, a national survey was developed for the substance abuse program directors. As a result, data collection efforts for substance abuse programs were generally sufficient to meet federal policymakers' oversight needs. The Congress has recently passed legislation to require the Secretary of Education to develop a cooperative system for the collection of education block grant data. A similar system is not required under the community services block grant.

In contrast, when there was no statutory requirement to encourage national leadership, comparable data were more difficult to obtain. For example, when the education block grant was created, neither the Department of Education nor a national association representing state and local education officials provided leadership in developing report format or content. Consequently, state reports on block grant-related activities could not be aggregated to provide a national picture. Now that the states have their data collection systems in place, changes to accommodate a national reporting format to provide comparable state data on educational activities, such as the number of students served and the use of funds to serve private school students, have been difficult to implement. Similarly, the absence of national leadership has hindered the collection of comparable state-level data on clients and services for mental health programs. (See pp. 23-26.)

Certain Program Characteristics Facilitate the Cooperative Approach

Several program characteristics, such as clear program objectives, also enhance the viability of the cooperative approach. Under the energy assistance and alcohol, drug abuse, and mental health services block grants, where federal funds support a narrow range of allowable program activities, the federal agency and national associations were able to encourage states to voluntarily collect and report data to meet national reporting requests. For both programs, states fully supported the voluntary national requests for data. (See pp. 20-23.)

The cooperative approach to data collection was also easier to implement when (1) federal funding was available to support data collection activities, (2) national-level staffs were designated to work with state officials, (3) state officials were involved in the system design, and (4) states had been involved in prior categorical grant programs.

Matters for Congressional Consideration

In considering future block grant data needs, the Congress may want to statutorily require the Secretary of Health and Human Services to develop a model for state data exchange in consultation with appropriate associations of state and local officials to facilitate uniform data collection under the community services block grant. The Congress has already required the cooperative approach for the energy assistance, education, and alcohol, drug abuse, and mental health services block grants.

The Congress should also consider providing seed money to encourage national leadership by helping federal agencies, national associations, and other organizations defray initial systems start-up costs and ongoing costs for the collection, processing, analysis, and publication of comparable block grant data across states. (See p. 27.)

Recommendations

GAO recommends that the Secretary of Health and Human Services work with the states through the cooperative data collection efforts to increase data comparability under the energy assistance, community services, and alcohol, drug abuse, and mental health services block grants. (See pp. 27-28.)

GAO also recommends that the Secretary of Education, when developing the cooperative data system recently required by the Congress, define specific data categories as part of the model format for the required state evaluations in order to facilitate uniform data collection. (See p. 28.)

Agency Comments

The Departments of Health and Human Services and Education concurred with GAO's recommendations to increase the viability of the cooperative approach to obtaining national block grant data. They also provided some technical comments, which were incorporated, where appropriate, in this report. While the Office of Management and Budget had some concerns about GAO's scope and the need for federal seed money for initial systems start-up costs and ongoing costs for cooperative data collection activities, it said that it did not object to the report's recommendations. (See pp. 28-29.)

Introduction

The enactment of several block grants in 1981 shifted responsibilities for many program management decisions from the federal government to the states. Since then, the Congress has been interested in how data can be collected nationally on the uses and results of block grants without imposing excessive reporting burdens on states. This report examines federal and state approaches to collecting national data through cooperative arrangements. These arrangements have evolved in seven of the block grants as alternatives to the detailed collection requirements imposed under many categorical grant programs.

Under block grants, states are generally required to submit periodic reports to the federal government on their use of block grant funds, but they are often given the flexibility to determine the exact form and content of these reports. Each state collects data primarily to meet its own budgetary and management needs, and each has unique laws and fiscal accounting systems. As a result, information collected by some states may not be comparable with that collected by other states. This is in marked contrast to data collection efforts under categorical programs, which required states to adhere to federal data collection standards that seek to standardize data across states for congressional oversight and program management purposes.

Although states prefer the flexibility to develop data systems based primarily on their own needs, they recognize the need for national block grant data to meet congressional requests. Therefore, many have cooperated in voluntarily developing standard reporting forms, definitions, and data elements for 7 of the 11 block grants. These data collection systems were often developed in conjunction with federal agencies and national associations. This cooperative approach attempts to minimize the differences among state data collection systems without resorting to the prescriptive federal data collection requirements under the former categorical grant programs.

Background

Of the 11 block grants operating in 1988, 8 were enacted as part of the Omnibus Budget Reconciliation Act of 1981 (Public Law 97-35). This statute substantially changed the administration of numerous federal domestic assistance programs by abolishing some and by consolidating 57 categorical grant programs into block grants and shifting primary administrative responsibility for these programs to the states. About \$13 billion was appropriated through these 11 block grant programs for fiscal year 1988.

**Statutory Requirements
for Federal and State Data
Collection and Reporting**

Block grant legislation imposes several minimum data collection and reporting requirements on both federal and state agencies. Federal agencies are generally required to (1) prepare agency reports to the Congress, which summarize the program activities supported with block grant funds; (2) collect program assessment data on specific types of activities; and (3) conduct compliance reviews, which are used to determine whether the states are carrying out their programs in accordance with federal laws and regulations.

To comply with federal statutes, states are generally required to collect data to meet four types of reporting requirements. (1) grant applications, which include information on how the states plan to use federal funds; (2) program and evaluation reports, which describe the actual use of federal funds; (3) fiscal expenditure reports, which provide a picture of expenditures within certain cost categories; and (4) financial and compliance audits, which examine the financial statements and internal controls of administering state agencies. Although the administering federal agencies generally have the authority to prescribe the form and content of these state reports, for block grants they have chosen not to impose requirements beyond those in the legislation. As a result, report format may be decided by each state with minimal guidance. The state reports often serve as the primary source of information that federal agencies report to the Congress.¹

Some Members of Congress and federal program officials are concerned that comparable data are not available across states to assess whether block grant funds are being used to address key national concerns. These concerns have led the Congress to add new data collection provisions to seven block grants since 1981 to ensure the existence of some comparable national data for these programs. Additionally, the Congress is considering increasing data collection requirements under the alcohol, drug abuse, and mental health services block grant.

In response to legislative requirements and concerns, several federal agencies have developed strategies to obtain national data through cooperative arrangements that are consistent with the block grant philosophy of decentralizing the management of federal programs. These strategies include funding state officials' associations and research firms to collect data in cooperation with federal agencies and conducting special studies and surveys on specific issues of national concern. In some

¹See Block Grants, Federal Data Collection Provisions (GAO HRD-87-59FS, Feb. 24, 1987) for specific data collection requirements for each block grant.

cases, national associations have taken the lead in collecting data without any federal support because they see the value of having data available for the Congress.

Objectives, Scope, and Methodology

The Chairman and Ranking Minority Member of the Subcommittee on Elementary, Secondary, and Vocational Education, House Committee on Education and Labor, and a member of the House of Representatives asked us to examine federal and state cooperation in collecting national data on block grant programs. Some Members of Congress, as well as federal and state officials, are concerned about the consequences of this approach, such as limited data comparability in the absence of federal data collection standards. Our primary objective was to assess the viability of the cooperative approach.

Selection of Programs Included in Review

We surveyed the reporting requirements for all block grants and focused on four programs that were representative of the varying characteristics of block grants. These characteristics include (1) the relative share of funding from state and federal sources, (2) the amount of federal and state financial support for national data collection activities, and (3) the data collection strategies used by federal agencies in different program policy areas. The block grants are as follows:

- Alcohol, drug abuse, and mental health services (ADMS)—under which state and private funds are about 82 percent of program funding in the substance abuse area and about 86 percent of funding for community mental health services. The states voluntarily report data on substance abuse and mental health (financial data only) to national associations through standardized data collection formats. The federal agency provides financial support to the national association collecting data on the substance abuse program area.
- Low-income home energy assistance program (LHEAP)—under which states contribute about 1 percent of program funding for four activities. They provide data directly to the Department of Health and Human Services (HHS), voluntarily using a format developed by a national association with federal financial support.
- Community services block grant (CSBG)—under which states contribute less than 5 percent of program funding. Most states voluntarily submit data to a national organization, which prepares a national report under

We did not assess the usefulness or test the accuracy of individual data elements, nor did we evaluate other methods of obtaining national block grant data, such as special studies and surveys.

a federal grant. However, there is no federal guidance on the types of data to be collected

- **Education block grant**—under which state and local funds represent more than 93 percent of funding for elementary and secondary education programs. Of the total funding for education programs, the block grant represents less than 1 percent.³ Most states submit their required evaluation reports to the Department of Education, using a format developed by an organization representing state officials with no federal financial support.

Scope of Work

We obtained information to assess the cooperative approach primarily from three sources: federal agencies, state agencies, and national associations and organizations (See app. I.) We did some limited work at the local level. We performed work at two federal agencies (the Department of Education and HHS) and in six states: California, Maryland, Pennsylvania, Rhode Island, Texas, and Virginia.⁴ We chose these states because of geographic location and differences in their data collection approaches, block grant program administrative structures, and size. We also examined the uses of the block grant data at the national level. We performed our work between October 1986 and October 1987.

Criteria Used to Assess the Viability of the Approach

We used three criteria to assess the viability of the cooperative approach in providing data useful for congressional and federal agency oversight: the data had to be (1) available in a timely fashion, (2) available without undue burden, and (3) technically adequate. These criteria were developed in consultation with a researcher at the Urban Institute, selected national associations, and various federal and state program officials. We assessed each of the four block grants based on these criteria. Table 1-1 describes the indicators for each criterion.

³The education block grant was reauthorized by the Augustus F. Hawkins-Robert T. Stafford Elementary and Secondary School Improvement Amendments of 1988 (Public Law 100-77). It is currently contained in chapter 2 of title I of the Elementary and Secondary Education Act of 1965, as amended.

⁴In Virginia, CSBG was not included as part of this review because the program records were unavailable at the time we performed our work.

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Table 1.1: Description of Criteria for Assessing the Cooperative Approach

Criterion	Description of Indicator
Timeliness	<p>Delivery of state agency reports to the respective national association in time to be included in the association's report by the due date</p> <p>Delivery of state agency reports to the respective federal agency in time to be included in the federal agency's report to meet the statutory due date</p>
Burden	<p>State officials' perceptions of burden to produce common and additional data elements/categories to meet national reporting requests when compared to prior categorical programs or other federal grant programs</p> <p>Amount of time/staff resources needed to meet national reporting requests</p>
Technical adequacy	<p>Types of data available to state agencies through local agencies and service providers to meet federal agency and/or national association data requests</p> <p>Comparability of data reported by state agencies to the federal agency and/or national association to provide a national overview</p> <p>Adequacy of internal control procedures that the state and federal agencies and national associations had in place to ensure that data reported are reasonably accurate for congressional and federal agency oversight purposes</p>

Not every indicator was available for each block grant program. For example, the data reporting burden perceived under block grants could not always be compared to that perceived for prior categorical programs because some state agency staffs were not familiar with predecessor programs. In such cases, we relied on the state officials' estimates of the amount of time and/or staff resources needed to meet national reporting requests in the six states visited.

To assess the timeliness of data collected and reported, we examined federal agency reports to the Congress, federal agency evaluation reports, and national association reports to determine whether state agencies reported in time to be included in the federal agency or national association reports.

To determine whether the data reported to the federal agency or national association were collected without undue burden on states, we relied on state officials' perceptions of burden in meeting national reporting requests in the six states. We also obtained state officials' perceptions of burden to produce a common data set and of the additional data requested to satisfy federal data requirements under categorical programs.

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**Judging the Viability of
the Cooperative Approach**

To assess technical adequacy, we determined whether the data that states collected were adequate and comparable. We determined what data were collected by local agencies and service providers and reported to the state agency. We also evaluated how well state data bases allow aggregation in each of the six states to produce nationwide data. Finally, we reviewed the six states' internal control procedures to ensure that the data were reasonably accurate. However, we did not test the accuracy of individual data elements.

To evaluate the viability of the cooperative approach, federal policymakers will need to weigh the findings under each criterion according to their own program objectives and data needs. For example, policymakers interested in minimizing the administrative burden by requiring only enough data to ensure oversight accountability will want to focus more on the burden criterion than on timeliness and technical adequacy. On the other hand, policymakers who need data for allocating funds or comparing programs across states will want to focus more on the findings for timeliness and technical adequacy.

We based our analysis of the findings that follow on the explicit legislative intent of block grants—to reduce the burden on the states and give them greater administrative flexibility. We also assessed the limitations of the cooperative approach in meeting other data needs of federal policymakers.

Chapter 2 summarizes our observations of the cooperative approach. In appendices II through V we describe the design and collection processes developed for each block grant, reviewed and assess the timeliness, burden, and technical adequacy of the data produced.

Our sample of four block grants was judgmentally selected to represent a diversity of approaches. Our findings are not intended to be projected to the other block grants. Likewise, the results from our sample of six states should not be viewed as representative of experiences in other states.

US, the Department of Education, and the Office of Management and Budget were given an opportunity to comment on a draft of this report.

We did not assess directly whether agencies and service providers collect and report to the state agency because these data are not always readily available to state agencies.

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In considering these comments, we made appropriate revisions. (See apps VI-VIII for detailed agency comments) Our work was done in accordance with generally accepted government auditing standards.

Overall Assessment of the Viability of the Cooperative Approach

The cooperative approach can be a viable way of obtaining national block grant data on funding, services, and client characteristics that should meet federal policymakers' oversight needs. This approach allowed states flexibility to accommodate national reporting requests by using their own information systems, thereby reducing administrative burdens. Further, it promoted broad state cooperation in the development of national data systems by involving states in the design of data collection and reporting systems.

However, because limited data comparability is an adverse effect of this approach, national leadership is needed to facilitate uniform state data collection to the extent possible. Also, the cooperative approach is not a viable way to obtain national data for other potential congressional and federal agency needs, such as allocating federal funds or determining state compliance with federal laws and regulations, since more comparable data are needed to minimize inequities in the results.

Where federal policymakers conclude that their data needs can be met through the cooperative approach, we have identified several factors that can enhance the viability of this approach. These include four program characteristics that made it easier to collect data through voluntary reporting: (1) there was a narrow scope of allowable activities, (2) federal funds were the primary source of program funding, (3) states had been involved in prior categorical grant programs, and (4) state governments had clear statutory authority to collect data from their localities.

In those block grants where the cooperative approach can be viable, we have identified six conditions that can increase data comparability: (1) national leadership in directing the development of model criteria and standardized forms, by either a federal agency or a national association, (2) states' recognition of the need for block grant data; (3) federal funding to support data collection activities; (4) designated national-level staff to work with state officials; (5) state officials' involvement in the design of the systems, and (6) federal statutes to encourage cooperation in data collection.

Assessment of the Cooperative Approach Based on Our Criteria

We assessed the timeliness, burden, and technical adequacy of data collected under the cooperative approach. We found that the four block grants generally met our criteria (see p. 12), with the following exceptions:

- Data comparability at the national level was generally a problem because report formats and definitions vary across states for each of the four block grants.
- Education and community services block grant data were generally not timely.
- Some state officials perceived the national survey of CSBG-supported activities and the preparation of the required education block grant evaluation to be burdensome.

Our analysis of the cooperative approach across the four block grants in six states and the procedures used by federal agencies and national associations to collect national program data are summarized in table 2.1. A discussion of the cooperative approach for each of the four block grants is contained in appendixes II through V.

Table 2.1: Assessment of the Cooperative Approach for Each of the Four Block Grants

Criterion	AD*	MS*	LIHEAP	CSBG	Education
Timeliness	Y	Y	Y	N	N
Burden	Y	Y	Y	N	N
Technical adequacy					
Availability					
Expenditures	Y	Y	Y	Y	Y
Services	Y	N	Y	Y	Y
Client numbers	Y	N	Y	Y	Y
Client characteristics	Y	N	Y	Y	N
Comparability					
State level	Y	Y	Y	Y	Y
National level	N	N	N	N	N
Activities					
State level	Y	Y	Y	Y	Y
National level	Y	Y	Y	Y	N

* Y = Yes, N = No. AD = Assessment of Data, MS = Monitoring System, LIHEAP = Low Income Home Energy Assistance Program, CSBG = Community Services Block Grant, Education = Education Block Grant.

Timeliness

The voluntary submissions of data by states to the federal agency and or national association to meet national reporting requests were generally timely, with the exception of the education and community services block grants. Under the education block grant, states were slow in meeting the reporting deadline requested by the Department of Education. Only 10 state evaluations for fiscal year 1986 were received by the January 1987 request date. After the request date, another 31 evaluations were received by October 1987, and another 5 by April 1988. Thus, 4 evaluations were outstanding 15 months after the request date.

For CSBG, only 13 state data submissions for some or all parts of the survey were received by the March 1987 due date, and another 33 were received by September 1987. Thus, 4 state data submissions were outstanding when the Center for Community Futures' final report was issued in November 1987.

Under LHEAP, all state agency reports were received in time to be incorporated into IHS's 1986 report to the Congress. Although some state data submissions were not received by the due dates, they were received in time to be included in both the National Association of State Alcohol and Drug Abuse Directors' (NASADAD's) and the National Association of State Mental Health Program Directors' (NASMHPD's) final reports.

Burden

Most state officials in the six states told us that the cooperative data collection efforts were generally less burdensome than their reporting experiences under the prior categorical grant programs. Under the AOMs block grant, both the national associations and states we visited told us that, compared to the federally mandated state reporting under the prior categorical programs, the cooperative efforts are less burdensome. Under LHEAP, state officials told us that they had few problems in following the national reporting format because their data systems were based substantially on federal requirements under the prior categorical programs. Thus, their costs to follow the national reporting format were minimal, usually amounting to less than one staff-day for each of the two required state reports.

On the other hand, state education officials told us that the preparation of the required evaluation reports were, to some extent, burdensome. Nonetheless, some state officials believe that, compared to reporting

¹ NASMHPD is not tied to a specific publication date and therefore did not issue its report until a later date than the other reports.

under numerous categorical grant programs, the cooperative efforts have simplified paperwork procedures and reduced administrative burdens. Also, according to state officials, meeting national reporting requests under CSBG represented a significant effort and required substantial work beyond that needed to maintain existing state data bases.

Technical Adequacy

Although data reported to the state agencies through the cooperative efforts were available for oversight purposes and states had internal control procedures to ensure its accuracy, data were not always comparable across states. Data on funding, services provided, and client characteristics were generally available and reported by states through the cooperative efforts for the substance abuse portion of the ADMS block grant, LIHEAP, and CSBG. However, states reported little data on the characteristics of clients served under the education block grant, and LIHEAP data on households receiving assistance to weatherize their homes were not always readily accessible to state cash assistance agencies. While the state educational agencies report extensive data on funding and services, information on the characteristics of clients served will be limited until more states report such data.

Although data on funding and services are generally available at the state level for all four block grants, data formats and definitions vary somewhat across states. Under the ADMS block grant, some states are unable to report selected client information according to national reporting categories because of differences in state definitions, and a few must estimate at least part of the data they report to meet national reporting requests. While data under LIHEAP are reasonably comparable, some differences in state definitions exist. For example, most states reported elderly recipients as persons over 60, but a few states defined the elderly as persons over 55 in their fiscal year 1986 reports. And, because of the broad range of allowable activities under CSBG and the education block grant, it is highly likely that the same clients served by more than one activity will be counted twice. In addition, under the education block grant, data identifying students that used instructional resources, such as library books and computers, appear to be inconsistent.

States reported that their internal control procedures were adequate to ensure that reported data are sufficiently accurate for federal agency oversight purposes. Across the four block grants, the six states we visited generally had internal control procedures in place to ensure that data meet minimum state standards of completeness and quality. For the ADMS block grant, some states conducted computerized validity

checks of local data and verified data entries. Under CSBG, state officials seek clarification from local service providers on specific items, and state education officials generally conduct periodic monitoring visits to local educational agencies (LEAs) and require separate quarterly or annual financial reports.

At the national level, one national association developed a checklist for assessing whether the state substance abuse data met its data collection standards. Another association requested states to submit supporting documentation to verify state revenues and expenditures data on state mental health services. At the federal level, existing internal control procedures were not adequate to verify that data reported by the states to federal agencies were reasonably accurate to meet federal policy-makers' data needs other than program oversight.

Usefulness of Data Collected Under the Cooperative Approach Is Limited

Our review of four block grants identified several promising uses of data collected under the cooperative approach and several uses that should be limited. Data collected cooperatively show promise for (1) obtaining a national picture of funding, services, and client characteristics to meet congressional and federal agency oversight needs; (2) identifying areas where states need technical assistance; (3) facilitating the exchange of data among states; and (4) tracking national trends in funding and services provided. Limited data comparability and the absence of federal data collection standards to ensure timely and accurate data, however, reduce the usefulness of this approach for other potential congressional and federal agency needs, such as determining the magnitude of needs among individual states and allocating federal funds.

In the absence of federal data collection standards, existing internal control procedures are not adequate to verify that data reported by the states are reasonably accurate and comparable. Consequently, if these data were used to allocate funds, some states could have an incentive to report data that would maximize their allocations under grant formulas used to distribute federal aid to states and localities. Also, methodological problems in analyzing and aggregating data that are not comparable across states could create some inequities in the results. For example, when HHS used NASAD's data, which account only for those patients served by "state" agencies, to allocate funds under the Anti-Drug Abuse Act of 1986 (Public Law 99-570), several members of the Texas congressional delegation formally protested. Texas patients receive services, for the most part, from city and county clinics that are supported with state funds. According to these Texas congressmen, not considering such

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state-funded clinics in a federal allocation formula would result in some states not receiving their fair share of federal funds.

Furthermore, data collected under the cooperative approach are of limited usefulness in making comparisons among states. While it can be used, with some caution, to compare the number of clients served, the types of services provided, and total dollars spent, it should not be used to compare the cost per client served or program effectiveness among states because of differences in state cost accounting procedures, such as depreciation methods for facilities and equipment. To compare program effectiveness among states, a system must be developed to measure the programs' success.

Additionally, data collected under the cooperative approach may not be sufficient for determining state compliance with federal laws and regulations. In the absence of federal data collection standards, definitions vary across states and thus the data are not adequate to judge whether a particular state is complying with federal laws and regulations. The data might, however, serve as an initial screening to signal the need for additional review.

**Certain Program
Characteristics
Enhance the Viability
of the Cooperative
Approach**

Several block grant program characteristics enhance the viability of the cooperative approach. The approach was easier to implement if (1) there was a narrow scope of allowable activities, (2) federal funds were the primary source of program funding, (3) states had been involved in prior categorical grant programs, and (4) state governments had clear authority to collect data from their localities. Table 2.2 summarizes these four characteristics for each of the four block grants in our review.

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Table 2.2: Program Characteristics That Influenced the Viability of the Cooperative Approach

Characteristic	Block grant				
	AD ^a	MS ^a	LIHEAP	CSBG	Education
Narrow range of allowable activities	Y	Y	Y	N	N
Federal funds are primary source of funding	N	N	Y	Y	N
Prior state involvement in program administration	Y	Y	Y	N	Y
Statutory authority for states to collect data from local entities	Y	Y	Y	Y	Y ^b

Y=Yes, the characteristic is associated with the block grant and appears to contribute to the viability of the cooperative approach.

N=No, the characteristic is associated with the block grant and appears to diminish the viability of the cooperative approach.

^aNational data on the ADMS block grant are collected by two national associations—one for substance abuse (AD) and one for mental health services (MS). To more clearly convey our results, we treated each program area separately.

^bWhile five of the six states we visited told us that there were barriers to collecting data from LEAs (e.g. paperwork reduction), the Elementary and Secondary School Improvement Amendments (EISIA) now require LEAs to report annually to the state educational agency on the use of funds.

Scope of Activities

When block grant funds supported a narrow range of program activities, it was easier for states to reach a consensus on the types of data to be collected and reported. When states had to regroup data to meet national reporting requests for fewer program activities, they were more willing to voluntarily participate in national surveys. For example, under LIHEAP and the ADMS block grant, where federal funds supported a narrow range of program activities, states fully supported cooperative efforts.

When block grant funds were used to support a broad range of program activities, the cooperative approach was more difficult to implement. Although in these cases developing a consensus on what types of data to collect and what reporting formats to use has been slow, state educational agencies, for example, were increasingly willing to collect specific data to meet uniform reporting formats on a broad range of education block grant activities. Similarly, state CSBG officials, whose data cover a broad span of allowable activities, were willing to use a uniform format developed by a national center through a national organization.

Funding Source

The relative share of funding from federal sources had an impact on whether states can associate their federal block grant funds with specific program outcomes. For example, under the ADMS block grant, when federal funds were a small portion of total program funding, states used

a single information system to meet their budgetary and management needs. On the other hand, when state funds were relatively small compared to federal contributions in programs such as LIHEAP, states collect data primarily to meet federal reporting requirements. As a result, LIHEAP data can be specifically associated with the block grant because the state funds were a small portion of total program funding. The exception to the reliance on integrated data systems when federal funds are small for the program area is the education block grant, for which states we visited had created separate data reporting systems.

State Involvement in Prior Grants

If state governments had been heavily involved in prior categorical programs, collecting national data on block grant programs tended to be easier because states had ongoing relationships with service providers and national associations, as well as established rules, regulations, and monitoring systems to oversee providers' performance. For example, under the ADMS block grant, when federal regulations were substantially reduced, states already had information systems that were uniform and that also met their needs. Even though state educational agencies administering over 40 former categorical programs already had information systems in place, the systems could not provide national data on all aspects of the education block grant because of the wide range of authorized allowable activities.

While the lack of previous state financial involvement could make national reporting more difficult at the outset of the block grant, the six states we visited were willing to support a national reporting format. For example, in the case of CSBG, states had little financial involvement in the program area before its enactment, but they followed a uniform reporting format.

Statutory Authority for States to Collect Data

The existence of statutory authority for states to collect data from their local governments increased the viability of the cooperative approach. Under the ADMS block grant, for example, when states required their localities to report individual client data, the localities reported such data. On the other hand, when states did not require local service providers to submit individual client data, some providers did not report such information. Two of the six states we visited did not require the submission of individual client data. As a result, these states had to estimate data to participate in the NASATWD survey.

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Under the education block grant, state educational agencies were encouraged to collect data from LEAs on the use of funds with a minimum of paperwork. As a result, some states did not require LEAs to report on the use of funds. In the six states we visited, however, the LEAs reported data to the state agencies, although five states told us that they were encouraged to reduce paperwork. While the states we visited did not have any difficulty obtaining data from their LEAs, the lack of clear statutory authority could hinder their efforts at the local level, thereby diminishing the viability of the cooperative approach. The Elementary and Secondary School Improvement Amendments of 1988 require LEAs to report annually to the state educational agency on the use of funds.

Conditions That Contribute to Increased Data Comparability

Data comparability was generally a problem for each of the four block grants because report formats and definitions vary across states. Limited data comparability is a consequence of any voluntary effort. However, there are several factors, primarily national leadership, that can improve data comparability. We identified six conditions that could increase comparability in the types of data states collect. For each of the four block grants, these conditions are shown in table 2.3.

Table 2.3: Prevalence of Conditions That Contribute to Increased Data Comparability

Condition	Block grant				Education
	AD ^a	MS ^b	LIMEAP	CSBG	
National leadership by either a federal agency or a national association	X	X	X	X	
States' recognition of need for block grant data	X		X	X	X
Federal funding to support national data collection	X		X	X	
Designated national level staff to work with state officials	X	X	X	X	
State officials' involvement in system design	X	X	X	X	X
Federal statutes to encourage cooperative data collection	X	X	X		X

X=Prevalence of condition for the block grant program.

^aNational data for the ACMS block grant are collected by two national associations: one for substance abuse (AD) and one for mental health services (MS). To more clearly convey our results, we treated each program area separately.

^bThe Elementary and Secondary School Improvement Amendments of 1988 now require the Secretary of Education to consult with state and local educational agency representatives to develop a model system that states and local agencies may use for data collection and reporting.

National Leadership

When a federal agency or national association provided leadership in developing a national data system for the four block grants we reviewed, states fully supported cooperative data collection efforts. For example, under both LIHEAP and the ADMS block grant, HHS was involved in developing formats for collecting data. HHS provided funds to the American Public Welfare Association (APWA) to develop a model format for states to use in reporting LIHEAP data. HHS also participated in annual NASADAD meetings to revise reporting forms to collect data on substance abuse for the ADMS block grant, but it has been careful not to be viewed as federally mandating the effort. NASMHPD provided national data on state mental health agency funding sources and expenditures for the same block grant without any HHS guidance. All 50 states as well as the U.S. territories fully supported these three cooperative efforts. Under CSBG, HHS provided a grant to the Center for Community Futures to conduct a national survey, parts of which have had high state participation.

In contrast, when the education block grant was created, little national leadership was provided by the Department of Education or a national association that represented state education officials. Now that states have their data collection systems in place, efforts to collect uniform data on educational activities, such as the number of students served and the use of funds to serve private school students, have been difficult to implement. Similarly, the lack of national leadership has hindered the collection of comparable state-level mental health client and services data under the ADMS block grant.

Recognized Need for Data

High state participation in the cooperative data collection efforts under each of the four block grants, according to national associations and state officials we visited, was a result of states' recognition of the political significance of cooperating with federal agencies and national associations to collect national data on block grant programs. This is evidenced by the states' willingness to make the necessary format changes to meet the national, voluntary data requests.

Federal Funding

While national leadership and states' recognition of the need for data played a significant role in developing national data systems, federal funding to support the data collection systems greatly enhanced the viability of the cooperative approach. For example, HHS funded the Center for Community Futures to collect data on CSBG, and did not specifically mandate the types of data to be collected. Nonetheless, the Center collected national data on the CSBG program beginning in 1984, and the

National Association of State Community Services Programs (NASCSF) began collecting CSBG data in 1988. In another instance, HHS funded NASADAD to collect national data on the substance abuse portion for the ADMS block grant.

When federal funding was not provided to help national associations defray the cost to collect and process data, the collection of national data has been slow. For example, HHS has not provided funding to a national association, such as NASMHPD, to collect state-level data on the mental health portion of the ADMS block grant, although HHS is working on a cooperative state effort to provide information on mental health clients, services, organizations, staffing, and fiscal indicators. Nor has the Department of Education set aside funds to specifically assist the state education officials in their cooperative data collection effort. As a result, the national data collection systems in these areas took longer to develop than did systems supported with federal funds.

National Staff

When a federal agency or national association provided national-level staff to work with state officials to collect and process national block grant data, implementation of the cooperative data collection was easier. For example, under CSBG and the ADMS block grant, national associations contributed staff time and expertise to help states develop uniform reporting formats. Under LHEAP the states followed a uniform format developed by a national association to report energy assistance data that HHS compiled to provide national data required by the Congress. HHS also helped states by mailing reporting forms and information on grantees' programs before its LHEAP voluntary telephone survey. There was no comparable support for the state education officials in preparing their fiscal year 1986 evaluations.

System Design

The involvement of state officials in the design and implementation of national data systems had a major influence on states' voluntary participation. For example, when LHEAP was enacted, a national association working in conjunction with the state governments developed a uniform reporting format to collect data on the program. Similarly, state officials were also involved in the design of national data systems for the ADMS block grant and CSBG. National associations attribute states' voluntary participation in their national surveys to states' involvement in designing these systems to use existing state data bases. The state education officials developed a uniform reporting format for the required state evaluations, which states are increasingly willing to follow.

Federal Statutes

Legislative requirements have encouraged federal agencies to work with states in developing national data systems. Under the ADMS block grant, for example, IHS was statutorily required in 1984 to work with appropriate national associations to design national data systems for the collection of substance abuse and mental health data. Consequently, IHS is working in cooperation with NASADAD to collect national data on substance abuse program activities, but as of July 1988, it had not entered into an agreement with national mental health associations to collect mental health data. IHS was also statutorily required in 1986 to develop a model state plan format for state use under LHEAP. Now states voluntarily use a uniform format designed by a national association with IHS guidance. In addition, the Elementary and Secondary School Improvement Amendments of 1988 require the Secretary of Education to work with state and LEA officials to develop a model system that states may use for data collection and reporting. There are no statutory requirements for IHS to work with states to develop a model format for the collection of CSWG data.

Conclusions

The collection of national block grant data through the cooperative approach was generally timely, was perceived by most state officials as less burdensome than reporting under former categorical programs, and was generally technically adequate for certain uses. We believe that the approach, if accompanied by national leadership, can be a viable way of (1) obtaining national block grant data on funding, services, and client characteristics to meet congressional and federal agency oversight needs, (2) providing states technical assistance, (3) facilitating the exchange of data among states, and (4) tracking national trends in funding and services provided.

However, limited data comparability is an adverse effect of this approach that reduces the usefulness of the data to serve other potential needs of federal policymakers requiring comparable data, such as allocating federal funds, determining the magnitude of needs among individual states, comparing program effectiveness among states, determining state compliance with federal laws and regulations, and comparing the cost per client served among states. The collection of comparable data to meet those needs would probably require mandatory federal data collection standards, which would result in additional costs and increased state and local administrative burdens. Even then, a federally mandated system may not provide fully comparable data. Where the cooperative approach can meet federal policymakers' data needs, however, we identified several program characteristics that influence the

viability of the approach and several conditions that contribute to increased data comparability while minimizing administrative burdens on state and local governments.

Matters for Congressional Consideration

In considering future block grant data needs, the Congress may want to encourage the federal agencies to use the cooperative approach to data collection in block grants where the primary data needs are for program oversight and tracking national trends in funding and services while minimizing the administrative burden on states. Since the Congress has statutorily required the cooperative approach for LIHEAP, education, and ADMS block grants, it should consider requiring the Secretary of HHS to develop a model for state data exchange in consultation with appropriate associations of state and local officials to facilitate uniform data collection under CSW.

The Congress should also consider providing seed money to encourage national leadership by helping federal agencies, national associations, and other organizations defray initial systems start-up costs and ongoing costs for the collection, processing, analysis, and publication of comparable block grant data across states.

Recommendations to the Secretary of HHS

We recommend that the Secretary of HHS work with national associations representing state officials to increase the comparability of data collected under the ADMS block grant by

- entering into an agreement with appropriate national mental health associations, such as NASMHPD, to collect annual state-level data on mental health activities and client characteristics;
- encouraging states to work with national associations, such as NASADAD and NASMHPD, to achieve greater comparability across state data systems in their use of standardized categories and definitions to collect data with respect to substance abuse and mental health activities; and
- participating in periodic efforts by the national associations to revise their data collection instruments.

We also recommend that the Secretary work with states to improve data comparability and increase the number of states reporting data on households receiving assistance to weatherize their homes under LIHEAP by

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- encouraging states to use the format developed by APWA to report LIHEAP data and
- encouraging more states to report LIHEAP weatherization assistance data

Further, we recommend that the Secretary work with states to increase data comparability and minimize burdens on state and local agencies under (SIC) by

- participating in cooperative efforts, such as with NASCSP, to ensure that data elements and categories provide information needed at the state levels and
- encouraging states to fully participate in the national survey

Recommendations to the Secretary of Education

We recommend that the Secretary of Education, when developing the cooperative data system recently required by the Congress, work with the state and local educational agencies to

- define specific data categories as part of the model format for the required state evaluations to facilitate uniform data collection and
- increase the timeliness of the required state evaluations

Agency Comments

HHS and the Department of Education concurred with our recommendations to increase the viability of the cooperative approach to obtaining national block grant data. HHS stated that it has adopted this approach for the six block grants for which it has responsibility. HHS also stated that voluntary systems, with national leadership, are the most effective and least wasteful way to ensure the relevancy and accuracy of the information collected. Education stated that it plans to develop the cooperative data system recently required by the Congress by working with state and local educational agencies.

While the Office of Management and Budget had some concerns about our scope and the timeliness of our data, it said that it did not object to our recommendations. It reiterated its support for the flexibility given to states in collecting data for block grant programs. However, it said it did not necessarily support federal seed money for initial systems start-up costs for the collection, processing, analysis, and publication of additional cooperative data collection systems in other programs. It stated that it would want to review funding proposals on a case-by-case basis.

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The Office of Management and Budget stated that it is proud of the flexibility given to the states in collecting data on block grant programs and strongly supports its continuation. However, unless additional funds are provided to support cooperative data collection activities, the timeliness and comparability of national block grant data may not improve. While states are increasingly willing to support cooperative data collection efforts, these efforts are primarily intended to produce data needed for congressional and federal agency oversight purposes. Therefore, it seems appropriate for the federal government to share the costs and help ensure that adequate oversight data are available to meet national policymaking responsibilities.

Appendix I

Agencies and Associations Included in Our Review

Federal Agencies

Department of Education

- Division of Educational Support

Department of Health and Human Services

- Alcohol, Drug Abuse and Mental Health Administration
- Family Support Administration

National Associations and Organizations

National Association of State Mental Health Program Directors

National Association of State Alcohol and Drug Abuse Directors

Center for Community Futures

National Association for State Community Services Programs

National Energy Assistance Directors Association

American Public Welfare Association

Council of Chief State School Officers

Chapter 2 Steering Committee (education block grant)

States

California

Maryland

Pennsylvania

Rhode Island

Texas

Virginia

State Agencies

- Departments of Alcohol, Drug Abuse, and Mental Health Services
- Offices of Energy Assistance
- Departments of Economic Opportunity
- Departments of Community Services
- Departments of Social Services
- Departments of Human Resources
- Departments of Community Affairs
- Departments of Education

Appendix II

Assessment of the Cooperative Approach Under the Alcohol, Drug Abuse, and Mental Health Services Block Grant

National data on the ADAMS block grant are collected by the National Association of State Alcohol and Drug Abuse Directors and the National Association of State Mental Health Program Directors on a voluntary basis. However, the substance abuse and mental health data are not limited to activities supported with block grant funds.

While national data on funding for substance abuse and mental health activities were available, differences in state data categories do not allow precise aggregation. Because states did not consistently use the data categories defined by the national associations, association reports contained estimated data or no responses for particular data categories. However, data were generally timely, and state officials perceived the cooperative efforts as less burdensome than federal reporting under prior categorical programs.

Program Characteristics

The ADAMS block grant consolidated 10 former categorical programs and allowed states increased flexibility in the funding and management of their alcohol, drug abuse, and mental health services. The block grant is one of several funding sources for state substance abuse and mental health services. ADAMS block grant funds are combined with state and private funds to support substance abuse and mental health programs for treatment and prevention. For fiscal year 1988, \$487 million was appropriated for the block grant. Federal block grant funds constituted about 16 percent of total spending in the substance abuse area and about 3 percent of spending for community mental health services in fiscal year 1986. Despite the fact that federal funds are relatively small compared to state and private contributions, states are willing to cooperate with federal officials to collect data, in part because of relationships established under the prior categorical programs.

The administration of the ADAMS block grant is not assigned to a single state agency. In five of the six states we visited, the programs were administered by two agencies— one for substance abuse and one for mental health. In the sixth state, it was administered by three agencies— alcohol abuse, drug abuse, and mental health.

The Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) is responsible for monitoring state compliance with the ADAMS block grant.

Since our review, however, Maryland's separate alcohol and drug abuse agencies have been merged into a single agency that administers all substance abuse programs. As of June 1988, only 4 of the 50 states— Arizona, New Jersey, New York, and Ohio— maintain separate alcohol and drug abuse agencies, and 2 of them, New York and Ohio, are considering merging the two agencies.

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legislation. ADAMHA uses required state reports as a basis for determining compliance. In addition, it conducts formal compliance reviews in several states each year. ADAMHA also coordinates the efforts of the three institutes—the National Institute on Drug Abuse, the National Institute on Alcohol Abuse and Alcoholism, and the National Institute of Mental Health (NIMH)—regarding block grant policy, technical assistance, and data collection issues.

Data Gathered Through Cooperative Efforts Supplement Required State Reports

ADAMHA relies heavily on required state reports as a source of information. While these reports do not contain common data elements or categories that would allow national comparisons across states, they provide summary information on individual state programs for substance abuse and mental health. As a result, to develop a national program perspective, ADAMHA uses data collected by national associations (NASADAD and NASMHPD) that are more comparable than those in the state reports. The NASADAD survey on substance abuse provides national data on funding sources, expenditures, clients, and services, but the NASMHPD survey on mental health provides data only on funding sources and expenditures.

ADAMHA annually obtains client, services, and expenditure data from states on substance abuse activities through a contract with NASADAD. Although NASADAD's survey provides data on all state substance abuse activities, not just those specifically supported with federal funds, the survey provides a perspective on how the block grant relates to the full range of state expenditures and services. Furthermore, these data are gathered using standard forms and definitions, thus allowing more cross-state comparisons.

In regard to mental health, ADAMHA supplements the data it collects through the reports required by the states and compliance reviews with a national inventory of mental health organizations prepared by NIMH and a revenues and expenditures survey conducted by NASMHPD. Both NASMHPD and NIMH data collection efforts are biennial and therefore not

¹State Resources and Services Related to Alcohol and Drug Abuse Problems (Fiscal Year 1986: An Analysis of State Alcohol and Drug Abuse Profile Data). National Association of State Alcohol and Drug Abuse Directors, Inc., July 1987, published in July.

²States submit data only on service providers of local health care that is partially supported by state funds.

³State Funding Profile: Funding Sources and Expenditures of State Mental Health Agencies (Revenue Expenditure Study Results, Fiscal Year 1987). National Association of State Mental Health Program Directors, July 1987.

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parallel to NASADAD's annual data collection effort. In addition, the states have been working on another cooperative effort with NIMH to implement the Mental Health Statistics Improvement Project, which establishes a minimum data set with standard definitions.

Although the 1984 amendments to the ADMS block grant legislation require HHS to develop, in consultation with a national organization, a model for the exchange of state data on mental health, as of July 1988, HHS had not provided the states with such a model for reporting mental health data. Thus, there are currently no state-level data being collected on mental health clients and services by any national association that are comparable to those of NASADAD in the substance abuse area.

However, NASMHPD does collect information on state mental health agency funding sources and expenditures, providing states standard forms and definitions to report the data. States voluntarily participate in this biennial survey. NIMH supported NASMHPD's 1981 and 1983 report preparation, but the report on fiscal year 1985 data was prepared without NIMH financial assistance. Although NASMHPD's data collection effort is no longer supported with NIMH funds, ADAMHA uses NASMHPD data as a source of comparable mental health financial information across states.

Assessment of the Cooperative Approach

Although data are collected through a combination of several efforts under the ADMS block grant, we assessed the cooperative state data collection efforts of NASADAD and NASMHPD, applying the timeliness, burden, and technical adequacy criteria for meeting federal oversight objectives. We found that the associations' efforts provided some national data on substance abuse and mental health activities, although data comparability is limited because definitions vary across states for some data categories.

Timeliness

The voluntary submissions of state data to both NASADAD and NASMHPD have been sufficiently timely. State program officials in the six states we visited submitted their data submissions to the two associations in time to be included into the final reports. None of the states told us that they had problems with submitting data on time since local units in all six states generally reported information according to required state time frames.

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For its annual report on substance data, NASADAD receives most of its state responses close to its December preliminary due date and encourages states that have not yet submitted data to respond. Usually during the spring, NASADAD issues a preliminary report and asks the states to verify the data provided. The six states we visited believe that NASADAD's due date was reasonable. Most data submissions from the six states occurred from November 1986 to March 1987 for the fiscal year 1986 NASADAD report. Although NASADAD submitted a draft of its report to ADAMHA in late spring, it did not issue its final report until all state responses were received. NASADAD's fiscal year 1986 report was published in July 1987.

Unlike NASADAD, NASMHPD has no reporting obligation to ADAMHA and therefore is not tied to a specific publication date. Final preparation of NASMHPD's fiscal year 1985 revenues and expenditures report began only after the association had received all 50 state responses. NASMHPD's fiscal year 1985 report was published in July 1987.

Burden

The NASADAD and NASMHPD data collection efforts provided national data without undue burden for states. State officials in the six states we visited generally do not perceive the cooperative approach as burdensome compared to federal reporting under prior categorical programs.

According to ADAMHA officials, when the ADMS block grant was first created, some states had difficulties in trying to report data to the national associations in the requested format because their data systems were designed to meet their own needs. However, both the national associations and the states we visited now believe that the current reporting is less burdensome than the federally mandated state reporting under categorical programs. According to NASADAD, states would not participate in its voluntary survey if it was burdensome. Participation by all the states is, to NASADAD, a clear indication that the survey presents little burden.

When NASADAD first began its survey, the association anticipated that it would be more burdensome for states than it proved to be. Substance abuse officials in four of the six states reviewed told us that the forms typically took little effort to complete, although NASADAD initially anticipated that it would take 1 to 2 weeks. In the other two states, agency officials viewed their efforts as burdensome.

On the other hand, the staff time spent on data collection, analysis, and presentation for the NASMHPD survey, according to the association, was

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extensive. NASMHPD also acknowledged that data submission for its survey is a lengthy, iterative process. State officials said that they often need to use several sources of information to complete NASMHPD tables and that conforming to the national associations' definitions can present a burden for states that have manual data systems or collect only summary client data from local units. State officials also said that inconsistency between NASMHPD and state reporting formats creates problems. Nevertheless, they prefer the current approach to federal reporting under the former categorical programs.

Technical Adequacy

Data are generally available and reported by states to provide a national overview of funding across states. Moreover, internal controls appeared to be generally adequate to ensure that data are reasonably accurate. However, the data did not allow precise aggregation.

Availability

Funding data requested by NASADAD and NASMHPD are generally collected by local agencies and service providers and reported to state agencies. Although all states submitted data to NASADAD and NASMHPD, many were not able to provide data in the requested format. Substance abuse data on clients, services, and funding are available annually to ATAMHHA. Mental health data on funding are also available, although they are published biennially. However, there are currently no state-level data on block grant mental health clients and services being collected nationally.

To increase the types of data requested by NASADAD and NASMHPD, state officials consult with these national associations to determine whether they can regroup state data to match the categories defined by the associations. Involving the states in the design of these surveys has also increased the consistency between national association data collection formats and those of the states. This has helped to increase the likelihood that all states could respond to their associations' data requests. In fact, all 50 states, the District of Columbia, American Samoa, Puerto Rico, and the Virgin Islands submitted data for NASADAD's 1986 report. In addition, 50 states, Puerto Rico, the District of Columbia, and the Virgin Islands submitted data for NASMHPD's 1985 revenues and expenditures report.

There was full state participation in the national association surveys because the types of data NASADAD and NASMHPD request are generally available from local service providers. States we visited generally experience little difficulty with local units reporting data according to

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state definitions and formats. Substance abuse agencies in two of the six states we visited believe they do not have clear state authority to require the submission of individual client data by local service providers. California does not require alcohol client information from its counties. As a result, only 17 of the 57 counties report such data. In Virginia, where voluntary state collection of client data for substance abuse and mental health programs was recently discontinued because of low local unit participation, state officials approximate percentages of clients served from summary data.

Both California and Virginia still participate in national surveys. The other four states require local units to report client data to the state agencies. The six states told us that local units report required financial information, the requirements for which are usually outlined in grant or contract arrangements between the states and local service providers.

Because of differences in state and national association definitions, some states cannot report data in the requested format. For example, in data submission to NASMHPD, states use the term "unallocatable" when they are unable to allocate expenditures or revenues according to specific service categories or client groups identified by NASMHPD. When states are unable to provide data to NASADAD using standard definitions or tables, states leave such categories blank or indicate that information is "not available." Many such responses appear in each association's tables. In NASADAD's fiscal year 1986 report, 11 of the association's 21 tables contained "not available" responses from at least eight states. In two NASADAD tables, 20 of the 54 respondents gave such a response in at least one category. Most NASMHPD tables contained a significant number of "unallocatable" responses. In one table, 38 of the 53 respondents gave such a response in at least one category.⁵

Comparability

Although the types of data that NASADAD and NASMHPD request are available at the state and local levels, data formats and definitions vary across states. Five of the six states we visited told us that their information systems are not entirely consistent with either NASADAD's or NASMHPD's data collection standards and formats. These states sometimes attempt to use their own definitions or disaggregate their data and then regroup them to match national association categories. As a result, national association data are not always comparable across states.

⁵The tables with the most "unallocatable" responses categorized state mental health agency expenditures according to age groups and types of service settings.

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Three of the six states we visited had difficulty in completing NASADAD's alcohol and drug client information tables because state definitions or groupings of summarized data differed from NASADAD's.⁴ In California, for example, alcohol services are grouped by the state into several environments of treatment approaches, such as residential detoxification and recovery services, nonresidential services, and prevention services. However, NASADAD requests that statistical data be reported in three environments: detoxification, rehabilitation/residential, and outpatient. Therefore, before submitting data, California must regroup them to match NASADAD's categories. Pennsylvania and Virginia also had difficulty in matching their states' data with NASADAD's definitions. Both states must regroup their data to fit into some of NASADAD's categories.

Because of state difficulties in matching the national associations' data categories, the associations include footnotes in their final reports that explain how a state's definitions or data collection procedures differ from NASMHPD's or NASADAD's. In NASMHPD's fiscal year 1985 expenditure data report, footnotes contained in a 14-page appendix explain differences in the 53 state and territorial data submissions. In NASADAD's report, there were a large number of footnotes in 3 of the 21 tables.

Accuracy

Internal control procedures at both associations and the six state agencies we visited appeared to be adequate to provide national data to meet congressional and federal agency oversight needs. NASADAD developed an intake checklist to ensure that data states report meet its minimum standards of completeness and quality. NASMHPD requests states to submit supporting documentation in order to verify state revenue and expenditure data. Both associations contact the state when either the data reported are insufficient or the associations have questions concerning the data. However, neither NASADAD nor NASMHPD visits states to verify or audit information collected through their voluntary data collection efforts.

The six states reported that they also had internal control procedures in place to verify local units' data. Maryland and Texas have formal internal control procedures that include (1) computerized validity checks of local reports, (2) data entry verification, (3) regular field visits by state monitoring units to verify samples of local records, and (4) audits of

⁴We have identified the six major categories in NASADAD's alcohol and drug client information tables to be the following: environment, type of care, age, sex, race, ethnic origin, and primary drug of abuse. States had no problems with providing data on the sex category.

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local financial reports. However, state internal control procedures are not always formalized. In Virginia, for example, state monitoring procedures consist primarily of comparing local service providers' actual figures with their previously projected figures. The six states we visited require their local units to provide reports, although California and Virginia do not require the collection of individual client data.

ADAMHA Plays a Limited Role in Cooperative Data Collection Efforts

Since the cooperative approach evolved under the ADMS block grant, ADAMHA has played a limited role in the design and implementation of national data systems. ADAMHA did not formally participate in the initial design of NASADAD's reporting form; the format was developed by the states, with the cooperation of the National Institutes on Drug Abuse and on Alcohol Abuse and Alcoholism. Although ADAMHA has since begun to participate in NASADAD meetings for annual revisions to the reporting forms, the agency has carefully limited its involvement, so as not to be interpreted as prescribing the format or content of this survey. In the mental health area, ADAMHA's involvement with NASMHPD's data collection effort ceased in 1985, but it uses NASMHPD data as its primary source of comparable financial data across states.

Neither the states nor the national associations we visited believe that the federal data collection role should be expanded. Moreover, states and national associations believe that such an effort would not be warranted or helpful to ADAMHA in meeting its block grant data needs. NASADAD views voluntary data collection, using such tools as its data collection instrument, as the best approach to track the use of ADMS block grant funds and therefore believes that a federally mandated system is unnecessary.

Furthermore, NASMHPD believes that a federally mandated system would not recognize the state data collection needs, thereby widening rather than narrowing differences between state and national level data collection objectives. Four of the six states we visited told us that they were satisfied with the current cooperative data collection approach and that a voluntary system is preferred, although several members of the Texas congressional delegation expressed concern about the use of voluntarily reported state-level data to allocate funds under the Anti-Drug Abuse

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Act of 1986 (a one-time emergency grant) Texas formally protested ADAMHA's use of the NASMAD data for this purpose.⁷

Conclusions

The collection of substance abuse and mental health data through cooperative efforts has reduced the burden on the states, when compared to federal reporting under prior categorical programs. Also, the data are generally available in a timely manner. However, the data are not comparable across all states.

Because of limited data comparability, the NASAD and NASMAD survey results should not be used for purposes other than obtaining national data on funding, services, and client characteristics to meet congressional and federal agency oversight needs. The range of uses for these data beyond oversight will remain limited unless ADAMHA becomes more actively involved in encouraging states to use the national associations' standardized categories and definitions.

⁷In early 1987, ADAMHA used NASAD's data, which account only for those patients served by "state" agencies, to allocate alcohol and drug treatment funds available under Public Law 99-570. Texas patients, for the most part, receive services from city and county clinics that are state-funded.

Assessment of the Cooperative Approach Under the Low-Income Home Energy Assistance Program

States are required to provide data on services provided and client characteristics through grant applications and their year-end reports. The American Public Welfare Association has developed a standard format that states voluntarily use when they prepare their required year-end program reports. This format has increased data comparability across states. In addition, states voluntarily provide data through telephone surveys conducted by HHS and grantee profiles prepared for HHS by APWA.

Together, these reports provide a national picture of states' estimates of obligations, oil overcharge funds, clients served, and types of energy assistance activities for congressional and federal agency oversight. The data are timely and reasonably comparable across states. In addition, states reported that they had adequate internal control procedures to ensure that the data are reasonably accurate. Furthermore, federal data collection activities for LIHEAP are not perceived as a significant burden by the states we visited when compared to federal reporting under the former categorical program for low-income energy assistance.

Program Characteristics

Energy assistance for low-income individuals is primarily a federal activity funded through LIHEAP, which redesigned the former categorical program. State and other funds, including oil overcharges, make up a small but increasing proportion of total program funding. Administered by the Family Support Administration (FSA) within HHS, the scope of LIHEAP activities is relatively narrow in that the block grant funds four possible activities: heating, cooling, crisis intervention, and weatherization.

Federal funding for LIHEAP has decreased since fiscal year 1986. For fiscal year 1988, LIHEAP was appropriated about \$1.5 billion. As of March 1988, only two states appropriated their own funds for the program area, totaling about \$17 million—about 1 percent of the federal contribution. In the six states we visited, only Maryland provided funding amounting to \$111,000 for the program. Most state cash assistance agencies set aside LIHEAP weatherization funds for other state agencies that administer Department of Energy weatherization programs.

The six states we visited used state agencies, local government agencies, nonprofit organizations, or some combination of the three to provide LIHEAP services. Each of the six states requires data reporting as a condition for subgrants. Moreover, in four of the six states, local funding awards depend on local agencies' reporting data to the state agency.

States Voluntarily Submit LIHEAP Data to FSA

FSA collects specific state data through three mechanisms: (1) grant applications, (2) semiannual telephone surveys, and (3) year-end reports. In an attempt to provide a national picture of LIHEAP activities, FSA uses data collected through these efforts. In addition, FSA contracts with the Bureau of the Census and the Department of Energy to collect uniform national and regional data on home energy assistance.

Required Reports

Grantees, including states, territories, and Indian tribes are required to apply annually to HHS for their LIHEAP grants. The annual applications give HHS officials general information on grantees' use of funds, describe the eligibility requirements, and describe weatherization programs provided. In the early years, state applications varied greatly in form and content mainly because HHS chose not to prescribe how these applications should be structured. However, the 1986 legislation reauthorizing LIHEAP required the Secretary of HHS to develop a model plan, which grantees may use in preparing their applications. The LIHEAP model plan has since been developed by FSA, and some states began using it to prepare their fiscal year 1988 applications.

The program report that grantees are required to submit is a one-page summary of the number of households receiving assistance under each of the four LIHEAP activities, the income level of those households, and the number of households served with handicapped and elderly residents. As with the application, HHS chose not to specify a format for states to use when preparing program reports. However, when the block grant was established, APWA, in conjunction with National Governors' Association and HHS, developed a consistent format for the program reports. Although the states' use of the form in the preparation of their reports is voluntary, HHS does encourage grantees to use the APWA form. About 90 percent of the states do so.

Voluntary Telephone Surveys

FSA supplements its grant applications and the year-end reports with data from a contract with APWA and a voluntary telephone survey. In 1983, HHS funded APWA to develop a national data collection project called the Voluntary Information System for Energy Assistance. In fiscal year 1987, APWA received a 1-year contract to profile information from the grantees' applications and to verify information reported. During fiscal year 1988, FSA awarded a contract to continue the profiling of grantees' applications that APWA started in 1987.

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 Under the Low Income Home Energy
 Assistance Program

FSA relies heavily on fiscal information collected directly from LIHEAP grantees through its voluntary telephone surveys conducted in winter and summer of each year. HHS mails survey forms about a month before the telephone contact to allow them time to prepare their information. The telephone surveys have served as a way of providing fiscal and caseload estimates to the Senate Committee on Appropriations. Information from the 1984 telephone surveys was used to support the request for a supplemental appropriation.

**Contracted National
 Household Surveys**

FSA also uses surveys conducted by the Bureau of the Census (Current Population Survey) and the Department of Energy (Residential Energy Consumption Survey) in preparing its annual report to the Congress. FSA contracts with these agencies to collect data related to home energy assistance. Information collected through these surveys allows FSA to conduct greater analysis of program activities. The Census Bureau's Current Population Survey uses standard definitions, such as total household income, rather than relying on each state's definition of household income. FSA officials believe that data collected nationally through state program reports can be useful in assessing the overall programmatic effects of LIHEAP when the information is combined with the results of Census' Current Population Survey and the residential energy consumption survey.

**Assessment of the
 Cooperative Approach**

We assessed the states' efforts to provide data to FSA on LIHEAP using a voluntary reporting format to meet federal oversight objectives. We found that these efforts provide national data on energy assistance activities in a timely manner for federal agency oversight and budgeting purposes. State officials believe that the reporting requirements present a minimal burden. Although state data estimates through the telephone surveys cause FSA officials some concern in making cross-state comparisons, the internal control procedures in place appear to sufficient to ensure data accuracy.

Timeliness

FSA gives state agencies about 1 month after instructions and forms are mailed to prepare for the voluntary telephone surveys. The 1986 telephone surveys and year-end reports were all completed and submitted in time to be incorporated in HHS's fiscal year 1986 report to Congress. The six states we visited told us that their local units generally reported data in time to be included in their year-end reports.

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 Assistance Program

Generally, timeliness is not a problem for the year-end reports except for a few local agencies in Pennsylvania that handle the state's cash assistance program. The Pennsylvania state agency responsible for administering LIHEAP also had some difficulty obtaining weatherization data estimates from other state agencies. The other five states said that they had no problems with the time frames.

Burden

LIHEAP data collection efforts are minimally burdensome to states. The six states we visited had few problems in using the voluntary reporting format developed by APWA because their data systems were based initially on federal requirements. Thus, data can be extracted from state management information systems to meet federal reporting requirements. The six states said that the costs of national reporting were minimal, usually amounting to less than one staff-day for each of the telephone survey and the year-end report.

Of the four LIHEAP data collection activities, some state agency officials said the telephone survey requires additional effort because the data for the mid-year survey may not be as readily available as are estimates for the year-end survey and combining weatherization with the cash benefit part of the program can be difficult. However, FSA officials believe that the estimates collected through the telephone surveys are readily available since the states are being asked to provide estimates that they use for their own management. Therefore, FSA believes that the telephone survey is a minimal administrative burden on states.

Technical Adequacy

We found that the data collected nationally for LIHEAP are sufficiently uniform across states to meet statutory reporting requirements, develop national trends, and promote state information exchange. While the data do not allow precise aggregation because report definitions vary across states, these voluntary efforts still provide a general overview of the program.

Availability

All 50 states and the District of Columbia participated in the 1986 telephone surveys and provided year-end reports in time to be incorporated in HHS's 1986 report to the Congress. Furthermore, the six states said that all local units reported client and financial data.

Overall, data are generally available for states to report to HHS. However, weatherization data are not always readily accessible to state cash

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assistance agencies because some of these agencies set aside a portion of their funds for other state agencies that administer the Department of Energy's weatherization programs. Some state cash assistance officials had difficulty obtaining data on the use of these funds. As a result, their reports to FSA did not always include data on income levels and the number of households with elderly and handicapped persons receiving weatherization assistance.

Comparability

Although the work performed by APWA in designing a form for preparing of the year-end program reports helped to standardize the reports, some differences in state formats and definitions exist. For example, Maryland defines income in terms of groupings that are different from those requested in the year-end report. Furthermore, according to FSA, most states reported elderly recipients as persons over 60, while a few states defined elderly as persons over 55. These differences are a result of differing eligibility definitions for program recipients receiving fuel assistance in these states.

Accuracy

FSA reported that it had internal control procedures to ensure that the data collected from states are sufficiently comparable and reasonably accurate. FSA staff review applications and year-end reports for completeness, and later for compliance with statutes. FSA does not, however, verify household counts. State program officials we visited said that they have adequate internal control procedures over their program data, because of their benefit eligibility concerns.

While internal control procedures appear to exist at the federal and state agency levels, the information on state expenditures and obligations is based on state estimates. These estimates can hinder data comparability and accuracy when aggregating data across states. Therefore, any national totals presented in HHS's reports to the Congress that are aggregated from program reports and telephone surveys have a number of footnotes explaining differences in state definitions. As a result, using certain data collected through the LIHEAP cooperative efforts for purposes other than meeting statutory reporting requirements, developing national trends, or promoting state information exchange may not be appropriate.

States Disagree Over Need for More Federal Definition

FSA officials strongly feel that a federally defined and mandated LIHEAP data collection system is not necessary because the existing data system provides reasonably uniform, quality data. Furthermore, FSA officials believe that a mandated LIHEAP data collection system would be contrary to the block grant philosophy of giving states managerial flexibility to administer their programs. Three of the states we visited believe that federal mandates would not improve data collection for LIHEAP. Yet, Maryland and Virginia believe that such standards could improve the program, while Pennsylvania believes that the LIHEAP system is already federally defined.

Conclusions

We generally agree with FSA's assessment that the LIHEAP cooperative data collection efforts provide data to meet its reporting requirements to the Congress in a timely manner without burdening states with excessive reporting requirements. While the LIHEAP cooperative efforts increased the comparability of data, there is incomplete reporting of weatherization data.

We also believe that because the statutes identify specific types of data that must be collected, states are more willing to use a uniform format to report such data to FSA. Furthermore, the fact that LIHEAP supports distinct program activities made it easier for states to collect the types of data needed at the federal level. More significantly, however, LIHEAP data collection efforts were enhanced by legislation requiring the Secretary of HHS to develop a model state plan format for state use.

Assessment of the Cooperative Approach Under the Community Services Block Grant

Under a grant from HHS, the Center for Community Futures conducted a national survey of CSBG-supported activities in which the National Association for State Community Services Programs encouraged states to voluntarily participate to provide an overview of the CSBG program. Although a few states did not participate, this data collection effort consistently had high state participation: that is, at least 46 states completed some parts of the survey since 1983, despite the perception that the effort required substantial additional work for the states we visited. The result has been an annual report each year providing national statistics on the numbers of clients, types of CSBG-supported activities, and additional revenues generated by the program that are otherwise unavailable.

While this cooperative effort improved the availability and comparability of data, preparation of the long form required a significant effort. This burden could be reduced by requesting only minimum data needed by states and local community action agencies to increase state participation and completion of more parts of the long form. In addition, some states were slow in submitting their responses, and others could do more to provide data on all parts of the survey. As a result, a complete picture of CSBG activities was not available.

Program Characteristics

The purposes of CSBG are broad and diffuse, reducing poverty and assisting low-income residents in gaining self-sufficiency. These objectives were authorized under the eight categorical programs consolidated into the block grant and were incorporated into the program with little change. CSBG funds support a variety of direct services, such as education, employment, housing, nutrition, income management, and emergency assistance.

States had little involvement in administering community services programs before the creation of the block grant because the federal government directly funded local community action agencies. With the advent of the block grant, states were given responsibility for the program and authority over local service providers.

Like LIHEAP, the CSBG program is primarily supported with federal rather than state funds. CSBG is also administered by ESA, within HHS. In 1986, 13 states supplemented \$320.6 million in federal CSBG funds with \$15 million in state funds. Of the states we visited, Rhode Island has provided fairly constant state funding of about \$250,000 for community services, while Maryland contributed \$205,000 for the first time in

1986. For fiscal year 1988, \$382 million in federal funds was appropriated for the program.

In addition to CSBG funds, local service providers receive substantial funding from other federal programs, the private sector, and state and local governments. The federal programs primarily include Head Start, community development, and weatherization.

States Cooperate to Prepare Voluntary National Reports With Federal Support

Since their assumption of administrative responsibilities under CSBG, states have actively participated in a cooperative national data collection effort undertaken by NASCSP and the National Governors' Association and subsequently administered by the Center for Community Futures, which has received an average of \$200,000 annually in federal funds for this purpose. The states provided data to the Center on clients served, activities funded, revenue sources, and expenditures under CSBG.¹

Although state participation in the Center's effort was voluntary, about 95 percent of the states have provided information for at least some parts of the survey since 1983. The state participation and the consistency of the data categories from year to year make it possible to identify trends in program services and expenditures.

Federal funds were provided to the Center in 1982 by the outgoing Community Services Administration to assist the states in the transition from the categorical programs to the block grant and from federal to state management. Since states lacked experience with administering the earlier programs, the Center's grant was designed to provide training and technical assistance to state CSBG staff and to create an information exchange among states. As a necessary first step, the Center surveyed states to obtain information on staffing, location, resources, and needs of state agencies involved in CSBG administration.

When IHS assumed responsibility for CSBG in 1982, it extended the Center's grant for training and technical assistance. IHS collaborated with the National Governors' Association and NASCSP in setting up state information systems that laid the foundation for the current national CSBG survey. The total national effort cost \$440,000 in 1984, according to information provided by the Center.

¹ IHS currently has a contract with NASCSP to collect national data on CSBG.

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Although changes are made annually to the survey based on the advice of NASCSI's data committee, the core of the survey remained essentially the same up to fiscal year 1988, when NASCSI began to conduct the survey. It collects statistical data on (1) CSBG funds available to states, (2) states' distribution of these funds, (3) other funding available to local service providers, (4) numbers and types of local service providers, (5) state agency administration, (6) expenditure of CSBG funds for each activity identified in the legislation, and (7) numbers of clients served in each activity. These seven activity categories are called the "short" form. The states have the option of using the short form or the "long" form, which consists of 88 subcategories. For fiscal year 1986, 31 states completed the long form. In addition to statistical data, a section of the survey requested narrative highlights of major management and programmatic accomplishments or outcomes.

Assessment of the Cooperative Approach

Although the cooperative approach to data collection for CSBG had a high state participation rate, state officials perceive the effort as burdensome. The comprehensiveness of the long form required a significant effort for both state and local officials. As a result, fewer states provided data requested on the long form. Differences in state definitions resulted in limited data comparability. Despite these differences, internal control procedures at the national level appeared to be sufficient.

Timeliness

Some states were slow in submitting their responses for the national survey. The 1986 national survey was mailed to states in December 1986, with a return due date of March 31, 1987. Only 13 states submitted their survey forms by the due date. Another 15 reports were received by April 30, and another 18 by September 30, thus leaving 4 reports outstanding 6 months after the due date.

None of the responses from the five states we visited was received by the due date, although Rhode Island's was received in April. Pennsylvania asked for a 3-month extension, which it met. Texas was received within 2 months, and California and Maryland responses were received within 3 months of the due date.

In Virginia, CSBG was not included as part of this review because the program records were unavailable at the time we performed our work. Therefore, we reviewed only five states under CSBG, although six states were covered for the other three block grants (ADMS, LIHEAP, and education).

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Although the Center's report was due to FSA in October 1987, its fiscal year 1986 report was published in November 1987. Forty-six states, the District of Columbia, and Puerto Rico submitted data for the Center's fiscal year 1986 report.

Delays in state responses are due, in part, to the national survey requirement that states report on 100 percent of their local service providers, rather than a sample or estimate. Consequently, states delayed their responses until they had received all local submissions. Maryland and Pennsylvania pointed out that responses of local service providers are slow in some cases because their priority is on providing services rather than statistics. These two states also said that differences between program years for financial and programmatic data, as well as changes in state personnel and data systems, slow down their survey responses.

Burden

The five states we visited felt that the preparation of the long form, which requested detailed information, required substantial work beyond that required to maintain existing state data bases. Four of the five states completed the short form and attempted to quantify the time spent to complete the form. These states estimated that it took 1 to 2 weeks of state agency staff time. Rhode Island, the only state we visited that completed the long form, estimated that it took about 12 weeks. States had difficulty filling out the national survey because their sub-state data systems are often not modeled after the national survey. However, several states were revising their data collection forms to conform to the national survey.

In 1987, three of the states we visited changed their data systems in order to obtain data needed for the Center survey. Pennsylvania made an incremental change, adding a new one-page report to those already required of local service providers. Maryland and Texas made major changes to incorporate the national service categories and definitions. These states emphasized that the process of changing data systems is particularly burdensome. Before the changes, these states did not respond to certain parts of the national survey. Despite the perceptions that the survey represented a significant burden, four of the five states we visited pointed out that they continued to participate primarily to provide information to the Congress.

Technical Adequacy

Although the types of data requested to complete the Center's short survey form (40 states) were generally available, the number of states (32 states) completing at least some parts of the long form indicated that client and program data collected by local service providers are more difficult for states to obtain than fiscal and management data. Despite the set of standardized definitions and forms provided by the Center, the comparability of data (long form) was limited because state definitions did not always conform to those of the Center. However, the Center had internal control procedures in place that appeared to promote data accuracy.

Availability

States have the statutory and contract authority necessary to obtain local data, although all states did not participate in the Center survey. The states we visited may withhold or deny funding if local service providers fail to provide required reports. They also require local service providers to submit annual applications, as well as quarterly program and fiscal reports. Local service providers submit applications on standardized state forms following definitions provided.

From the outset, the national survey has had very high overall response rates, with at least 46 states completing some parts of the survey. Following the piloting of the survey in 1983, 47 states responded in 1984, 47 in 1985, and 46 in 1986. Of the states that participated in the 1986 national survey, only 39 completed the long form. Of these, seven states provided only partial data. Of the five states we visited, only Rhode Island completed the long form of the 1986 survey. Until all states participate in the survey and more states complete all of the long form, a national picture of the program will not be complete.

The states' responses on separate sections of the survey varied, with high response rates for the six major sections focusing on state administration and numbers and types of local service providers. For fiscal year 1986, all participating states responded to these sections. These data are generated directly by states as part of their management function.

Fewer states provided complete responses for other sections of the survey that requested programmatic data on the expenditure of CSBG funds and number of clients served by type of program activity. These data are maintained and reported by local service providers. For fiscal year 1986, about 74 percent of participating states responded to this section.

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Comparability

The Center's set of standardized forms and definitions increased the comparability of CSBG data. The survey consisted primarily of closed-ended questions requiring numerical responses. The 31-page questionnaire was accompanied by a 29-page glossary defining CSBG services and a 15-page set of instructions for completing each data category. Although the services and clients supported by CSBG are quite diverse, the extensive instructions and definitions made it difficult for states and local service providers to describe them in uniform terms.

For example, client numbers requested are unduplicated counts of individuals. The instructions recognized that some states gather data on households, or service units, rather than on individuals, but recommended that these data be converted to client numbers. Where this was not possible, the survey offered six codes to identify numbers that represent unduplicated or duplicated individuals, households, or service units. Duplicate counts may occur when clients are enrolled simultaneously or sequentially in more than one service activity.

Accuracy

The Center reported that it had adequate internal control procedures to ensure that data were reasonably accurate. First, Center staff devoted considerable time to training and assisting states in making decisions about the specific category to which data should be entered. For example, states can obtain direct assistance by calling a telephone hotline located at the Center. This service is designed to improve the comparability of the national data and assist states in developing their own information systems. Second, a glossary and list of potential services are distributed along with the national survey to assist states in entering data into similar categories. Finally, because the Center recognized that reporting funds before the end of a program year required some estimating, survey instructions provided a methodology for such estimation.

States also reported that they had internal control procedures to ensure that local service providers enter data accurately onto the state and national forms. These activities include (1) providing written instructions, (2) seeking clarification from local service providers on specific items, and (3) responding to telephone inquiries. Pennsylvania augments these actions with scheduled training sessions for groups of service providers. Three states we visited indicated that they had made improvements in internal controls over data collection and reporting since the inception of the block grant.

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Continued Federal Support Sought

States have sought, through the Center and NASCSP, federal support for their cooperative effort, and ISA has been responsive. Since the inception of the block grant, HHS has provided annual average funding of \$200,000 to support the preparation of the national survey and compilation of the responses. States, through NASCSP, were involved in the survey design. Federal funding, combined with state support, enabled professional staff at the Center to analyze data across states and prepare the national report.

The annual statistical report generated by the national survey gives the Congress essential information on how states use CSBG funds. However, increasing earmarks of federal appropriations have severely limited the amount of federal ISA administrative funds that are available for the national survey from year to year.

Conclusions

The Center's national survey increased the availability and comparability of CSBG data despite difficulties inherent in the program, such as diffuse program objectives. However, the preparation of the long form required a significant effort. This burden could be reduced by requesting only minimum data that are needed by the states and the local community action agencies. In addition, some states were slow in submitting responses by the due date, and a few states did not participate in the national survey. Until all states participate in the CSBG national survey and more states complete all parts of the survey that request detailed information, a complete national picture of CSBG activities will not be available on a timely basis.

The key element contributing to increased national data on CSBG activities was the availability of national-level staff, federal financial support, and the states' involvement in designing the survey. This initial investment has paid off in consistently high state participation for at least some parts of the national survey and a willingness by the states to model their data systems after the national system, despite the burden. This increase in national data may also be attributed to the value the states place on accountability to the Congress and the importance of program information and statistics in maintaining continued support.

Assessment of the Cooperative Approach Under the Education Block Grant

Cooperative efforts to collect basic national data on the education block grant are achieving results, despite difficulties inherent in the extensive local autonomy granted by the program, the large number of participating school districts, and the breadth of allowable activities authorized by law. Concerned that the Congress needs basic program data to justify continued federal support, state program officials have taken the initiative to issue their own guidance for the uniform preparation of state evaluation reports required by law. Sixty-three percent of state submissions followed the format in fiscal year 1986, the most recent year for which submission information was available.

While the states' initiative has improved the availability and comparability of basic program data, the data were generally not timely. Also, the data varied in their technical adequacy, in part because of the lack of specific standard categories for reporting. However, most state officials we spoke with believe that the preparation of a single evaluation report covering over 40 former categorical programs has simplified paperwork procedures and reduced administrative burdens.

State officials are increasingly willing to follow a uniform reporting format because of the recognized need for national data on the education block grant. Yet the Department of Education did not compile and summarize data from fiscal year 1986 individual state reports to provide a national overview, beyond a brief summary contained in its annual evaluation report to the Congress to minimize its role in administering the program. Furthermore, state officials have not been able to obtain Education's support in developing a cooperative data collection system or secure federal funding to support preparation of a national report because the Department wants to limit its role in program administration. The Elementary and Secondary School Improvement Amendments of 1988, however, require the Secretary of Education to submit a report annually to the Congress on the use of education block grant funds and a report summarizing the required state evaluations in 1992.

Program Characteristics

States, rather than the federal government, are primarily responsible for administering the education block grant, which consolidated over 40 former categorical programs into a single block grant. The block grant is to be used to support a broad range of educational activities: for example, to promote basic skills in reading, mathematics, and communications; to support teacher training, guidance counseling, and equipment purchases; and to target funds to specific students and curriculum enrichment activities.

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For fiscal year 1988, \$508 million was appropriated for the program. States must distribute at least 80 percent of the block grant funds to local educational agencies; the other 20 percent may be reserved for state use in supporting state and local programs. While the states are required to develop an equitable formula for distributing the 80-percent share of federal funds, the LEAs are granted total discretion, subject to the requirements of the legislation, over how they choose to use their share of funds. The six states we visited told us that they also have increased administrative and financial responsibility for the program, but no statutory authority to influence LEAs' decisions on the use of funds.

To receive funds, states must submit applications to the Secretary of Education at least every 3 years indicating how they plan to allocate the state share among authorized activities. Similarly, LEAs must submit applications to states indicating their plans. To meet federal reporting requirements, states must obtain necessary information from LEAs with a minimum of paperwork and administrative burden.

Agency Relies on Special Studies for a Program Overview

Since the passage of the education block, the Congress has been interested in how states and LEAs have exercised their new responsibilities and what changes in education have occurred. As a result, Education has received congressional requests for national data on such issues as the use of the state share, the state allocation formulas for distribution of the LEA share, and the LEA share for specific activities.

Education has two strategies to respond to requests for national data. Its primary strategy consists of contracting with research firms to conduct special studies on specific block grant issues, based on samples of states. The largest of these studies was a \$1 million project on the use of LEA funds for the 1984-85 school year, which was undertaken by SRI International in 1983 and published in January 1986. A secondary strategy has been to obtain data from all states through their required triennial applications and annual evaluations, although the states were not required to submit the evaluations to Education.

Education officials view the two strategies as complementary, with advantages and disadvantages to both. Special studies can address specific issues of current interest, while minimizing state and local costs and administrative burden by using a sample of states. However, the studies require separate federal outlays, do not identify national trends

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over time since data are generally collected on a specific school year, and generalizations may not represent the full universe.

Information from the required state reports minimizes Education's costs, identifies trends, and would represent the universe if all states submitted reports containing comparable data in a timely manner. However, Education officials expressed concerns about the adequacy of the data obtained. For example, a major difficulty has been the variety of formats, categories, and definitions used by states, which has hindered attempts to provide a national picture of the education block grant.

States Develop Uniform Reporting Format for Required Evaluations

State officials have taken the initiative to develop a cooperative, uniform reporting format for the required state evaluations, but the process has been slow, and the format has lacked federal support. According to state officials, early requests for technical assistance to develop a format were denied by the Department of Education because it believed that it lacked statutory authority to become involved in developing the form or content of required state evaluations.

At the 1984 national conference of state education block grant officials, state officials responsible for preparing the evaluations established a work group, which, at a later meeting, developed an outline of data categories to be used for the evaluations, which was circulated for comment. In November 1985, the work group distributed the final version to all state education officials and clearly indicated that use of the outline was optional.

The outline provides a uniform reporting format for the data most states collect. It requests basic program data on dollars spent and services provided but leaves the inclusion of numbers served to the discretion of individual states. It also seeks program outcome data in statistical or narrative form. In addition to program data on the state and local shares, the outline gives states an opportunity to highlight local block grant projects in narrative form and to identify educational changes and benefits derived from the block grant.

Assessment of the Cooperative Approach

States' efforts to develop an outline have increased the comparability of data, but the data were generally not timely and not available from all states to provide a complete picture of the education block grant. Despite these problems, the single evaluation report reduced burden on

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state and local educational agencies compared to those required for the former categorical programs.

Timeliness

States' voluntary participation in the cooperative data collection effort was generally not timely. The states were slow in meeting the date requested by Education, although two states we visited told us that they had adequate time to prepare the evaluations. Because data are not sufficiently timely, information on all state programs are not available when Education prepares its brief summary for the annual evaluation report. While Education informally requests the states to submit copies of the evaluations to it, states were not statutorily required to submit them to Education until the passage of the Elementary and Secondary School Improvement Amendments of 1988.

The existing legislation did, however, require that states make the evaluations available to the public. As a public entity, Education first requested copies of the fiscal year 1984 evaluations by January 31, 1985. Education requests states to continue to provide copies of their evaluations each year by January 31. States that do not submit their evaluations by the requested date are contacted by Education to provide them.

Our review of fiscal year 1986 state evaluations submitted to Education showed that only 10 evaluations were received by the January 31, 1987, request date (7 months after the close of the program year for most states). Another 31 evaluations were received by October 1987, and another 5 by April 1988, thus leaving 4 evaluations outstanding—15 months after the request date.

Department of Education officials told us that the fiscal year 1986 timetable is representative of other years, and that the bulk of submissions typically arrive at the Department during late spring and early summer in the year after the funds were spent. Fiscal year 1985 state evaluations were summarized by Education during this peak submission period. However, as data from special studies have become available, the agency's timetable for summarizing data from the state evaluations has slowed.

Burden

The states' cooperative data collection effort was generally less burdensome than reporting under the former categorical programs. Most state officials we visited believe that a single evaluation report covering over

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40 former categorical programs simplifies paperwork procedures and reduces the burden. While most of the state officials described the preparation of the evaluation report as a significant effort, they prefer the cooperative approach to reporting under the categorical programs.

State officials indicated that a single state application and evaluation now suffice, where multiple applications, reports, and evaluations were required under the categorical programs. Three states we visited told us that the education block grant data collection is less burdensome than former categorical programs, and two others said that it is less burdensome than other current federal education programs, such as Chapter 1 of the Education Consolidation and Improvement Act.

Despite the reduced federal requirements, five of the six states characterized data collection and reporting under the education block grant as a significant effort. Both California and Texas estimated that the total costs of preparing the required annual evaluation exceeded \$35,000. Other state program officials estimated state costs in terms of the time spent by staff in data collection, analysis, and report preparation. For example, this process takes 35 percent of the time of one state evaluation specialist in Rhode Island and 33 percent of the time of two evaluation staff members in Pennsylvania.

States generally have not made significant changes in their data collection systems to accommodate the cooperative reporting format for evaluations. Three of the states we visited told us that their data collection systems yielded the necessary information without major changes. Pennsylvania assisted in the design of the uniform reporting format, using its existing state data collection system as a model, thus easing its burden of accommodation. California, on the other hand, does not use the cooperative reporting format, because state officials believe that collecting data on all the national categories would significantly increase its administrative burden.

Virginia state education officials told us that they were more flexible and willing to work toward a national reporting format at the outset of the program before they developed and put in place their own systems to meet the federal reporting requirements. Once in place, though, they expressed some reluctance to make changes.

Technical Adequacy

Full state participation has not yet been achieved, although states are increasingly willing to voluntarily submit data to Education. The states

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we visited require LEAs to use standard categories for reporting data to the state agency, but the lack of standard categories for preparing annual evaluation reports resulted in a wide variation of data that were not comparable at the national level. However, individual states generally had internal control procedures to ensure that the data reported by the LEAs were reasonably accurate.

Availability

The state evaluation reports generally provide basic programmatic data on the LEA share of dollars used for educational activities and student participation in the program. Financial data in the evaluation reports could provide a national picture of the use of education block grant funds by LEAs. However, until all states submit their evaluations, a national picture of the program will not be complete.

Comparability

The states' voluntary use of the outline improved the comparability of basic program data, but many states have not adopted the national reporting format. Nonetheless, use of the outline has increased from 27 percent for fiscal year 1985 to 63 percent for fiscal year 1986 submissions. Because of states' increased willingness to follow the outline in preparing their evaluation reports, financial data could be compiled for those states.

The outline is organized around the allowable uses of education block grant funds that are specified by law. Since grant applications must indicate how funds will be distributed among programs within these allowable uses, most states already collect these data.

The outline, however, does not include standard definitions of terms; instead, activities are defined by reference to federal laws and regulations governing the former categorical programs. The national outline does not define state administrative activities either. However, this lack of guidance is of less significance given that these activities are to be described rather than quantified.

Numbers of students or staff served with local education block grant funds are not requested in the outline because of definitional difficulties. Most states do report these data. However, there is a high likelihood of double-counting where the same students are served by more than one activity. Also, there are possible inconsistencies in identifying students that used instructional resources, such as library books and computers. The policy of one state we visited, for example, is to count

total school enrollment, unless the resource is used by an identifiable group of students.

Accuracy

States we visited reported that they had internal control procedures in place to ensure that data reported by LEAs were consistent and reasonably accurate. They require applications from LEAs on state forms using standard state definitions of educational activities expenditure categories. Before approval, these applications are reviewed by state staff for completeness and internal consistency. For example, Maryland and Pennsylvania enter data into computers that are programmed to conduct error checks.

The states we visited require LEAs to submit annual evaluations using state forms. Most of these forms are tailored to individual projects and consist of a few open-ended questions calling for a narrative response. Five of the six states also require separate quarterly or annual financial reports; all require audits. In addition, five states conduct periodic monitoring visits to LEAs at which time several federal- and state-funded activities are reviewed.

Despite the fact that the education block grant funds represent less than 1 percent of total spending for education programs, the states we visited told us that they did not commingle federal and state funds, and they required LEAs to keep separate records of education block grant expenditures.

States Seek Agency Support for Cooperative Effort

Although state program officials we spoke with are generally satisfied with the cooperative approach to data collection and reporting under the education block grant, they are aware of the problems of timeliness and lack of voluntary use of the national format by all states. They believe that the Department of Education's support may encourage more states to use the national format and that a streamlined evaluation format would reduce the burden on states and LEAs.

Education has attempted to minimize federal involvement in administering the education block grant as well as the states' reporting burden by limiting requirements to those specified in law. As a result, no data requirements, report formats, or standardized definitions beyond those in the education block grant legislation have been imposed through federal regulation. Program guidelines are provided as advisory and nonregulatory guidance and have tended to paraphrase the law. State

officials we visited said Education has not obliged their requests for assistance in developing state and national evaluation formats because Education officials believe they lack clear statutory authority to prescribe the form and content of the state evaluations. Requests for federal funding of a national voluntary effort have also been denied to minimize federal involvement.

Education views its major function under the education block grant as that of assuring state compliance with federal law. Since the law identifies the procedures states must follow in preparing their evaluation reports, rather than the content of these reports, Education's review focuses on evidence that the required procedures have been followed.

Conclusions

The states' initiative to develop a uniform reporting format has improved the availability and comparability of data across states, resulting in an expanded overview of how the education block grant funds are spent and what education activities are being supported. For the fiscal year 1986 evaluations, more than two-thirds of the states voluntarily followed a uniform reporting format. While states' voluntary participation is increasing, timeliness and comparability of data remain a problem. While states are making positive efforts, the lack of national leadership in encouraging states to use a uniform reporting format has slowed the potential of the cooperative effort.

The Congress has recently passed legislation to require the Secretary of Education to (1) work with state and LEA officials to develop a model system that states may use for data collection and reporting; (2) submit annually a report to the Congress on the use of funds, the types of services provided, and the students served; and (3) submit a report to the Congress summarizing the results of the evaluations in 1992. This legislation should increase the availability of basic national data on the education block grant, such as local use of funds and state allocation formulas for the distribution of federal funds.

Appendix VI

Comments From the Department of Health and Human Services



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

Washington, D.C. 20201

SEP 26 1999

Mr. Lawrence H. Thompson
 Assistant Comptroller General
 U.S. General Accounting Office
 Washington, D.C. 20548

Dear Mr. Thompson:

Enclosed are the Department's comments on your draft report, "Block Grants: Federal and State Cooperation in the Development of National Data Collection Strategies." The enclosed comments represent the tentative position of the Department and are subject to reevaluation when the final version of this report is received.

The Department appreciates the opportunity to comment on this draft report before its publication.

Sincerely yours,

Richard P. Kusserow
 Inspector General

Enclosure

COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES
ON THE GENERAL ACCOUNTING OFFICE (GAO) DRAFT REPORT,
"BLOCK GRANTS: FEDERAL AND STATE COOPERATION IN THE
DEVELOPMENT OF NATIONAL DATA COLLECTION STRATEGIES,"
REPORT NO. B-217560, AUGUST, 1988

General comments

We agree with the draft report summary that a cooperative, voluntary approach to data collection is a viable way for Federal policy makers to obtain national block grant data for program oversight purposes. The Department has adopted this approach for the six block grants for which we have responsibility. Voluntary systems, with national leadership, are the most effective and least wasteful way to ensure the relevancy and accuracy of the information collected. Although mandatory systems have superficial appeal, experience demonstrates they quickly lose both relevance and reliability.

GAO Recommendation

We recommend that the Secretary of HHS work with national associations representing state officials to increase the comparability of data collected under the ADMS block grant by:

1. Entering into an agreement with appropriate national mental health associations, such as NASMHPD, to collect annual State-level data on mental health activities and client characteristics.

Department Comment

The Department, through the Alcohol, Drug Abuse, and Mental Health Administration, has been working with the National Association of State Mental Health Program Directors to enhance state-level data, including those pertaining to client characteristics. We will continue these efforts.

GAO Recommendation

2. Encouraging states to work with national associations, such as NASADAD and NASMHPD, to achieve greater comparability across state data systems in their use of standardized categories and definitions to collect data with respect to substance abuse and mental health activities.

Department Comment

We concur. The Department is attempting to help states achieve greater data comparability. ADAMHA is working with national associations to help establish data subcommittees to address

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and Human Services

uniformity and consistency in reporting formats and definitions. We contribute to this effort through financial support of state staff participation and by convening state work groups.

GAO Recommendation

3. Participating in periodic efforts by the national associations to revise their data collection instruments.

Department Comment

We concur. The Department, acting through ADAMHA, will continue to participate in the efforts of the states and their national associations to improve the data collection instruments.

GAO Recommendation

We also recommend that the Secretary work with states to improve data comparability and increase the number of states reporting data on households receiving assistance to weatherize their homes under LIHEAP by--

--encouraging states to use the format developed by AFWA to report LIHEAP data, and

--encouraging more states to report LIHEAP weatherization assistance data.

Department Comment

We concur and are pursuing these objectives by working with weatherization components in states, with the National Energy Assistance Directors, and with the Department of Energy's Weatherization program officials. We have sponsored joint conferences with DOE and will continue these efforts.

GAO Recommendation

We recommend that the Secretary work with states to increase data comparability and minimize burdens on state and local agencies under CSBG by

--participating in cooperative efforts, such as with NASCSP, to ensure that data elements and categories provide information needed at the state levels, and

--encouraging states to fully participate in the national survey.

Department Comment

We agree and are doing so through our grant to the NASCSP.

Comments From the Department of Education



UNITED STATES DEPARTMENT OF EDUCATION
OFFICE OF THE ASSISTANT SECRETARY
FOR ELEMENTARY AND SECONDARY EDUCATION

SEP 19 1988

Mr. Lawrence H. Thompson
Assistant Comptroller General
United States General Accounting Office
Washington, D.C. 20548

Dear Mr. Thompson:

The Secretary has asked that I respond to your request for our comments on your draft report.

The Department of Education concurs with the recommendations addressed to the Secretary of Education in the draft report on Federal and State cooperation in the collection of national block grant data.

The Secretary of Education plans to develop the cooperative data system recently required by Congress by working with State and local educational agencies (SEAs) and (LEAs). The Chapter 2 Steering Committee composed of SEA coordinators of Chapter 2 activities, will be the vehicle used to coordinate this effort. The composition of the Committee is representative of the SEAs in the Nation.

In order to facilitate uniform data collection, the Office of Elementary and Secondary Education will define specific data categories as elements of the model format for the required State evaluations. In addition, the steering committee will work cooperatively to develop a system to increase the timeliness of the required State evaluations as well as a format for a national report based on the results of these State evaluations.

We expect that these activities will be completed by October 1, 1989 to ensure that data are gathered in accordance with program needs as soon as the activities are implemented.

Enclosed are pages with specific comments. Thank you for the opportunity to comment. I and members of my staff are prepared to respond, if you or your representatives have any questions.

Sincerely,

Beryl Dorsett
Assistant Secretary

Enclosures

400 MARYLAND AVE SW WASHINGTON DC 20202

Appendix VIII

Comments From the Office of Management and Budget



EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, DC 20503

SEP 16

Mr. Lawrence H. Thompson
Assistant Comptroller General
General Accounting Office
Washington, DC 20548

Dear Mr. Thompson:

Thank you for requesting our comments on GAO's draft report entitled "Block Grants: Federal and State Cooperation in the Development of National Data Collection Strategies" (HRD-88-60 Block Grant Data Collection). We are proud of the flexibility given to States in collecting data on block grant programs and we strongly support its continuation.

Basically, we do not object to the report's recommendations, but we do not necessarily support Federal "seed money" for "initial systems start-up costs and ongoing costs for the collection, processing, analysis, and publication" for additional cooperative data collections. We would want to review on a case-by-case any funding proposals.

As for problems with the report itself, we worry that the findings may no longer be fully accurate since the data were collected in 1986-7 and came only from six States which were "judgmentally" versus randomly selected. The report states that "Our findings are not intended to be projected to the other block grants. Likewise, the results from our sample of six States should not be viewed as representative of experiences in other States." With time, we suspect that, with minimum Federal interference, States will not only improve in all aspects of their administration of block grants but also improve in their cooperation with each other to achieve nationally comparable data.

Sincerely,

Jimmie D. Brown
Jimmie D. Brown
Chief, Financial Systems and
Policy Branch

PEDIATRIC AIDS

HEALTH AND SOCIAL SERVICE NEEDS OF INFANTS AND CHILDREN

GAO

United States
General Accounting Office
Washington, D.C. 20548

Human Resources Division

B-236379

May 5, 1989

The Honorable Lloyd Bentsen
Chairman, Committee on Finance
United States Senate

Dear Mr. Chairman:

Acquired immunodeficiency syndrome (AIDS) is rapidly becoming a major health threat to children. It is now the ninth leading cause of death among children 1 to 4 years old; within the next 3 to 4 years it could be among the top five leading causes of childhood death.¹ The Department of Health and Human Services (HHS) predicts that this epidemic among children will continue to spread to as yet unaffected communities.

In response to this growing problem, you asked us in December 1988, to provide information on services available to children infected with the human immunodeficiency virus (HIV), which causes AIDS. Pursuant to our March 9, 1989, briefing you specifically asked us to report on (1) whether children and adults are affected differently by HIV infection, (2) the health and social service needs of HIV-infected children, (3) how selected cities have responded to the service needs of these children, and (4) certain federal programs available to address these needs.

Background

As of February 28, 1989, the Centers for Disease Control (CDC) had identified 1,440 AIDS cases among children under 13 years old.² Of these children, 800 have died. Nearly 76 percent of the pediatric AIDS cases have been black and Hispanic. Appendix I provides a current profile of pediatric AIDS in the United States.

The Public Health Service predicts that by 1991, as many as 20,000 children will become HIV-infected and 3,000 will have contracted AIDS. In April 1987, the Surgeon General of the United States reported that as many as 2,000 more children may have symptoms of HIV infection, yet not fit specific AIDS diagnostic criteria. Moreover, for each reported case of pediatric AIDS, HHS officials estimate that 2 to 10 times more HIV-infected children may not manifest overt symptoms of the disease.

¹Final Report of the Secretary's Work Group on Pediatric HIV Infection and Disease, Department of Health and Human Services, Nov. 18, 1988.

²This estimate understates the pediatric AIDS problem because of underreporting and because the CDC surveillance definition for AIDS does not include all children with HIV infection.

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Objectives, Scope, and Methodology

As agreed in discussions with your staff, we surveyed the status of health and social services for HIV-infected children in five communities: New York, New York; Newark, New Jersey; Los Angeles, California; Houston, Texas; and Cleveland, Ohio. We selected these cities to reflect differences in geographic location and pediatric caseloads. The distribution of AIDS cases in these five cities is shown in table 1.

Table 1: Cumulative Number of Pediatric AIDS Cases in Selected Cities (As of February 28, 1989)

Metropolitan area of residence	Number of pediatric AIDS cases	Percent of total pediatric AIDS
New York	391	27.2
Newark	85	5.9
Los Angeles	48	3.3
Houston	24	1.7
Cleveland	5	0.3
Total	553	38.4

Source: Centers for Disease Control, HIV/AIDS Surveillance Report, March 1989.

For these cities, we conducted telephone interviews about local services for HIV-infected children with state and local health departments, foster care agencies, Medicaid offices, and community-based health and child care providers. We also discussed federal programs that serve HIV-infected children and their families with HHS officials, including representatives of the Health Resources and Services Administration (HRSA), the Health Care Financing Administration (HCFA), and CDC. Finally, we reviewed the literature on pediatric AIDS (see bibliography).

Although we did not obtain written agency comments on this report, we verified specific sections with key state and local government officials and community-based providers for completeness and accuracy. We conducted our review between January and April 1989 in accordance with generally accepted government auditing standards.

HIV Infection Differs in Children

The HIV virus causes AIDS by damaging the human immune system. However, virus transmission, diagnosis, manifestation, and treatment differ between adults and children.

Mothers Transmit the Virus to Their Children

Adults are infected primarily through sexual contact or intravenous drug use; in contrast, nearly 80 percent of children with AIDS acquired the virus from their infected mothers. The vast majority of these women

contracted the disease through intravenous drug use or sexual contact with HIV-infected partners. Epidemiological evidence suggests that an infected mother transmits the virus to her infant either across the placenta during pregnancy or through blood contact during delivery. Recent data also indicate that HIV can be transmitted after birth by ingesting infected breast milk.

The majority of the remaining pediatric AIDS cases (about 18 percent of all cases) acquired the virus through transfusion of contaminated blood or blood products. (About one-third of these children are hemophiliacs.) However, the screening of donated blood for HIV antibodies since March 1985, and the heat treatment of blood plasma products to kill the virus have virtually eliminated this mode of HIV transmission. The route of transmission for the remaining cases is undetermined.

Diagnosis in Children Is Difficult

Unlike adults, the presence of HIV antibodies in newborns does not always indicate that the child is actually infected with HIV. During pregnancy, HIV-infected women transmit their own HIV antibodies to their unborn babies. During this time, they may also transmit the virus to the fetus. For as long as 15 months after birth, infants can test positive for antibodies, although they may not be HIV-infected. Between 20 to 60 percent of those infants are actually infected with the virus and at risk of eventually contracting the disease.

Recent studies show that some children without HIV antibodies may carry the virus. Therefore, laboratory tests to detect the virus as well as antibodies may be needed to diagnose HIV infection in children.

Clinical Manifestations Differ in Children

In 1987, CDC revised its surveillance definition to highlight clinical and diagnostic differences between adult and pediatric AIDS. Unlike adults, children with AIDS can develop lymphoid interstitial pneumonitis (a form of lung inflammation), but rarely develop Kaposi's sarcoma (an invasive skin cancer). Moreover, many infected children are low birth weight babies and fail to grow according to norms for their chronological age. Over half of the infected children have central nervous system deficiencies, resulting in developmental delays and neurological abnormalities.

The typical life span for children with AIDS ranges from 12 to 18 months, but may be longer. Survival times are shorter for infants and longer for children who are infected later in life. The life span of children who

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acquired AIDS before or at birth does not appear to differ significantly, however, from the life span of children with transfusion-acquired AIDS.

Treatment for Children Lags Behind Adults

Clinical specialists acknowledge that drug therapy research for HIV-infected children has lagged behind that for adults due to cultural and ethical concerns. Moreover, in certain states HIV-infected children who are wards of the state may be barred from participating in clinical trials because of legal restrictions.

The National Institutes of Health is expanding its pediatric clinical trials (see app. II) to develop treatment therapies for various infections associated with HIV infection. Current therapies have been shown to reduce the incidence of infections likely to affect HIV-infected children.

HIV-Infected Children Need Many Health and Social Services

Children with HIV infection experience a wide range of illnesses requiring different levels of care. Specifically, in acute stages, these children need inpatient hospital care, often in intensive care units. When symptoms subside, these children can be cared for in the home, with varying levels of medical support and social services.

The literature we reviewed showed that most HIV-infected children are born to families who are already facing poverty, drug abuse, parental HIV infection, and educational problems. As a result, their complex social and medical needs strain the resources and energies of families and of health and social services systems. Without home-based care, foster care, and support services, these children are at risk of extended and costly hospital care, most of which is provided by public hospitals and paid for by the Medicaid program.

Home-Based Care

Health experts agree that, whenever possible, health services for HIV-infected children should be delivered at home to promote maternal bonding and to provide adequate environmental stimulation for the child's development. Because the HIV-infected child requires considerably more specialized in-home medical care than a normal healthy child, parents and caretakers need special training.³

³CDC recommends that parents and caretakers should follow infection control measures, such as hand washing and the use of gloves, when the potential exists for exposure to the infected child's blood and other bodily fluids.

In many instances, the child's medical needs require the help of home health care nurses. These specialists can provide medical monitoring, oxygen, supplemental nutrition, intravenous drug therapy, and intravenous nutrition. In addition, home health aides can help parents with the child's daily care and homemakers with managing the household.

Foster Care Families and Group Homes

When the parents or relatives of HIV-infected children are unable or unwilling to care for such children, health care experts believe that foster care families or group homes are better alternatives than inpatient hospital care. Foster care for these children may be difficult to find, however, because the foster care systems in some communities are already overburdened.

Some studies indicate that foster parents may be less willing to take these children into their homes because of the psychological stress or the stigma that caring for an AIDS child brings with it; at the same time, they may not be able to obtain respite care that they occasionally need to ease these burdens. Other studies cite the foster care parents' fear of infection as a major constraint in recruiting foster care families.

Foster families need to be aware of the HIV antibody status of children to provide appropriate health care. In 1985, CDC recommended that adoption and foster care agencies consider screening children who are at increased risk of HIV infection as part of their routine medical evaluations before placing the child in a foster or adoptive home. CDC specifically advised close medical monitoring for HIV-infected children because they are more susceptible to frequent infections and may react adversely to childhood immunizations.

Human services agencies can identify high-risk children to determine the need for HIV screening. However, these agencies must also deal with the need for confidentiality of test results. Furthermore, they may be liable for either breaching confidentiality of test results or failing to inform foster families about potential exposure to HIV. The cities in our review follow their state's screening policy. Only New Jersey routinely tests all high-risk foster care children. The other four states require HIV screening of high-risk children only when it is medically indicated.

When natural or foster families are not available, small group homes providing congregate care for HIV-infected children are considered to be a more appropriate setting than inpatient hospital care. Group homes hire staff or recruit volunteers to care for foster children. By law, they

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serve no more than 25 children. These homes can be temporary residences for children waiting to return to their parents or awaiting foster care placement.

Group homes can also be used as permanent placements to provide higher levels of care, including intermediate or hospice care, for HIV-infected children. Health experts agree that intermediate care facilities are appropriate for HIV-infected children who need subacute medical services, such as oxygen, catheterization, or physical rehabilitation. Also, hospice care provides pain relief to the terminally ill child with AIDS and supportive services to both the child and family.

Support Services

Families with an HIV-infected child also require social support, such as transportation to health services and legal guidance to arrange for custody in the event of the parent's death. In addition, specialized day care programs for HIV-infected children who cannot be integrated into regular day care can provide medical, social, and educational supervision of the child and respite care for their parents. Parents, siblings, and relatives of AIDS children may also need extensive mental health and psychosocial counseling services to cope with terminal illness in the family. This counseling may concern the illness of the child and other family members. Often, the diagnosis of a child's HIV infection is the first indication that the mother, and possibly the father and siblings, are infected.

Cities' Response to the Needs of HIV-Infected Children

Health and social services providers in our review have established certain community-based services to prevent unnecessary hospital care for HIV-infected children. Despite their efforts, some services in these cities are limited or nonexistent. Communities who face large pediatric AIDS cases may have to expand their health and social service systems.

Home-Based Care

Providers in all cities reported that home health care for HIV-infected children and their families was available, but more was needed. Providers in New York and Los Angeles also told us that they believe that home health providers were not adequately trained and skilled to care for these children.

Foster Care Families and Group Homes

Los Angeles, Houston, and Cleveland do not have large numbers of HIV-infected children in foster care. However, providers in Los Angeles and Houston report that they will need more foster families and group homes in the future. On the other hand, New York and Newark currently face a shortage of foster families willing to care for HIV-infected children. These two cities use strategies to improve recruiting of foster care families that include contracting with private child placement agencies and setting higher reimbursement rates for HIV-infected children.

New York City's child welfare agency (the New York City Human Resources Administration) contracts with private agencies to recruit foster care parents. Two private agencies, Leake and Watts Children's Home and Project Hope of the New York Foundling Hospital, specialize in locating homes for HIV-infected children. According to the clinical director at Mount Sinai Medical Center in New York City, the city's active recruitment of foster homes for HIV-infected children has reduced the number of babies unnecessarily hospitalized.

As incentives to recruit foster families to care for HIV-infected children, New York and New Jersey have set high foster care rates for such children. New York pays \$1,177 per month for foster care for an HIV-infected child, compared to \$355 to \$483 per month for care of a non-HIV-infected child. In New Jersey, the enhanced rate for HIV-infected children is \$950 to \$1,200 per month, depending on the stage of illness, compared to \$266 per month for non-HIV-infected children. Although Texas, California, and Ohio do not have specific rates for these children, they have set higher maintenance rates for all foster care children who have been determined to have special needs. These include HIV-infected children.

Four cities in our review—New York, Newark, Houston, and Cleveland—provide transitional or permanent group homes for HIV-infected children. The AIDS Resource Foundation established St. Clare's Home near Newark as a transitional group home for a maximum of five HIV-infected children. The Hale House for Infants, Inc., is a group home in New York City that serves seven HIV-infected children in addition to drug-dependent children. In Los Angeles, a group home for HIV-infected children has been incorporated, but has not yet obtained initial funding to become operational.

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Providers in New York, Newark, and Houston identified the need for more permanent homes for HIV-infected children who require extra medical attention. The Children's Center operated by Herbert G. Birch Community Services, Inc., is a permanent group home offering comprehensive residential services, including medical surveillance for HIV-infected developmentally disabled children in New York City. The Children's Home in Houston provides hospice care and the Collette Marie Infant Home in Avon, Ohio cares for terminally ill children with AIDS.

Support Services

Providers in New York, Los Angeles, Houston, and Newark told us of the need for more mental health and counseling services or social support groups for families who care for HIV-infected children. In addition, providers in all cities noted that transportation to and from physician offices is needed. Providers in Los Angeles and Newark stated that legal support for HIV-infected children is also needed.

Therapeutic day care centers with respite care for parents at the Bronx Municipal Hospital Center in New York City served 25 HIV-infected children and Babyland Nursery, Inc., in Newark served 10 such children. Despite these specialized day care facilities for HIV-infected children, providers in these two cities reported the need for more day care. In addition, providers in New York, Los Angeles, Cleveland, and Newark reported that respite care was an unmet need.

Federal Programs Available to Address the Service Needs of HIV-Infected Children

Certain federal programs are available to fund health and social services for HIV-infected children and their families. The objective of two of these programs—the Medicaid Home and Community-Based Waiver and the HRSA Pediatric AIDS Demonstrations—is to allow these children to continue to live in the community in a more cost-effective setting.

Medicaid Home and Community-Based Waiver

Section 2176 of the Omnibus Budget Reconciliation Act of 1981 established what are referred to as home and community-based waivers. These waivers, designed by the state and submitted to HCFA for approval, expand Medicaid eligibility and the range of allowable services.

HCFA granted waivers to New Jersey, California, and Ohio to provide targeted health care and related services—such as case management, home care, and nursing—to persons with AIDS or AIDS-related complex

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(ARC), which can also be debilitating or fatal. Texas submitted a waiver application in 1988, which HCFA rejected because all program requirements were not met. The state is planning to resubmit its waiver application in June 1989. Of the cities in our review, only Newark was affected because New Jersey had implemented its waiver and as of December 1988 was providing targeted services to 31 HIV-infected children under 5 years old and children with AIDS or ARC of any age in Essex County (Newark).

The Medicare Catastrophic Coverage Act of 1988 added a new Medicaid Home and Community-Based Services Waiver authority under section 1915(e) of the Social Security Act. Under this provision, states could use these new waivers to provide services for children who are HIV-infected or drug-dependent at birth. The waiver program targets children under 5 years old who are or will be placed in foster or adoptive homes. According to an HCFA official, no state has yet applied for this waiver.

Pediatric AIDS Health Care Demonstrations

To improve coordination between services, HRSA funded Pediatric AIDS Health Care Demonstration projects for children, youth, and women of childbearing age who are HIV-infected or at risk. These projects support comprehensive ambulatory and community-based services for HIV-infected children to minimize health care costs.

In fiscal year 1988, the program awarded 13 grants for about \$4.8 million. Organizations in three of the cities we reviewed—New York, Newark, and Los Angeles—received funding from these grants. HRSA expected to spend about \$7.8 million in fiscal year 1989, and requested another \$7.9 million to fund these projects for fiscal year 1990.

Title IV-E Foster Care Maintenance

Title IV-E of the Social Security Act authorizes funds for foster care of children who are eligible for Aid to Families With Dependent Children. Under this title, the federal government provides matching funds to the states for both the maintenance and administrative costs of foster care. All cities we reviewed used title IV-E funds to pay a higher reimbursement rate for foster children with special needs, including HIV-infection. In addition, New York State supports foster group homes with title IV-E funds.

**CDC AIDS Information
Clearinghouse**

CDC's National AIDS Information Clearinghouse, established in 1987, is developing data bases of available resource organizations and materials and is already responding to professional inquiries. According to a CDC official, the clearinghouse is expanding its data bases on AIDS and the demand for clearinghouse services to assist localities in developing information networks is overwhelming.

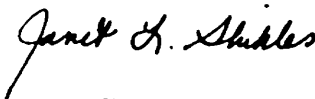
Summary

Most HIV-infected children are from low-income and disadvantaged families who have limited access to adequate health care services. As a result, these children and their families rely on public health and social services systems. In some communities, these systems are already overburdened. Consequently, these children are at risk of long and costly hospital stays that tend to reduce the overall quality of life compared to a home environment.

In communities we reviewed, foster care, home health care, and support services have been developed or expanded to help reduce the time HIV-infected children spend in the hospital and the resultant health care costs. All communities reported, however, inadequate current capacity to meet the demand for certain services, such as day care, group homes that provide intermediate level care, respite care, mental health counseling, and transportation. Some federal support is available to fund these services.

As agreed with your office, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days after its issue date. At that time, we will send copies to interested parties and make copies available to others on request. A list of major contributors is in appendix III.

Sincerely yours,



Janet L. Shikles
Director of National and
Public Health Issues

Contents

Abbreviations

AIDS	acquired immunodeficiency syndrome
ARC	AIDS-related complex
AZT	azidothymidine
CDC	Centers for Disease Control
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HIV	human immunodeficiency virus
HRSA	Health Resources and Services Administration
IVIG	intravenous gamma globulin
NCI	National Cancer Institute
NIH	National Institutes of Health
NIH	National Institute of Allergy and Infectious Diseases
NICH	National Institute of Child Health and Human Development
NIH	National Institutes of Health

Appendix I

Number and Characteristics of Pediatric AIDS in the United States (As of February 28, 1989)

Transmission categories	Cases	Percent	Race	Cases	Percent
Perinatal	1,126	78.2	White	339	23.5
Blood transfusion (including hemophilia)	261	18.1	Black	759	52.7
Undetermined	53	3.7	Hispanic	330	22.9
			Other/Unknown	12	0.8
Cumulative Total	1,440			1,440	

Note: Percentages may not add to 100 percent due to rounding.

Source: Centers for Disease Control, HIV/AIDS Surveillance Report, March 1989.

National Institutes of Health AIDS Pediatric Clinical Trials

As of April 14, 1989, three institutes at the National Institutes of Health (NIH)—the National Institute of Allergy and Infectious Diseases (NIAID), the National Cancer Institute (NCI), and the National Institute of Child Health and Human Development (NICHD)—have treated over 500 pediatric patients in protocols designed to test the efficacy of drug treatments for HIV infection. Five more protocols are currently under development at NIH.

The drugs under study or about to be studied, alone or in various combinations, are

- azidothymidine (AZT),
- dideoxycytidine (ddC),
- dideoxyinosine (ddI),
- soluble CD4,
- immune system stimulator Human Macrophage Colony Stimulating Factor (rH-GM-CSF), and
- intravenous gamma globulin (IVIG).

The Office of AIDS Research at NIH provided information on the protocols underway as of April 14, 1989. Specifically, NIAID protocols include

- phase I evaluation of AZT in children with AIDS or ARC,
- a multicenter trial to evaluate oral AZT in the treatment of children with symptomatic HIV infection,
- clinical trial of the efficacy of IVIG in the treatment of symptomatic children infected with HIV,¹
- a multicenter phase I trial to evaluate the safety and pharmacokinetics of intravenous and oral AZT in infants with perinatal HIV exposure, and
- a double-blind placebo controlled trial to evaluate IVIG in children with symptomatic HIV infection receiving AZT.

The NCI protocols include

- evaluation of AZT by intravenous infusion of delivery in children with symptomatic HIV infection;
- evaluation of AZT by Bolus infusion and/or intravenous infusion;
- phase I evaluation of ddC;
- phase II evaluation of oral AZT;
- evaluation of continuous intravenous infusion AZT administered together with rH-GM-CSF to overcome bone marrow suppression;

¹This protocol is sponsored by NICHD.

Appendix II
National Institutes of Health AIDS Pediatric
Clinical Trials

- phase I evaluation of ddI in children with symptomatic HIV infection;
- evaluation of alternating AZT and ddC in children with HIV infection;
- randomized clinical trial comparing continuous intravenous infusion of AZT to oral sustained release as oral intermittent therapy; and
- evaluation of recombinant soluble CD4 for children with symptomatic HIV infection, including newborns and pregnant women.

Table II.1 shows the locations of the AIDS pediatric clinical trials units.

Table II.1: NIAID AIDS Pediatric Clinical
Trials Units

Trials Unit	City
University of California at San Diego Medical Center	San Diego, CA
University of California at San Francisco	San Francisco, CA
University of California/ L A Center for Health Sciences	Los Angeles, CA
University of Miami School of Medicine	Miami, FL
Children's Memorial Medical Center	Chicago, IL
The Johns Hopkins University	Baltimore, MD
Children's Hospital Corporation	Boston, MA
Boston City Hospital	Boston, MA
New Jersey Medical School	Newark, NJ
Bellevue Hospital Center	New York, NY
Mount Sinai School of Medicine	New York, NY
The Presbyterian Hospital/ Columbia Presbyterian Medical Center	New York, NY
Baylor College of Medicine	Houston, TX

Source: National Institutes of Health, Office of AIDS Research, April 1989

Appendix III

Major Contributors to This Report

**Human Resources
Division,
Washington, D.C.**

Janet L. Shikles, Director of National and Public Health Issues,
(202) 276-5461
Cynthia Bascetta, Assignment Manager

Boston Regional Office

Donald B. Hunter, Regional Management Representative
Teruni Rosengren, Evaluator-in-Charge
Anne Thomas, Evaluator
Susan W. Cooper, Evaluator
Tracey G. Westbrook, Evaluator

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HEALTH CARE

HOME CARE EXPERIENCES OF FAMILIES WITH CHRONICALLY ILL CHILDREN

GAO

United States
General Accounting Office
Washington, D.C. 20548

Human Resources Division

B-231228

June 20, 1989

The Honorable Lloyd Bentsen
Chairman, Committee on Finance
United States Senate

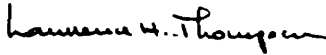
Dear Mr. Chairman:

In response to your request, we are submitting this report on home health care for chronically ill children. We reviewed the experiences of families with such children in obtaining necessary medical and support services in the home.

Copies of the report will be sent to the Department of Health and Human Services and to others.

This report was prepared under the direction of J. William Gadsby, Director, Intergovernmental and Management Issues. Other major contributors are listed in appendix VII.

Sincerely yours,



Lawrence H. Thompson
Assistant Comptroller General

Executive Summary

Purpose

From 10 to 15 percent of all U. S. children have a chronic health condition, health researchers estimate, and about 1 million of these have a severe form of the condition. Historically, children with severe chronic conditions remained in hospitals for treatment. However, advances in medical technology have moved much of the treatment to the home. The Senate Finance Committee asked GAO to review the experiences of parents with chronically ill children in obtaining necessary medical and support services in the home.

Background

In general terms, a chronic illness is a condition that lasts for a substantial period of time and has continuing and often debilitating effects. Some conditions are rare, while others are common; some illnesses are life-long, but a number can be corrected during childhood. Years ago, children born with certain of these conditions would not survive, but medical advances over the past 25 years have reversed that situation. Today, the majority of chronically ill children survive into adulthood.

While some changes in service delivery and financing have supported the home care concept, families still reported difficulties in obtaining needed services. To identify the factors that have hindered or eased service delivery in the home care setting, GAO surveyed parents of children who had the more severe forms of one of 10 selected medical conditions. (See p. 9.) In a major study, these conditions were considered representative of the various chronic illnesses for which parents have difficulty in obtaining home care.

Working in 11 states and the District of Columbia, GAO (1) contacted 14 hospitals that cared primarily for children, (2) surveyed 892 parents whose children were discharged from these hospitals concerning their experiences and spoke with 96 of the parents to obtain more detailed information, and (3) queried 60 service providers and organizations in the local service areas of 9 hospitals about service availability. (See pp. 9-10.)

This work gave GAO broad perspectives on the problems parents experienced in obtaining care for chronically ill children. These perspectives became the basis for examining systemic barriers to obtaining community-based care and recommending solutions for overcoming the problems. GAO did not develop potential solutions in the financing area because these were being explored by the requestor through other efforts.

Results in Brief

The majority of families had no difficulty obtaining medical services, but most said they had difficulty obtaining needed support services. In all but a few instances, the medical services were obtained, while in many cases support services were not.

Parents told us that three factors commonly accounted for their difficulties. Lacking were financing because of health insurance coverage limitations, information on services available, and a focal point to contact when help was needed with home care. Parents who did not have difficulty reported that information was available and/or outside help was provided that made it easier for them to obtain services.

The positive experiences reported by some parents suggest means by which access to needed services might be improved. Among possible improvements are (1) consolidating information on existing services and making it available to all organizations serving chronically ill children, (2) providing this information to parents during the hospital discharge planning process, and (3) referring parents who need help in the home care setting to organizations providing case management services (help in getting information and coordinating care).

GAO's Analysis

Need for Services Varies

Nearly all (98 percent) of the parents surveyed reported their children needed one or more of seven medical services (see p. 12), particularly physician office visits and medications. About one-half also needed equipment and supplies. Their needs varied according to which of the 10 medical conditions the child had.

About three-quarters of the parents reported needing one or more support services. (See p. 14.) The services most frequently mentioned were baby sitting, counseling, day care, and transportation. Support service needs generally did not vary much by the child's medical condition.

Medical Services Easier to Obtain Than Support Services

A little over one-fourth (27 percent) of the parents whose children needed medical services and just over one-half (56 percent) of the parents needing support services experienced difficulty in getting them. (See pp. 17-18.) Parents reported that three factors accounted for many medical and support service difficulties:

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1. Paying for services was most frequently a problem. Insurance copayments and deductibles resulted in significant out-of-pocket expenses for such medical services as medications, medical equipment, and therapies. While costly and not covered fully by insurance, medical services needed by the child generally were obtained. On the other hand, insurance coverage limitations for support services sometimes forced families to forego services or incur large out-of-pocket expenditures for such services as baby sitting, day care, and transportation. (See p. 21.)

2. Lack of information about support services and availability of the services was another common difficulty. At the time of the child's discharge from the hospital, parents generally received information on medical services but not always on support services. Left on their own, they said they spent an inordinate amount of time and effort finding services. Some parents could not obtain support services because of the lack of providers or the refusal of providers to serve their children. (See p. 23.)

3. Lack of help with home care was experienced by some parents. Such parents said that their home-care situation would have been eased considerably had someone contacted them after their child's discharge to see how they were adjusting and to help them provide care. (See p. 25.)

Some Parents Had Little Difficulty

Some parents had little or no difficulty in obtaining services. In many areas, providers told GAO that information was available that enabled parents to locate needed services. Also, some parents received outside help in the form of case management in the transition to home care. Different forms of case management were provided through a variety of public, private, and voluntary agencies. (See pp. 27-31.)

Recommendation

Policy and program guidance are needed to facilitate the consolidation and publication of information on services for chronically ill children and ensure that case management services are available when needed. GAO recommends that the Secretary of Health and Human Services direct the Office of the Assistant Secretary for Health to take a leadership role in developing such guidance for state maternal and child health agencies. The policy should be aimed at ensuring that (1) information on providers and services in a given community is consolidated and made available to organizations serving chronically ill children, (2) this information is provided to parents at time of discharge, and (3) case

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management services are made available to those who need direct assistance.

Agency Comments

A draft of this report was provided to the Department of Health and Human Services, which concurred with GAO's recommendation. (See p. 33.)

Scope

We based our review on children who had the more severe forms of the following 10 conditions:

- Juvenile-onset diabetes
- Asthma
- Spina bifida
- Cleft palate and other craniofacial anomalies
- Congenital heart disease
- Leukemia
- End-stage renal disease (kidney failure)
- Sickle cell anemia
- Cystic fibrosis
- Muscular dystrophy

Some of these conditions (such as diabetes, cystic fibrosis, and spina bifida) are long-term, while others (such as heart conditions and cleft palates) often can be corrected early in life (see app. 1). Also, the 10 conditions are among those included in a 1985 study at Vanderbilt University of public policies affecting chronically ill children and their families.¹ According to the study, the experiences of the families studied were representative of the problems and costs generally faced by parents in obtaining care for all kinds of chronic illnesses. As the basis for our detailed review, we used 55 primary diagnoses that medical experts identified as representing the more severe forms of the 10 conditions.

Our review was performed in 11 states and the District of Columbia. These locations were selected on the basis of geographic diversity and variety of public health programs. We visited 14 hospitals that primarily cared for children, choosing those that enabled us to compare parents' experiences in urban and nonurban areas. Appendix II lists the states, localities, and hospitals selected.

In addition, we obtained information from recent studies related to chronically ill children, such as a 1987 report by the Office of Technology Assessment and a 1988 report by the Department of Health and Human Services (HHS).²

¹Nicholas Hobbs, James M. Ferrin, and Henry T. Ireys, *Chronically Ill Children and Their Families: Problems, Prospects, and Proposals from the Vanderbilt Study*, Josey-Bass Inc., 1985.

²Office of Technology Assessment, *Technology-Dependent Children: Hospital v. Home Care*, A Technical Memorandum, May 1987, and Department of Health and Human Services, *Fostering Home and Community-Based Care for Technology-Dependent Children*, Report of the Task Force on Technology-Dependent Children, April 7, 1988.

Methodology

To address our study objectives, we contacted parents of chronically ill children and care providers. In addition to surveying parents by mail about their general experiences, we spoke with some of them to obtain more detailed information. We contacted providers in selected local areas to obtain information about service availability and other matters. The details of our methodology are presented in appendix III.

Parent Mail Survey

Most children with the 10 chronic conditions we selected are treated at children's hospitals. Therefore, we asked the 14 children's hospitals in our review to help us identify families with such children. During the 12 months ending June 30, 1987, 8,557 children meeting our criteria were discharged from these hospitals. We selected 2,191 children to survey, and hospital officials mailed our survey form to their parents (one form to a family); of these forms, 1,990 went to valid addresses and 201 were returned as undeliverable.

Parents returned 892 completed forms or about 45 percent of the 1,990 surveys mailed to valid addresses: 621 (70 percent) from urban areas and 250 (28 percent) from nonurban areas. About 26 percent of the usable returns provided narrative comments. According to our public survey consultant, the normal return rate for a survey of this type would have been about 15 to 20 percent, so that our return rate of 45 percent is considered high, particularly given the sensitivity of the subject. We were not able to determine the profile of those who did not respond because of our confidentiality arrangements with the hospitals.

Parent Interviews

We talked with 96 parents who returned our survey, either in group settings or individually. Their profile was similar to the profile of those who returned the survey form as to income, insurance coverage, education, and the child's condition. In the meetings, we asked them why they did or did not have difficulty obtaining services in the home care setting.

Local Organization Interviews

When chronically ill children and their parents look for services after the child's discharge, they turn to the health care and support service providers in their local area. To ascertain their role, we contacted health care and support service organizations and providers in the localities we visited. We asked whether they served our population of chronically ill children and their families and what information and/or services they provided. Also, we sought to learn whether and how the service providers coordinated and interacted with one another.

Chapter 1
Introduction

The interviews gave us broad perspectives on the problems parents experienced obtaining care for chronically ill children. These perspectives became the basis for examining systemic barriers to obtaining community-based care and recommending solutions for overcoming the problems.

Limitations

As this was not intended to be a comprehensive survey of the availability of medical and support services in a community, we focused our review on the experiences of parents. Further, our report contains views and experiences of only those parents who responded to our survey, and does not represent all parents nationally or other parents in the areas surveyed.

Our review was performed in accordance with generally accepted government auditing standards between February and September 1988.

Families' Needs for Services Vary

Families with chronically ill children at home have diverse needs for services. Among those most often needed are physician office visits, medications, baby sitting, counseling, day care, and transportation. The needs of families in urban and nonurban areas are similar for most services. For medical services, the need is great and generally varies by medical condition. For support services, the need is less and generally does not vary much by condition.

Need for Medical Services Great, Varies by Condition

Nearly all families needed medical services for their children, parent survey responses showed, and the vast majority needed more than one. As table 2.1 shows, 848 respondents (about 98 percent) said that they needed one or more of seven medical services.

Table 2.1: Families' Needs for Specific Medical Services

Service	Number	Percent
Physician office visits	823	97
Medications	759	90
Medical equipment	470	55
Medical supplies for equipment	464	55
Rehabilitative and other therapies	273	32
Skilled nursing visits	208	25
Physician home visits	102	12

Note: Of the 865 valid responses to GAO's question about medical service needs, 17 (2 percent) said they did not need any medical services.

Because some services were not needed as often as others, we analyzed how frequently services were cited as needed among the 10 conditions. Frequency of need varied by the child's medical condition, as table 2.2 shows.

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Families' Needs for Services Vary

Table 2.2: Average Number of Medical Services Needed, by Child's Condition

Medical condition	Number of services needed
Muscular dystrophy	50
End-stage renal disease	46
Spina bifida	45
Cystic fibrosis	45
Juvenile-onset diabetes	42
Leukemia	40
Asthma	39
Congenital heart disease	31
Cleft palate/craniofacial anomaly	31
Sickle cell anemia	28
Multiple conditions	45

The differing medical service needs can be illustrated best by contrasting parents' survey responses on cystic fibrosis with those for cleft lip or palate:

- Children with cystic fibrosis need office visits, medical equipment, supplies, and medications. In addition, the typical child with cystic fibrosis also needs vitamin supplements, postural drainage therapy at least once each day, and periodic hospitalization for more intensive treatments, according to parents with whom we spoke.
- Children with cleft lips or palates frequently need office visits and medications, and, less frequently, rehabilitative and other therapies. Beside this, parents need to learn how to feed their children using special nipples and squeeze bottles, because the clefts do not enable them to suck normally.

Some parents whose children's chronic conditions have been corrected or stabilized need fewer medical services. For example, the hole in one child's heart had been corrected through surgery, her parent wrote, and the child now was able to lead an "active" life, needing only physician office visits. Similarly, after corrective surgery for a cleft lip or palate, children's needs for medical services were reduced, some parents commented.

Needs for Support Services More Uniform and Less Affected by Condition

About three-fourths of our respondents (634) reported that they needed support services—some 25 percent fewer families than those needing medical services. Four support services were needed by at least one-half of the respondents: baby sitting, counseling, day care, and transportation (see table 2.3).

Table 2.3: Families' Needs for Specific Support Services

Service	Families needing service	
	Number	Percent
Baby sitting	412	65
Counseling	368	58
Day care	336	53
Transportation	320	51
Case management	266	42
Respite care	152	24
Homemaker	129	20

Note: Of 840 valid responses to GAO's question about the need for support services, 206 (25 percent) indicated that they did not need these services.

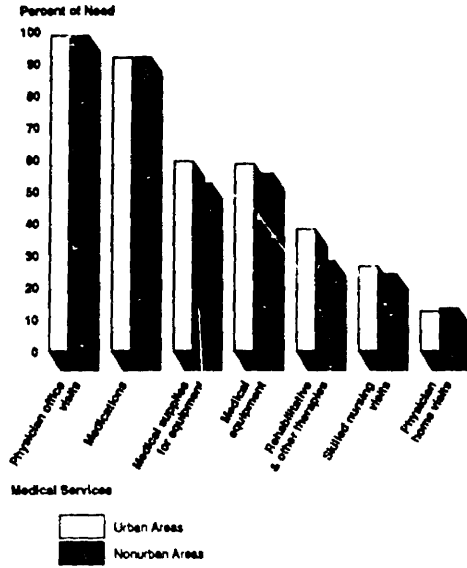
This overall pattern of need generally was consistent for the 10 medical conditions. On average, about three different support services were needed per child, ranging from about four for muscular dystrophy to about three for juvenile-onset diabetes, asthma, cleft lip/palate, and sickle cell anemia.

In addition to the foregoing services, a few parents of school-age children said tutoring services were needed when their child had to remain at home or in a hospital periodically for treatment of the condition.

Needs of Families in Urban and Nonurban Areas for Most Services Similar

The medical needs of families living in nonurban areas were generally similar to those in urban areas, although families in urban areas had a somewhat greater need for medical supplies and therapies (see fig. 2.1).

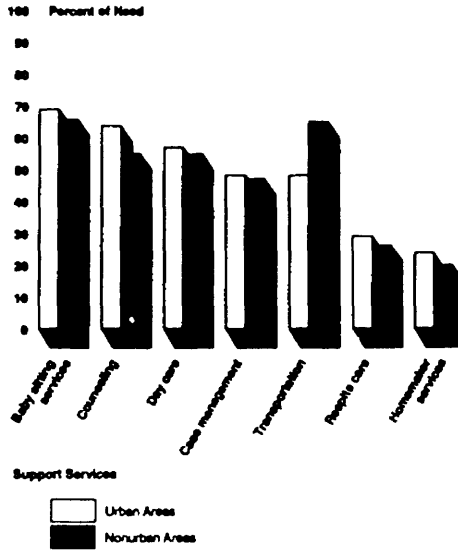
Figure 2.1: Need for Medical Services in Urban Versus Nonurban Areas



Similarly, nearly equal proportions of urban and nonurban families needed five of the seven support services (see fig. 2.2). There was a somewhat greater need for counseling among urban families and a much greater need for transportation among nonurban families.

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Families' Needs for Services Vary

Figure 2.2: Need for Support Services in Urban Versus Nonurban Areas



Lack of Financing, Information Make Some Services Difficult to Obtain

Most families had no difficulty obtaining medical services, but many who needed support services did not get them. Nonurban respondents had somewhat more difficulty obtaining both types of services than did urban respondents. Accounting for parents' difficulties were certain common factors. Among these were high out-of-pocket expenditures, frustrations caused by lack of information about service availability and providers, and lack of a focal point to contact when they needed help.

Support Services Present More Difficulty Than Medical Care

While the majority of parents who needed medical services had no difficulty getting them, most of those that needed support services experienced problems. The difficulties generally did not vary by the child's medical condition, but did vary by area of residence (urban, non-urban).

For Most Parents, Medical Services Not Difficult to Obtain

Overall, nearly three-quarters (616) of the 848 survey respondents who needed medical services had no difficulty getting them, while 232 (27 percent) did. The extent of difficulty for each of the seven medical services, based on the need for each service, is shown in table 3.1.

Table 3.1: Extent of Difficulty in Obtaining Medical Services

Medical service	Number with need	Number having difficulty	Percent having difficulty
Physician home visits	102	59	58
Rehabilitative therapies	273	81	30
Skilled nursing visits	208	57	27
Medical equipment	470	75	16
Medical supplies for equipment	464	71	15
Medications	759	70	9
Physician office visits	823	53	6

The difficulty parents encountered varied considerably among the services with a 52 percent spread between the greatest and least difficulty. The services needed by most respondents, physician office visits and medications, were the least difficult to obtain, but the service needed by the fewest respondents, physician home visits, was the most difficult to obtain. These results were generally similar for all 10 conditions.

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For Many, Support
Services Hard to Get

Overall, more than half (358 of 634) of the respondents who needed support services had difficulty obtaining them. The extent to which families needed and experienced difficulty obtaining each of the seven support services is shown in table 3.2.

Table 3.2: Extent of Difficulty in
Obtaining Support Services

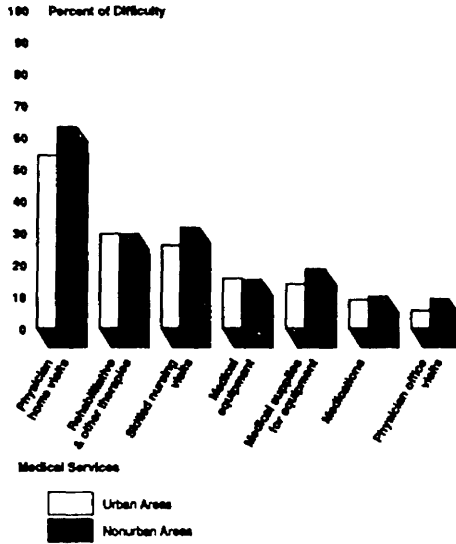
Support service	Number with need	Number having difficulty	Percent having difficulty
Baby sitting	412	238	58
Day care	336	190	57
Respite care	152	80	53
Homemaker services	129	64	50
Transportation	320	103	32
Counseling	368	117	32
Case management	266	82	31

About one-third of the 358 respondents had difficulty with one support service, another one-third with two services, and one-third with three or more services. Support service difficulties were similar for nearly all 10 medical conditions. Most respondents experienced difficulty with two services more than half of the time.

Nonurban Parents
Experience Somewhat
More Difficulty
Obtaining Services

Respondents living in nonurban areas experienced more difficulty in obtaining most medical and support services than those in urban areas. But the differences were not always great. Obtaining five of seven medical services was somewhat more difficult for nonurban respondents than for urban respondents, as figure 3.1 shows.

Figure 3.1: Difficulty Obtaining Medical Services in Urban Versus Nonurban Areas

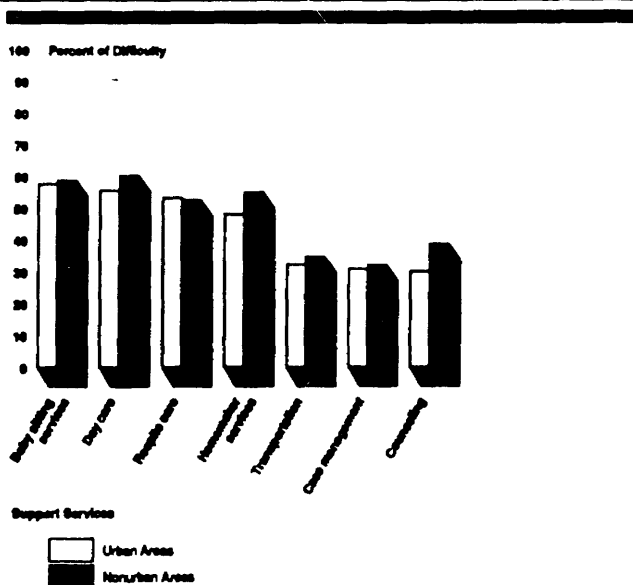


For support services, nonurban parents had somewhat more difficulty obtaining six of the seven services (see fig. 3.2). Only for respite care did they experience less difficulty than did urban parents.

Problems Obtaining Medical, Support Services Often Similar

Parents encountered similar difficulties obtaining both medical and support services, they said in discussions and in their survey comments. Most frequently cited was paying for services; because of insurance coverage limitations, copayments, and deductibles, parents had large out-of-pocket expenses. Another common difficulty was the process parents went through to obtain services; they expended considerable time and effort before they could locate providers and get the services needed. Finally, parents lacked a focal point to contact when they needed help with home care. In all but a few instances, the medical services were obtained, but in many cases the support services were not.

Figure 3.2: Difficulty Obtaining Support Services in Urban Versus Nonurban Areas



Paying for Services Difficult

Paying for medical and support services was a major difficulty, many parents said. Their comments, which were elaborated on by the local organizations we contacted, are presented below.

Parents Comment on Cost

Parents most often commented that, even though they had health insurance, they still incurred significant out-of-pocket expenses for medical services because of copayment and deductible requirements for covered services, and because certain services were not covered. The specific services they most often mentioned were medications, medical equipment, and therapies. For example, the parent of a child with spina bifida living in Florida said:

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"The availability of services is not the problem. The expense is the problem. Even with insurance, we have to pay approx. \$2500.00/year, and that would be with no hospitalizations that year."

Parents said they also had significant out-of-pocket expenses for support services not covered by insurance. They often singled out baby sitting and day care. Some parents said that transportation and associated expenses also were difficult because of (a) the distance they had to travel, (b) the frequency of travel, or (c) their own food and lodging costs when their child was hospitalized for medical treatment away from home. For example:

- "The very serious problem we had was babysitting and expenses during [son's hospital] stay. [Son] was 5.5 years old and really needed mom or dad to be with him all the time ... We ... had the expenses of food, travel, housing ... we ran thousands of dollars." (Parent of a child with a heart condition living in Massachusetts)
- Arizona parents said home-care expenses were out-of-pocket and that they were living "paycheck to paycheck."
- "... the costs - financial and emotional - have been staggering. Our child care expenses have more than doubled." (An Ohio parent of a child with leukemia)
- Ohio parents found day care providers that would serve their children, but they could not afford them. One said, "The in-home day care centers are outrageous. The cheapest one I found was \$7.95 an hour. They make more than me."
- Baby sitting and day care for a child with leukemia were difficult to obtain. "We have had to hire a baby sitter to come to our home to care for our child ... Insurance does not pay anything on the child care." (A Georgia parent)

Sometimes, there were broader financial ramifications for families as a result of their situations, parents' comments suggested. Examples of these comments follow:

- "About the insurance. I've paid more than I was supposed to and CHAMPUS [Civilian Health and Medical Program of the Uniformed Services] still has not paid and now I have bad credit." (Parent of a child in Ohio with asthma)
- Concerning copayments for an Ohio child with a cleft lip/palate and complications of brain damage, "... if the patient fails to pay, the[ir] accounts are turned over for collection. The patient gets squeezed by the pirates and can do nothing about it."

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- "I cannot go back to work because it is impossible to find a competent baby sitter." (Divorced parent of an Ohio child with a cleft palate)
- "... copayments and uncovered or under-covered expenses have depleted our resources. We also fear 'pre-existing condition' clauses and that has had a detrimental effect on [husband's] career (he is in a field where upward mobility is achieved by changing companies)." (Texas parent of a child with a heart condition and other complications)
- "The most difficult area for our family is having to rely on one income as opposed to two." (Texas parent whose child had a kidney transplant)
- "In the case of a chronically ill child, only one parent can work and the financial burden becomes a daily problem for the family ..." (Parent of a child with leukemia in Mississippi)
- "Income has been hard because we also have three other children and it is very hard, in fact, impossible for mother to work because we cannot leave our son." (California parent whose child has diabetes)
- "I do not work, to be home with my son ... because how would I keep him healthy in [a day care center] ... he catches everything and keeps it longer than the average child. So we did not put him in [the center] and survive on less." (Arizona parent whose child has a congenital heart condition)
- An Ohio mother gave up her career to care for her sick child. "I stay home because I can't pay day care."

In other instances, parents said they were fortunate that they did not need to work and were able to be home to care for their chronically ill children.

Service Providers Offer Insights

Various organizations we contacted in nine local communities provided some insight as to why parents reported financial difficulties in obtaining services. In some instances, the organizations commented on private insurance industry practices; in others, on public program provisions. They cited three problem areas:

1. Some services are not covered by public or private insurance. For example, the costs of braces, special diapers, and special shoes for children with spina bifida are not covered by a local health maintenance organization and a state health program, a Los Angeles local provider told us. Some private insurance companies in Florida generally view medical day care as unskilled custodial care, which they do not cover, officials told us, while two state programs cover this service. Most private insurance plans cover hospital and physician costs but seldom

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cover treatment in the home and family support services, such as counseling or respite care, according to an October 1987 report by a Minnesota advocacy group

2. Both public and private insurance reimbursement rates are low. Because California's Medicaid insurance payments are usually below market rates for services such as nursing specialists, a provider in Los Angeles told us, quality, affordable care for chronically ill children is difficult to find. Private insurance companies in the Washington, D.C. area have placed limits on the amounts they will pay for orthodontia treatment that children with cleft palates need, according to a local cleft lip/palate support group. Also in Washington, an official of a local sickle cell anemia clinic told us that private insurance pays for 52 percent of clinical treatment costs and Medicaid, 25 percent.

3. Program eligibility requirements presented barriers to care. For example, hospital representatives in California and Arizona said that middle-income families can face difficulties if they do not qualify for public programs. Medicaid eligibility requirements exclude some middle-income families who need financial assistance with their medical costs, according to hospital officials in Minnesota and Ohio.

Information and Services
Often Lacking

Finding providers of needed medical and support services was also a problem. A common theme was parents' frustration in locating providers because they lacked adequate information about service availability. In most cases, however, they were able to obtain the medical services but not as often the support services.

With regard to medical services, hospital discharge processes, for the most part, adequately addressed the medical care needs of their children and the parental roles in this, including follow-up care at the hospital. But the hospital discharge process did not always include information on service providers other than the hospital. In some cases, parents felt that the hospital staff seemed to assume that the parents knew where to obtain services. Parents did not know, they told us, and consequently had to do a lot of searching before they found providers. Parents used such sources as telephone books, other parents, and support groups. An example of these kinds of experiences came from a parent in Minneapolis:

"I had to get some supplies ... I tried to call around. You get the yellow pages out and call all the medical suppliers and find out who has what ...

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You go one place for one thing and one for another thing. And you have to go out and get it. It's way out in the suburbs "

Although some parents experienced these difficulties, in all but a few instances they were able to get the medical services. When they were unable to, it was mostly because either there were no providers or the service was too expensive. For example, the parent of a child with a heart condition in California wrote:

"The only home care problem was in the rehabilitation area. We attempted to get services for this but could not find anyone with services available other than the children's hospital. By the time someone became available, our child did not need the service."

Parents also encountered a variety of difficulties when seeking support services. Among the most frequent were (1) spending considerable time and effort locating providers and obtaining the services and (2) lack of providers. Home care instructions from the hospital generally did not include information about support service availability and providers, parents told us. The following examples typify parents' difficulties:

- "... trying to get information concerning grants, funds, special schools or programs is difficult at best. It's like a secret society - no one wants to share information that should be public knowledge." (Parent of a child with muscular dystrophy in Maine)
- "It takes a lot of research to find adequate services for and information about our child's disability. Some parents don't know how to find help and the child suffers." (Parent of a child with asthma and the complications of Down syndrome in Georgia)
- A parent in Minneapolis told us that "Any kind of help that we needed as far as durable health supplies, mental health counseling, day care, respite care, respiratory therapy — all of that you had to get for yourself ... the hard way"

In some cases, parents were unable to get support services mainly because providers were lacking or existing providers refused to serve their children. Most often mentioned in this context were baby sitting and day care, followed by respite care and counseling. The following comments are typical:

- "The only problem that I wish could be resolved is that people wouldn't be so afraid of a child's condition. As soon as I mention he has a heart

- condition people back off and won't even hold him. It is as if they are afraid he will have a heart attack." (Ohio parent)
- "To this day we don't have a baby sitter ... People are afraid ... They don't want to take care of him, so we don't go out." (Ohio parent)
 - Concerning a child with a heart condition, "Everyone was afraid to care for her in case an emergency happened ... " (California parent)
 - Regarding where to find day care or respite care, "I'm not aware of anything being out there and if it is, I'm sure it's not in my budget." "The only care givers I have for [child] are my family ... No one else would touch him ... " "We have nobody to take care of our kids on the weekend who's willing to give shots." (Minnesota parents)
 - Concerning a child with a heart condition, "The main problem we experienced was finding in-home baby sitters with some nursing experience. They were nearly impossible to find and the cost (approx. \$10 per hour) was prohibitive." (Minnesota parent)
 - "The doctors and social workers did not mention any supportive services to us. We would like any information on these services sent to us please" (Parent of a child with cystic fibrosis in California)

Focal Point for Help Needed

Parents needed help in coping with their home care situation, they said. In some cases, the home-care situation would have been eased considerably had someone visited them after their child's discharge from the hospital to see how they were adjusting and to give them advice on providing care. In other cases, just having had someone to talk to who shared the same or similar experiences would have helped them greatly, they said, in being able to initially deal with and adjust to the home-care situation. Typical comments along these lines were:

- "The aspect of [child's] care that I feel is most lacking involves our lack of association with a regional or national foundation for asthma. I would like to have access to timely information on this disease, but I have found no one to give me any encouragement or direction in this area." (An Ohio parent)
- "At the time my child had his surgery - and the time leading up to his surgery - I would have appreciated a support group or some sort of counseling . Doctors are usually cooperative; but when it is not their children, you wonder how much to believe them. To talk to some who had been through the same thing - with their own children would have been greatly appreciated." (An Ohio parent)
- Concerning a child with a cleft lip/palate, "Medical services were very good as far as the surgeon was concerned ... Support groups and contact persons were not available and it would have been such a relief to talk

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- to a person who had gone through as we after the birth of our daughter." (Minnesota parent)
- "I wish we had someone who knew the ropes ... how to get what I need and avoid all the tiny frustrations." (Minnesota parent)
 - Regarding another child with a cleft lip/palate, "I had to gavage [tube] feed my baby her first 3 months. They should have a nurse come to the house and see that the parent or main person taking care of the child is doing the procedure right. This way of feeding is very dangerous if not done right." (A Texas parent)

Positive Experiences Point to Possible Solutions

Although many parents of chronically ill children had difficulty obtaining services, especially support services, some did not. Two factors accounted for positive experiences: (1) availability of information that enabled parents to locate needed services and/or (2) the direct assistance of an individual in identifying providers and obtaining needed services.

Linking Parents to Information

Some parents obtain information on service availability from various medical care and support service providers and organizations. The key factors here are to have information available and to link parents to it.

Various Information Sources Exist

Many public and private service providers and organizations in the nine communities maintained directories of providers and services. The completeness of the directories varied but some were considered by the local organizations we contacted to be quite complete, for example:

- Cincinnati had three major sources of information on service providers: a United Appeal and Community Chest directory of community services contained an estimated 2,000 providers; a directory of services for persons with disabilities listed 360 providers; and an early intervention service matrix contained 246 providers.
- The Atlanta area's United Way directory listed 638 service providers.
- In Pinellas County, Florida, the United Way directory of human services listed 168 service providers.
- Dallas' Community Council's directory of services was identified by 8 of the 10 organizations we contacted as being a complete inventory of medical and support services; all used the directory.

Yet parents we interviewed from the last three areas either did not mention the directories or told us that they were unaware of them. Likewise, although a San Antonio hospital social worker told us he knew of two day care centers in the city that accept children with disabilities, two San Antonio parents said they were unable to find centers that would accept their children.

Other organizations also had information on services and service providers. Some of these organizations considered their information complete, while others did not. For example, two local health departments told us they had complete information on services and providers, while three said their information was incomplete.

Chapter 4
Positive Experiences Point to
Possible Solutions

Parents' access problems would be eased if information regarding service availability and providers were centralized, as a California state official remarked. At the University of South Carolina, a framework for a national, centralized system has been developed. The National Information System, supported in part with federal funds, contains information on medical conditions, services, and service providers in each state. Like most of the local service provider directories we encountered, however, this national database is not complete because it contains only those who have volunteered to be included in the system.

Nevertheless, the system has been developed, tested, and is operational and would be more useful if additional organizations participated. Access to it is through a tollfree number (800-922-9234). According to officials operating the system, several states have developed state-wide systems modeled on the national system. In the local communities we surveyed, the most centralized information sources were the United Way directories.

Information at Time of
Discharge

Often, when a chronically ill child is discharged from the hospital, insufficient information is provided on the availability of support services, many parents told us. The discharge planning process and plans tended to focus information on the medical care needed by the child, our work in several hospitals showed, and usually did not address the support services the family needed. Physicians often do not take the whole family into account when making discharge decisions, a hospital social worker commented. While social workers are part of the discharge planning team, their roles are advisory, the worker said. According to one hospital's assistant director of social work, the hospital maintained no central listing for support service referrals. An official from a parent support group who had continually given information on the group to hospital personnel said they always seemed to lose it.

Ways to provide information on services were suggested by health officials. For example, each tertiary center, such as a children's hospital, could employ coordinating persons to help parents gain access to available services, an Ohio official said. Also, parents might be given a list of all community resources by illness, including telephone numbers, when a child is discharged, according to a Texas hospital official. On the other hand, a hospital official in California did not think that the hospital should assume ultimate responsibility for identifying all services available and directing parents to appropriate providers. As the geographic

area covered by the hospital was large, the official thought it impractical to manage this outside the immediate area.

Some children, at time of discharge, had been identified as being eligible for services under public programs and had been referred to the organizations operating these programs. However, children not identified as eligible for these programs were not always given information on where to obtain help. For these children, we believe a referral to the local health department or other appropriate sources would be a good way to facilitate access to needed services.

Providing a Focal Point for Information and Help

Some parents had little or no difficulties in obtaining services because they received help. These parents were assisted by various organizations in the community that helped them avoid or minimize service problems.

Various Sources of Help Cited

The most frequent source of help in obtaining services that parents mentioned was the children's hospital; others were health maintenance organizations, support groups, and state and local programs. The organization or an individual either provided the services or helped the parents find out about services and get them. Typical comments were the following:

- "If not for an exceptional Social Worker at [hospital] all the services listed on this survey would have been unknown to me including SSI [Supplemental Security Income] disability which had been invaluable to me." (Parent of a Massachusetts child with leukemia)
- "... since the day my son was born he has gotten the best of care. The staff at [hospital] have provided the utmost care and health services possible. They also provided H.M.O. [Health Maintenance Organization] medical services, when we were no longer eligible for Medicaid, and our insurance would not cover the entire cost of his medical expenses. They also provided transportation to and from the hospital, whenever we needed it." (Ohio parent of a child with a heart condition)
- "Our experiences at [the hospital] have been very good. They supply medication, support groups, and everything we have needed." (California parent whose child has leukemia)
- "[The Children's Medical Services program] has a good triage nurse, who is our go-between when we need help; she does an excellent job of finding what we need." (Florida parent of child with asthma)

- "After we were referred by [the hospital] to Children's Medical Services because of a financial problem, we have received good case management services" (Another Florida parent of an asthmatic child)
- "... [Child with a cleft palate with complications] is enrolled in a county [early intervention] program which covers physical therapy, occupational therapy, hearing & speech & a general, overall teacher to put all programs together to view him as a whole. It is hard to keep up with the visits, but is easy to obtain the care needed." (Maryland parent)

Common to these examples was the involvement of an organization or individual who undertook the responsibility to help the family obtain services.

Case Management Provides Framework

A focal point concept, commonly referred to as case management, has been used over the years in health programs. Under this concept, an individual—the case manager—provides, among other things, information and coordinates services. The concept has been implemented by many organizations, but in various forms and sometimes limited in scope. For instance, case management may deal with only the child's medical needs or it may address the total needs of the child and the family, as discussed above.

Our review identified various case management practices and providers. For example, case management as performed by hospitals and the state's crippled children's services agency in Los Angeles was usually a short-term, episodic approach during a crisis, service providers there said. An Ohio state agency provided case management that focused solely on the medical needs of the child. Local health departments also offered case management services. For example, the Hennepin County health department case-manages certain children, beginning while they are in the hospital and continuing until they no longer need services. Their case management activities include coordinating needed services and equipment, acquiring nursing services, managing finances, solving problems, and visiting children every 2 to 3 months.

Some parents, however, seemed inundated with case management. A Florida state official told us the problem was too many case managers. For example, each developmental services client had an assigned case manager. If the child also received medical services through the state's Children's Medical Services, the child was assigned a case manager from that agency. The child also may have had a case manager in the school system. A parent in our Minneapolis group interview told us:

- "...We have a social worker through the county, a social worker from [name omitted] who does the waived services coordination, and I understand we'll get another one because of the school district changes. I don't think we need three social workers. I think I need a social worker to coordinate all of them."

Views as to what case management is, who should provide it, and under what circumstances varied among parents, service providers, and organization officials. For instance:

- A case manager was defined as a person who coordinates services and tells parents what services they need. (A Florida service provider)
- The long-term needs of the patient should be considered by someone who is independent of the hospital. This individual should be trained to advise families on long-term financial and medical planning throughout the child's illness. (An Ohio state health official)
- When parents lack the capabilities or means to coordinate their child's care, a case manager should be made available to fulfill that function. (A Cincinnati health care provider)
- A case manager is frequently required when the child's multiple needs necessitate involvement of various agencies and support services. (A Texas service provider)

Not everyone discharged from the hospital needs an individual to provide case management. As discussed previously, some parents need only information, and can act as their own case managers. Others need help with the transition from hospital to home environment. Providing case management services can help parents with their information and home care needs.

Under one definition of case management, each family is provided with a single service coordinator—the case manager. The family's needs for medical and support service information, planning, coordination, and patient advocacy are recognized. This concept is defined in the April 1988 report on technology-dependent children by a Department of Health and Human Services task force. We believe, however, that it also applies to the broader population of seriously chronically ill children.

In discussing varying case management practices, the HHS task force report also pointed out that there was no single widely accepted definition. Thus, the task force proposed a common interpretation of case management to ensure that all necessary services would be provided when needed. It also recommended that the programmatic responsibility

for organizing and monitoring case management be assigned to the states' maternal and child health agencies. At the federal level, the task force recommended that HHS Bureau of Maternal and Child Health and Resources Development be responsible for policy and program development, coordination, and oversight of the state processes.

We agree with the HHS task force that case management should be uniformly defined and that placing case management responsibilities under the Maternal and Child Health program is appropriate because the main objective of that program is to help ensure that basic health care is available to mothers and children. We also agree that federal officials need to work with state officials to implement case management programs at the local level, so that information on services and providers is available to parents needing it.

Conclusions

It is probably impossible to guarantee that all parents who need information on services and providers will obtain it. However, the positive experiences of some parents we contacted suggest that three steps could improve the process of linking parents to the information they need:

1. Consolidate information on services and providers in the community and ensure that it is available to all organizations serving chronically ill children.
2. Make this information available to parents during the hospital discharge planning process.
3. Refer parents who need help with the home care situation to a public or private organization providing case management services.

Some of this is being done to varying degrees by numerous public and private organizations at the state and local levels. Yet parents experienced problems in obtaining services. This occurs because there is no clear responsibility for consolidating and publicizing sources of information on services for chronically ill children or ensuring case management is available when needed. Any one of various organizations at the local level, such as hospitals, local health departments, or children's medical services agencies, could assume the responsibility. The appropriate organization will depend upon the health care structure in the state.

Recommendation

To facilitate the consolidation and publication of information on services for chronically ill children and ensure that case management services are available when needed, we recommend that the Secretary of Health and Human Services direct the Office of the Assistant Secretary for Health to take a leadership role in developing necessary policy and program guidance for state maternal and child health agencies. Such policy should be aimed at ensuring that (1) information on providers and services in a given community is consolidated and made available to organizations serving chronically ill children, (2) this information is provided to parents at time of discharge, and (3) case management services are made available to those who need direct assistance.

Agency Comments

A draft of this report was provided to HHS and its comments, summarized below, appear in appendix VI. HHS concurred with our recommendation and said it will develop a plan of action to implement it. HHS noted that some of the past activities of the Bureau of Maternal and Child Health and Resources Development in the Health Resources and Services Administration will aid in developing the necessary policy and program guidance. HHS cited the Bureau's involvement in the June 1987 Surgeon General's Report on children with special health care needs, its guidance to states regarding service networks and case management services, and its funding of a national information network.

HHS believed that we should have addressed programs administered by its Office of Human Development Services programs. These programs, HHS said, affect chronically ill children by providing Head Start, child welfare, respite care, and family support services. Our review at the local level was not intended to inventory all programs serving chronically ill children. Instead, information on a sample of local programs was gathered in each of the nine communities visited. Some social service agencies were included, such as Developmental Services in Florida, Department of Social Services in Prince George's County, Maryland, and Family Self Support Services in San Antonio. Besides social services agencies, our local contacts also included health agencies, human service agencies, educational agencies, parent support groups, and others. However, we did not inquire into the funding sources of any of the local organizations we contacted and thus could not determine which federal programs, if any, were providing financial support.

Descriptions of the 10 Chronic Conditions Used for the Review

The 10 chronic medical conditions on which we based our review are described below. The descriptive information on these conditions was drawn from the Vanderbilt study on chronically ill children and their families (cited on p. 9) and various other sources.

Juvenile-Onset Diabetes

In a healthy body, the pancreas secretes insulin, which breaks down sugar in the blood. These secretions occur when the person eats or is hungry, but if the person doesn't eat, the secretions stop. In the case of juvenile-onset diabetes, the pancreas either stops secreting insulin or produces an insufficient amount, resulting in a high blood sugar content. If not controlled, high blood sugar has debilitating effects on the body over time. Diabetes may affect one or more of several major organ systems (kidney, heart, eyes) and reduce life expectancy. To control the blood sugar content, insulin must be provided artificially to the body, such as by injection. However, the body may not use all of the insulin, leaving some in the blood. If too much remains, the body is in danger of an insulin reaction. To avoid a reaction, the blood sugar level must be increased through eating. Between meals, this can be done by drinking a sweet beverage or eating a candy bar. Consequently, a child with this condition needs to monitor his/her blood sugar content periodically and be able to take appropriate measures to keep the blood sugar content at acceptable levels.

Asthma

Asthma, one of the major causes of health impairment in children, is the most common long-term physical disorder of childhood. It is a chronic lung disease in which the muscles controlling the bronchial air passages are subject to spasms that restrict the air flow into the lungs and make breathing difficult. In addition, about 60 percent of children with severe chronic asthma also suffer from sinus blockage. The reasons for the spasms vary with each person, and in some cases may not be known. The more common causes are allergants (certain foods, fabrics, dust, pollen) and stress. Asthma attacks, which can be reduced in their intensity and/or prevented through a combination of monitoring and medications, take time to develop. An impending attack can be detected with a device called a peak flow meter, which measures the air capacity of the bronchial passages. If periodic monitoring during the day with the meter indicates that the bronchial air capacity is being reduced, the child can take medications that help to relax the bronchial muscles and prevent an attack or reduce its severity. Medications also are taken for sinus blockages.

Spina Bifida

Spina bifida is a birth defect in which the vertebrae in the spine fail to close properly as the fetus is developing and part of the spinal cord is exposed at birth and nerve damage occurs. Although the spinal cord is closed by surgery, the damage to the nerves cannot be corrected, resulting in varying degrees of paralysis in the lower half of the body and bowel and bladder complications. A child with this condition may need several medications, undergo multiple surgical procedures, and need physical and occupational therapy. Also, the child may be wheelchair-bound or dependent on braces or crutches.

Cleft Palate and Other Craniofacial Anomalies

Present from birth, cleft palate and other craniofacial anomalies are defects in the normal formation of the face and related structures. The range of conditions varies from minimal abnormalities in the formation of the roof of the mouth or soft palate (not visible at birth), to larger openings (clefts) involving the palate, jaw, and lip that are visible disfigurements. These conditions make eating for a baby difficult, as the cleft does not allow normal sucking. Thus, the baby must be held in a special position and specialized feeding nipples and squeeze bottles used. These conditions are correctable, depending on the severity, by one or more surgical procedures during childhood.

Congenital Heart Diseases

Congenital heart diseases are structural abnormalities in the development of the heart, such as holes and transposition of the major blood vessels, which reduce the oxygen content in the blood and the ability of the body to get oxygen. In the typical case, the condition can be surgically corrected when the child has grown to the point that the body is strong enough for the surgery. Until that occurs, there may be a need for frequent visits to physicians to monitor the condition and specialized care to deal with the body's weakness from lack of oxygen. The care includes medications to ward off diseases and special equipment to help in breathing and feeding.

Leukemia

Leukemia is the most common cancer of childhood and typically develops in the first 4 years of life. In leukemia, cells that would usually differentiate into normal white blood cells multiply instead in great amounts. They often prevent the body from making other normal blood components and may lead to the growth of abnormal cells in other parts of the body. The condition is treated with chemotherapy and medications. Currently, about 65 percent of children with leukemia are in the remission stage; i.e., they have lived 5 years past their last treatment.

Appendix I
Descriptions of the 10 Chronic Conditions
Used for the Review

End-Stage Renal Disease

In end-stage renal disease, the kidneys have ceased their function of removing impurities from the blood. To compensate for the loss of kidney function, several types of dialysis are used. These are methods of filtering that remove waste products from the body. For children, however, the preferred treatment is a kidney transplant, so that dialysis is used until a transplant can be done.

Sickle Cell Anemia

In sickle cell anemia, the red blood cells, which carry oxygen to the body, are abnormal in shape. They have a jagged irregular sickle shape instead of a disk or round shape. As a result, they contain less oxygen and pass less easily through veins and the smaller blood vessels. Also, their shape makes them prone to clumping, resulting in swelling and blockages of blood vessels and to damage to those organs and bodily areas from lack of oxygen. A child with the condition is particularly susceptible to infection. Infections and other effects of the condition usually are treated at specialty clinics.

Cystic Fibrosis

Cystic fibrosis is a genetic disorder that affects the digestive and respiratory systems. A body with this condition produces a thick sticky mucous that impedes proper digestion and lung function and makes the body susceptible to frequent lung infections. Blocking the ducts of the pancreas, the mucous prevents digestive enzymes from reaching the small intestine. The mucous also coats the insides of the lungs, blocking breathing passages and acting as a "glue" that enables bacteria to grow.

The digestive problems usually are controlled with medications and vitamins. To unclog the lungs, physical therapy called "postural drainage" is given two or more times each day for about 1 hour. This therapy involves vigorously clapping the ill person on the back and chest to dislodge the mucous so that it can be expelled from the lungs. At times, this is combined with the use of an inhalant spray. Lung infections are treated with antibiotics. The foregoing treatments can be provided daily in the home setting. But a person with the condition usually needs to enter a hospital two or more times annually for about a 2-week period to receive more intensive forms of these therapies.

Muscular Dystrophy

Muscular dystrophy is a generic term that encompasses four basic types of genetic diseases of the muscles, which are represented by 40 specific diagnoses. In all of the diseases, the muscles slowly weaken and degenerate, resulting in early death. Some of the conditions are present at

Appendix I
Descriptions of the 10 Chronic Conditions
Used for the Review

birth, while others develop during early childhood. There is no known "cure" for any of the conditions (i.e., no way to reverse the weakening of the muscles), so the basic therapy is to make the individual as comfortable as possible through various physical therapies and surgeries.

Appendix II

Hospitals Visited for GAO Study and Mail-Out Areas

Hospital	Mail-out area	Type of area	Type of meeting
Children's Hospital National Medical Center, Washington, D.C.	Prince George's County, MD	Urban	Group
Boston Children's Hospital, Boston, MA	New England states	Urban and nonurban	Individual (Maine)
Cincinnati Children's Hospital Medical Center, Cincinnati, OH	Hamilton County, OH	Urban	Group
Columbus Children's Hospital, Columbus, OH	12 rural counties in Ohio	Nonurban	Individual
Children's Medical Center, Dallas, TX	Dallas County, TX	Urban	Group and individual
Santa Rosa Children's Hospital, San Antonio, TX	Bexar County, TX	Urban	Individual
University Hospital, Jackson, MS	21 counties surrounding the city of Jackson, MS	Nonurban	Group and individual
Scottish Rite Children's Hospital, Atlanta, GA	DeKalb County, GA	Urban	Group
Henrietta Egleson Hospital for Children, Atlanta, GA	28 counties in southern Georgia	Nonurban	None
All Children's Hospital, St. Petersburg, FL	Pinellas County, FL	Urban	Group
Children's Hospital of Los Angeles, CA	Los Angeles County, CA	Urban	Group
Valley Children's Hospital, Fresno, CA	Fresno County, CA, area	Nonurban	Individual
Phoenix Children's Hospital, Phoenix, AZ	Maricopa County, AZ	Urban	Group
Minneapolis Children's Medical Center, Minneapolis, MN	Hennepin County, MN	Urban	Group

Methodology

Our methodology for this study included a mail survey of parents of chronically ill children and interviews with selected parents and selected local service providers.

Parent Mail Survey

Children with the 10 conditions selected for our survey (see ch. 1) are most likely to be treated at children's hospitals, medical experts told us. Accordingly, we selected 14 hospitals that provided care to chronically ill children in urban and nonurban areas to serve as the base from which to survey parents' home-care experiences. Thirteen were children's hospitals and one was a university hospital in a state that lacked a children's hospital. We considered urban areas to be metropolitan counties and nonurban areas to be nonmetropolitan counties.

We asked the 14 hospitals to identify for us children, ages 13 and under, who were discharged to home care during the 12-month period ending June 30, 1987, and who had any of the 55 primary diagnoses that represent the severer forms of the 10 conditions. Age 13 was our cut-off because medical experts told us the diagnoses of the 10 conditions occur either at birth or during childhood, usually by age 13. In total, 8,567 children meeting our criteria were discharged from the 14 hospitals during the review period.

The information provided by the hospitals included the child's age, the diagnosis, the length of and the amount charged for the hospital stay, and the postal zip code of his/her residence. Children were not identified by name but by a number randomly assigned by the hospital. We sorted the discharge data by zip code to identify children who had been discharged to the states in which we were doing our review. Within each state, we selected urban and/or nonurban areas for our survey mail-out. For urban area mailings, we selected metropolitan counties having the greatest number of discharges. Between 73 and 200 survey forms were mailed to these. For nonurban area mailings, we selected counties outside metropolitan areas that had the greatest number of discharges; between 70 and 200 survey forms were mailed to these.

The mail-outs went to a cross section of the youngest children with the 10 conditions. We chose the youngest children because we wanted to contact parents who had experienced the transition from the hospital to the home-based care setting for the first time during the review period. Using the randomly assigned numbers, we provided our selections and our parent survey forms to each hospital for mailing. The hospitals made the initial and one follow-up mailing.

Appendix III
Methodology

The parent survey form was designed to (1) obtain information on income, health insurance coverage, and the need for and the difficulty in obtaining one or more of 14 medical and supportive services in the home-based setting and (2) determine parent willingness to participate in a group meeting. From our review of past studies and other information related to home-based care, we had identified the 14 services as being generally needed by families with chronically ill children at home. The parent survey form appears as appendix IV and the responses to each question are in appendix V.

Parent survey forms were mailed to 2,191 parents (25.6 percent) in the selected areas. We received 892 usable returns, as shown in table III.1.

Table III.1: Results of Parent Survey Mail-Out

Total surveys mailed		2,191
Less		
Post office returns	201	
Nonresponsive returns	16	
Not returned	1,082	1,299
Net usable returns		892

The 892 usable returns represent about 45 percent of the 1,990 surveys mailed to valid addresses: 621 (70 percent) were from urban areas and 250 (28 percent) from nonurban areas. About 26 percent of the usable returns also included narrative comments. According to our public survey consultant, the normal return rate for a survey of this type would have been about 15 to 20 percent, so that our return rate of 45 percent is high, particularly considering the sensitivity of the issues and subject matter. We were not able to determine the profile of those who did not respond because of the confidentiality arrangement we had with the hospitals.

Parent Interviews

Of the 474 respondents who indicated their willingness to meet with us, we met with 96, either in group settings or individually. In these meetings, we inquired into why parents either had or did not have difficulty obtaining services in the home care setting.

Nine group meetings were held, each with 5-12 parents and lasting about 2 hours. Eight of the nine groups had parents from urban areas, and the other group had parents from a nonurban area. The parents we talked to individually were from both urban and nonurban areas. We

selected parents to invite to the group meetings judgmentally, using the same criteria as for the mailings. The profile of parents we met with was similar to the profile of those who returned the survey form in terms of income, insurance coverage, the child's condition, and education.

Local Organization Interviews

When ill children are discharged to home care, their parents in trying to get services turn to the health care and support service providers in the local area. To ascertain the role of local service providers, we contacted 60 health care and support service organizations and providers in the nine localities where we conducted group interviews. In particular, we asked whether they served our population of ill children and their families, and the information and services they provided. We also inquired into whether and how the service providers coordinated and interacted with one another.

We selected these organizations judgmentally to obtain a mix of public and private service providers. Accordingly, the organizations included public and private home health agencies, children's medical services clinics, medical day care centers, parent support groups, and various disease associations and foundations.

GAO Parent Survey Form

United States General Accounting Office	
GAO	Study of Chronically Ill Children
Instructions	The local children's hospital prepared a list of patients discharged from their facility during the period July 1, 1986, through June 30, 1987, and your child was included on that list. The child was not identified by name or any other information which would identify the child. The questions below pertain to that child. Please check or circle each response as indicated.
	<p>1. Please indicate which one of the following illnesses your child has. (Check one)</p> <p>1. Juvenile-onset diabetes 2. Asthma 3. Spina bifida 4. Cleft palate or other craniofacial anomaly 5. Congenital heart disease 6. Leukemia 7. End stage renal disease 8. Sickle cell anemia 9. Cystic fibrosis 10. Muscular dystrophy 11. Other: _____ 12. Don't know</p>
	<p>2. Your sick child's date of birth: _____</p>
	<p>3. Date on which your child was first discharged from a hospital to home-based care for treatment of the illness:</p> <p style="text-align: center;">_____/_____/_____ Month/Year</p>
	<p>4. Primary health insurance coverage for the child. (Check one)</p> <p>1. Medicaid 2. Medicare 3. Medical insurance received through your employer 4. Medical insurance purchased as an individual 5. Other: Explain: _____ 6. The child is not covered by any medical insurance</p>

Appendix IV
GAO Parent Survey Form

6. Since your child was first discharged from the hospital with his or her illness, to what extent has it been difficult or easy for you to obtain the different medical and nonmedical supportive services, listed below, for your child and family?
Check one box for each service

Services	Service not needed	Very difficult to obtain	Difficult to obtain	Neither difficult nor easy to obtain	Easy to obtain	Very easy to obtain
	1	2	3	4	5	6
Medical Services						
1. Physician home visits						
2. Physician office visits						
3. Medical equipment						
4. Medical supplies (e.g. equipment)						
5. Medications						
6. Scheduling visits						
7. Other						
Nonmedical supportive services						
1. Respite care						
2. Home care services						
3. Transportation						
4. Day care						
5. Babysitting services						
6. Rehabilitative & other therapies						
7. Counseling						
8. Case management						
9. Other						

Appendix IV
 GAO Parent Survey Form

6. Over the past year, what were the approximate average total monthly medical and nonmedical supportive expenses for the care of your child? (Check one)

- 1 Under \$250
- 2 \$250 to \$999
- 3 \$1,000 to \$5,000
- 4 Over \$5,000
- 5 Don't know

7. Approximately what percent of your child's medical and nonmedical supportive services expenses are paid by insurance? (Check one)

- 1 The child is not covered by insurance
- 2 Up to 25%
- 3 About 26% to 50%
- 4 About 51% to 75%
- 5 About 76% to 100%
- 6 Don't know

8. Would you be willing to participate in the study as part of a group interview? (Check one)

- 1 Yes
- 2 No (Please Go to Question 13)

9. What days are most convenient for you to participate in the group meeting? (Please circle)

Weekdays Weekends

10. What times are most convenient for you to participate in the group meeting? (Please circle)

Morning Afternoon Evening

11. Please print your:

Name _____

Address _____

Zip _____

Daytime telephone () _____

12. Please indicate which of the following languages you speak. (Check all that apply)

- 1 English
- 2 Spanish
- 3 Other (State which) _____

3

**Appendix IV
GAO Parent Survey Form**

13. What is the highest level of education you or your spouse have received?
(Check one)

- 1 Grades 1 through 8
- 2 Some high school
- 3 Graduated from high school or G.E.D.
- 4 Associate Degree
- 5 Bachelor's Degree
- 6 Master's or Doctorate Degree

14. What is your family's approximate annual income?
(Check one)

- 1 Under \$5,000
- 2 \$5,000 to \$9,999
- 3 \$10,000 to \$19,999
- 4 \$20,000 to \$29,999
- 5 \$30,000 to \$39,999
- 6 Over \$40,000

15. Thank you for responding to our questions. If you have any comments about our study or if there is any other information that you would like to share with us at this time, please do so in the space below or on additional sheets as necessary.

Please remember to return the completed questions in the enclosed business reply envelope to:

Appendix V

Parents' Responses to GAO Parent Survey Form

Between January and May 1988, we mailed 2,191 copies of the parent survey form (see app. IV) to parents of chronically ill children. (The recipients were selected as described in ch. 1.) Of the total, 201 were returned as having invalid addresses; of the 1,990 remaining, we received 892 usable returns or about 45 percent of the valid addresses. The responses analyzed below are from the 892 parents. Because some parents did not answer all questions, the percentages may not be the same as those presented in the tables in chapters 2 and 3. Percentages, where used, may not add to 100 due to rounding.

Table V.1: Medical Conditions of Children in Survey (Question 1)

Coverage	Percent of responses
Juvenile-onset diabetes	9.4
Asthma	24.5
Spina bifida	2.5
Cleft palate/craniofacial anomaly	11.0
Congenital heart disease	27.2
Leukemia	5.7
End stage renal disease	2.8
Sickle cell anemia	7.1
Cystic fibrosis	5.8
Muscular dystrophy	0.6
Other	2.9
Don't know	0.4

Note: No. of responses 890

Table V.2: Primary Health Insurance Coverage of Children in Survey (Question 4)

Coverage	Percent of responses
Medicaid	18.3
Medicare	3.5
Medical insurance through employer	59.6
Medical insurance purchased as an individual	6.7
Other	8.0
Child not covered by insurance	3.9

Note: No. of responses 883

Appendix V
Parents' Responses to GAO Parent
Survey Form

Table V.3: Need for Medical and Support Services by Parents Surveyed
(Question 5)

Services	Service not needed (Percent)	Service needed (Percent)	Number of responses
Medical services			
Physician home visits	67.7	12.3	830
Physician office visits	3.4	96.6	852
Medical equipment	43.9	56.1	835
Medical supplies for equipment	44.2	55.8	832
Medications	9.9	90.1	842
Skilled nursing visits	75.0	25.0	831
Rehabilitative & other therapies	66.0	34.0	804
Support services			
Respite care	79.7	20.3	747
Homemaker services	83.7	16.3	792
Transportation	60.4	39.6	808
Day care	58.5	41.5	810
Baby sitting	49.6	50.4	817
Counseling	53.9	46.1	799
Case management	65.3	34.7	767

Table V.4: Ease of Obtaining Services Reported by Parents Surveyed (Question 5)

Service	Degree of difficulty/ease (percent)					Number of responses
	Very difficult to obtain	Difficult to obtain	Neither difficult nor easy	Easy to obtain	Very easy to obtain	
Medical services						
Physician home visits	41.2	16.7	15.7	16.7	9.8	102
Physician office visits	2.4	4.0	12.4	41.7	39.5	823
Medical equipment	6.0	10.0	17.9	44.7	21.5	470
Medical supplies for equipment	5.6	9.7	16.4	44.8	23.5	464
Medications	2.6	6.6	12.5	45.5	32.8	759
Skilled nursing visits	15.9	11.5	26.9	27.9	17.8	208
Rehabilitative & other therapies	13.6	16.1	23.4	31.5	15.4	273
Support services						
Respite care	34.2	18.4	24.3	15.8	7.2	152
Homemaker services	31.0	18.6	29.5	15.5	5.4	129
Transportation	15.0	17.2	21.9	29.4	16.6	320
Day care	32.7	23.8	18.8	16.7	8.0	336
Baby sitting	34.5	23.3	16.5	17.7	8.0	412
Counseling	13.6	18.2	22.6	31.5	14.1	368
Case management	14.7	16.2	27.4	29.7	12.0	266

Appendix V
Parents' Responses to GAO Parent
Survey Form

Table V.5: Average Monthly Expenses for Services Reported by Parents Surveyed (Question 6)

Range of monthly expenses	Percent of responses
Under \$250	27.7
\$250 to \$999	23.6
\$1,000 to \$5,000	15.9
Over \$5,000	13.8
Don't know	18.9

Note: No of responses, 867

Table V.6: Insurance Coverage for Services for Children Surveyed (Question 7)

Range of coverage	Percent of responses
Child not covered by insurance	9.9
Up to 25%	2.4
About 26-50%	3.7
About 51-75%	14.7
About 76-100%	59.4
Don't know	10.0

Note: No of responses, 871

Table V.7: Education Level of Parents Surveyed (Question 13)

Highest education level	Percent of responses
Grades 1 through 8	4.0
Some high school	7.6
Graduated from high school or G.E.D.	42.7
Associate Degree	12.8
Bachelor's Degree	20.6
Master's or Doctorate Degree	12.4

Note: No of responses, 885

Table V.8: Annual Family Income of Parents Surveyed (Question 14)

Income level	Percent of responses
Under \$5,000	12.4
\$5,000 to \$9,999	10.3
\$10,000 to \$19,999	16.2
\$20,000 to \$29,999	18.9
\$30,000 to \$39,999	16.0
Over \$40,000	26.2

Note: No of responses, 870

Appendix VI

Agency Comments



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

Washington, D.C. 20201

MAY 24 1989

Mr. Lawrence H. Thompson
 Assistant Comptroller General
 United States General
 Accounting Office
 Washington, D.C. 20548

Dear Mr. Thompson

Enclosed are the Department's comments on your draft report, "Health Care: Home Care Experiences of Families with Chronically Ill Children." The enclosed comments represent the tentative position of the Department and are subject to reevaluation when the final version of this report is received.

The Department appreciates the opportunity to comment on this draft report before its publication.

Sincerely yours,

Richard P. Kusserow
 Inspector General

Enclosure

Appendix VI
Agency Comments

COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES
ON THE GENERAL ACCOUNTING OFFICE'S DRAFT REPORT, "HEALTH
CARE: HOME CARE EXPERIENCES OF FAMILIES WITH CHRONICALLY
ILL CHILDREN," APRIL 1989

General Comments

We believe that the General Accounting Office (GAO) review should have addressed the other programs impacting on chronically ill children which are administered by the Office of Human Development Services (OHDS), e. g., administration for children, youth and families, administration on developmental disabilities, administration for Native Americans. In addition to these service programs, OHDS also funds through discretionary authorities research and demonstration programs, i. e., child welfare, respite care, head start, and family support.

GAO Recommendation

To facilitate the consolidation and publication of information on services for chronically ill children and ensure that case management services are available when needed, we recommend that the Secretary of Health and Human Services direct the Bureau of Maternal and Child Health and Resources Development to take a leadership role in developing necessary policy and program guidance for state maternal and child health agencies. Such policy should be aimed at ensuring that (1) information on providers and services in a given community is consolidated and made available to organizations servicing chronically ill children, (2) this information is provided to parents at time of discharge, and (3) case management services are made available to those who need direct assistance.

Department Response

We concur. The Bureau of Maternal and Child Health and Resources Development (BMCHRD), Health Resources and Services Administration, has and will continue to exercise an active role in developing the necessary policy and program guidance. For example, BMCHRD assisted in the preparation of the June 1987 Surgeon General's Report entitled "Children With Special Health Care Needs, Campaign 1987." This report established a national agenda for developing a commitment to family-centered, community-based, coordinated systems of care, and addressed the three steps recommended by GAO. The agenda has the support of major volunteer and public and private agencies concerned with health care of chronically ill children in this country. Additionally, the Maternal and Child Health Services (MCHS) Block Grant statute already supports a wide range of activities including the three steps detailed in this recommendation. Moreover, BMCHRD has issued guidance to the States regarding service networks and case management services. In addition, MCHS Block Grant funds have been used to establish a national information network which includes an 800 number.

Appendix VII

Major Contributors to This Report

**Human Resources
Division, Washington,
D.C.**

J. William Gadsby, Director, Intergovernmental and Management Issues,
(202) 275-2854
John M. Kamensky, Assistant Director
Robert F. Derkits, Evaluator-in-Charge
Endel Kaseoru, Site Senior

**Atlanta Regional
Office**

Nancy T. Toolan, Site Senior
Katherine Dubuisson, Evaluator

**Cincinnati Regional
Office**

Michael F. McGuire, Site Senior
Christine D. Dooley, Evaluator

Dallas Regional Office

Mary K. Muse, Site Senior
Jerilyn Green, Evaluator

**Los Angeles Regional
Office**

Alexandra Y. Martin, Site Senior
Aleta L. Hancock, Evaluator

PREPARED STATEMENT OF LOUIS B. HAYS

MR. CHAIRMAN, MEMBERS OF THE COMMITTEE, I AM PLEASED TO BE HERE TODAY TO DISCUSS THE ADMINISTRATION'S BILL, S.902, WHICH WOULD EXPAND ELIGIBILITY FOR PREGNANT WOMEN AND INFANTS UNDER THE MEDICAID PROGRAM. THIS LEGISLATION WOULD PUT INTO EFFECT THE PRESIDENT'S STRONG COMMITMENT EXPRESSED IN HIS FEBRUARY 9 ADDRESS TO THE NATION TO IMPROVING THE HEALTH OF MOTHERS AND CHILDREN. TO QUOTE THE PRESIDENT, "INFANT AND MATERNAL HEALTH IS AN AREA WHERE WE MUST INVEST IN THE FUTURE...AND WHERE WE MUST ALL BE COMMITTED TO IMPROVEMENT."

SECRETARY SULLIVAN HAS MADE THIS ISSUE A TOP PRIORITY AT THE DEPARTMENT OF HEALTH AND HUMAN SERVICES. HE TOO IS DEEPLY CONCERNED FOR THE WELL BEING OF THIS UNDERSERVED POPULATION.

AND, MR. CHAIRMAN, I AM AWARE OF YOUR OWN PERSONAL COMMITMENT TO BETTER HEALTH CARE FOR CHILDREN AS EVIDENCED BY THE LEGISLATION YOU HAVE SPONSORED IN THIS AREA.

AS THIS COMMITTEE IS WELL AWARE, THE UNITED STATES CONTINUES TO LAG BEHIND OTHER DEVELOPED NATIONS IN MEASURES OF INFANT MORTALITY. EVEN MORE DISTURBING IS THE FACT THAT THE INFANT MORTALITY RATE FOR BLACK INFANTS IS NEARLY TWICE THAT FOR WHITES. CLEARLY, WE MUST COMMIT OUR RESOURCES AND TALENTS TO IMPROVING THE LIVES OF OUR YOUNGEST CITIZENS.

THE PRESIDENT'S PROPOSALS

MEDICAID PLAYS A CRUCIAL ROLE IN MAKING HEALTH CARE AVAILABLE TO THE DISADVANTAGED. IN 1990 FEDERAL AND STATE SPENDING ON THIS PROGRAM WILL APPROACH \$70 BILLION. THE ADMINISTRATION IS COMMITTED TO FULL FUNDING OF THE MEDICAID PROGRAM RESULTING IN NEARLY A 10 PERCENT SPENDING INCREASE OVER 1989 EXPENDITURES.

BUT THE PRESIDENT RECOGNIZES THE NEED TO IMPROVE HEALTH CARE FOR LOWER INCOME AMERICANS AND HAS CHOSEN TO FOCUS FIRST ON THE POPULATIONS MOST AT RISK--PREGNANT WOMEN AND INFANTS. THE ADMINISTRATION'S BILL--INTRODUCED BY THE MINORITY LEADER SENATOR DOLE ON MAY 3, AND CO-SPONSORED BY MEMBERS OF THIS COMMITTEE, IS AN IMPORTANT FIRST STEP IN CARRYING OUT THAT GOAL.

S.902, -- THE MEDICAID PREGNANT WOMEN, INFANTS, AND CHILDREN AMENDMENTS OF 1989--ADDRESSES THE NEED BY:

- O EXPANDING ELIGIBILITY UP TO 130% OF THE POVERTY LINE FOR PREGNANT WOMEN AND INFANTS UNDER MEDICAID, MAKING SOME 374,000 NEWLY ELIGIBLE;
- O ENCOURAGING ELIGIBLE PREGNANT WOMEN TO USE MEDICAID BY PROVIDING PRENATAL SERVICES UPON REQUEST AND BEFORE A FORMAL ELIGIBILITY DETERMINATION IS MADE, AND REQUIRING OUTREACH PROGRAMS IN STATES WITH AREAS OF HIGH INFANT MORTALITY;
- O ENTITLING ALL CHILDREN UNDER THE AGE OF 6 WHO RECEIVE FOOD STAMPS TO MEDICAID COVERAGE OF IMMUNIZATIONS;

- O INVESTING \$20 MILLION IN BOTH FY 1990 AND 1991 FOR DEMONSTRATION PROJECTS TO IMPROVE THE CO-ORDINATION AMONG THREE FEDERAL PROGRAMS--THE MEDICAID; MATERNAL AND CHILD HEALTH; AND, THE WOMEN, INFANTS, AND CHILDREN NUTRITION PROGRAMS.

- O FUNDING THESE EXPANSIONS BY GRADUALLY REDUCING SPECIAL FEDERAL ADMINISTRATIVE MATCHING RATES TO A UNIFORM 50 PERCENT, THUS USING THIS SAVINGS TO FUND PROGRAM EXPANSIONS WITHIN THE CURRENT PROGRAM SPENDING LEVELS.

EXPANDING ELIGIBILITY

CURRENT MEDICAID LAW REQUIRES STATES TO COVER PREGNANT WOMEN AND INFANTS (UP TO AGE ONE) WITH INCOMES AT OR BELOW THE POVERTY LINE BY JULY 1, 1990. STATES MAY CHOOSE TO COVER SUCH FAMILIES WITH INCOMES UP TO 185 PERCENT OF THE POVERTY LINE.

THE ADMINISTRATION'S PROPOSAL WOULD REQUIRE STATE MEDICAID PROGRAMS, BY APRIL 1, 1990, TO COVER PREGNANT WOMEN AND INFANTS WHOSE INCOME DOES NOT EXCEED 130 PERCENT OF THE FEDERAL POVERTY LEVEL. (THE OPTIONS FOR STATES TO EXTEND COVERAGE UP TO 185 PERCENT OF POVERTY WOULD REMAIN IN THE LAW.) UNDER THE PRESIDENT'S PROPOSALS A PREGNANT WOMAN WITH ANNUAL INCOME OF UP TO \$13,078 WOULD BE ELIGIBLE; AND, A HOUSEHOLD OF FOUR COULD HAVE \$18,382.

ENCOURAGING PARTICIPATION

BECAUSE OF THE IMPORTANCE OF EARLY PRENATAL CARE, THE PRESIDENT'S PROPOSAL SEEKS TO ENCOURAGE ELIGIBLE WOMEN TO OBTAIN SERVICES COVERED BY MEDICAID. UNDER CURRENT LAW, STATES MAY DESIGNATE QUALIFIED HEALTH CARE PROVIDERS TO MAKE IMMEDIATE MEDICAID ELIGIBILITY DETERMINATIONS AS WOMEN PRESENT THEMSELVES AT

COMMUNITY HEALTH CENTERS, PUBLIC HEALTH DEPARTMENTS, AND MATERNAL AND CHILD HEALTH CARE CLINICS. THIS PRESUMED ELIGIBILITY ENTITLES A WOMAN TO CARE FOR UP TO 45 DAYS DURING WHICH TIME SHE MUST FILE FOR A FORMAL ELIGIBILITY DETERMINATION WITH THE STATE. TWENTY STATES HAVE ELECTED THIS OPTION.

THE ADMINISTRATION'S PROPOSAL WOULD REQUIRE ALL STATES TO OFFER PRESUMPTIVE ELIGIBILITY DETERMINATIONS. FOR EXAMPLE, ANY PREGNANT WOMAN WITH A FOOD STAMP CARD COULD BE FOUND TO BE IMMEDIATELY ELIGIBLE FOR MEDICAID. AND, THE PERIOD OF PRESUMPTIVE ELIGIBILITY WOULD BE EXTENDED TO 60 DAYS. STATES WILL HAVE TO DEMONSTRATE THEIR EFFORTS TO MAKE THIS AVAILABLE TO PREGNANT WOMEN IN ALL PARTS OF THE STATE. FINALLY, STATES WILL BE REQUIRED TO CONDUCT OUTREACH AND PUBLIC EDUCATION CAMPAIGNS IN AREAS WITH HIGH RATES OF INFANT MORTALITY.

ENTITLING CHILDREN TO IMMUNIZATIONS

ONE OF THE MOST COST-EFFECTIVE WAYS TO ENSURE CHILDRENS' HEALTH IS TO PROTECT THEM FROM THE DISABLING AND SOMETIMES FATAL DISEASES OF CHILDHOOD. TO THIS END, THE PRESIDENT'S PROPOSAL WOULD ENTITLE ALL CHILDREN UNDER THE AGE OF 6 WHO RECEIVE FOOD STAMPS TO GET MEDICAID COVERAGE FOR IMMUNIZATIONS.

INVESTING IN DEMONSTRATION PROJECTS

MEDICAID ALONE WILL NOT SOLVE THE PROBLEM OF HIGH INFANT MORTALITY. THERE ARE SEVERAL IMPORTANT GOVERNMENT PROGRAMS THAT ADDRESS THE PROBLEM. THE DEPARTMENT OF AGRICULTURE OPERATES THE WOMEN, INFANTS, AND CHILDREN NUTRITION PROGRAM. THIS PROGRAM DEALS WITH ONE PART OF GOOD MATERNAL AND INFANT HEALTH--ADEQUATE NUTRITION. OUR DEPARTMENT ADMINISTERS BOTH THE MEDICAID AND MATERNAL AND CHILD HEALTH BLOCK GRANT PROGRAMS, THE LATTER OF

WHICH PROVIDES GRANTS TO THE STATES TO ASSURE MOTHERS AND CHILDREN ACCESS TO HEALTH SERVICES.

THE PRESIDENT'S PROPOSAL INCLUDES \$20 MILLION FOR FY 1990 AND 1991 TO TEST WAYS OF CO-ORDINATING THESE PROGRAMS TO MAXIMIZE THEIR EFFECTIVENESS IN COMBATTING HIGH INFANT MORTALITY. THE RESULTS WILL BE USED TO FASHION FUTURE REFORMS OF SERVICE DELIVERY UNDER THESE PROGRAMS.

FUNDING MEDICAID ENHANCEMENTS

TO MAKE THESE IMPORTANT ENHANCEMENTS TO THE MEDICAID PROGRAM BUDGET NEUTRAL, THE PRESIDENT'S BUDGET HAS PROPOSED OFFSETS FOR CONGRESS' CONSIDERATION. WHILE THE PRESIDENT ACKNOWLEDGES THAT THIS LEGISLATION "...DOES NOT DO ALL WE WANT TO DO....IT DOES DO WHAT WE CAN DO AT THIS TIME." INVESTING IN MATERNAL AND INFANT HEALTH IS THE HIGHEST PRIORITY FOR THE MEDICAID PROGRAM, THUS IT DRIVES US TO LOOK AT LOWER PRIORITY SPENDING AS A MEANS TO FINANCE THIS EXPANSION. THE PRESIDENT NOTED THAT "...AT A TIME LIKE TODAY WHEN RESOURCES ARE TIGHT, WHEN WE HAVE MORE DESIRES THAN FUNDS, WE MUST MOVE RESOURCES FROM CERTAIN LOWER PRIORITIES TO THE HIGHER PRIORITY OF MATERNAL AND INFANT HEALTH."

THE ADMINISTRATION PROPOSES TO FUND THESE EXPANSIONS BY GRADUALLY DECREASING THE FEDERAL MATCH FOR ALL ADMINISTRATIVE SERVICES TO 50 PERCENT. OVER THE YEARS ENHANCED ADMINISTRATIVE MATCHING RATES HAVE BEEN AUTHORIZED TO ENCOURAGE STATES TO UNDERTAKE MANAGEMENT IMPROVEMENTS. FOR EXAMPLE, TO PROVIDE INCENTIVES TO STATES TO DEVELOP MEDICAID INFORMATION SYSTEMS, THE FEDERAL GOVERNMENT MATCHES AT 75 PERCENT TO OPERATE THESE SYSTEMS AND AT 90 PERCENT TO DEVELOP NEW USES. ALL 50 STATES HAVE IMPLEMENTED COMPUTER SYSTEMS, AND CLEARLY WILL CONTINUE TO USE SUCH

TECHNOLOGY TO RUN MEDICAID IN AN EFFICIENT MANNER. STATES NO LONGER NEED "ENCOURAGEMENT" TO OPERATE COMPUTER SYSTEMS, THUS CONTINUATION OF ENHANCED MATCHING RATES CLEARLY GOES WELL BEYOND THE ORIGINAL INTENT. THUS WE PROPOSE TO PHASE-DOWN OVER A SEVERAL YEAR PERIOD ENHANCED MATCHING RATES THAT HAVE OUT-LIVED THEIR PURPOSE AND TO PUT THAT MONEY IN PROGRAM ENHANCEMENTS. NONE OF THE FEDERAL MATCHING RATES WOULD GO BELOW 50 PERCENT WHICH IS THE RATE GENERALLY USED FOR ADMINISTRATIVE ACTIVITIES. AND, THERE WOULD BE NO CAP ON THE AMOUNT OF FEDERAL FUNDS MATCHABLE. BY PHASING DOWN OVER A PERIOD OF YEARS STATES WILL BE ABLE TO TAKE NECESSARY ACTION TO ADJUST TO THE REDUCTION.

MR. CHAIRMAN, THE PRESIDENT HAS SUBMITTED A RESPONSIBLE PROPOSAL TO ADDRESS THE NATIONAL PROBLEM OF CHILDRENS' HEALTH. IT IS A BEGINNING--IT IS WHAT WE CAN AFFORD RIGHT NOW. MORE NEEDS TO BE DONE, AND WE INTEND TO DO IT IN A THOUGHTFUL WAY THAT MEETS PRIORITY HEALTH CARE NEEDS WITHOUT VIOLATING BUDGET AGREEMENTS. I NOTE THAT YOU HAVE SEVERAL PIECES OF LEGISLATION PENDING BEFORE THIS COMMITTEE WHICH SHARE THE SAME GOALS AS THE ADMINISTRATION'S PROPOSAL. OUR OBJECTIVES ARE THE SAME ON THIS ISSUE.

CONCLUSION

IN CLOSING, I WOULD LIKE TO REAFFIRM OUR COMMITMENT TO THE PRIORITY OF MATERNAL AND INFANT HEALTH. THERE IS NO DEBATE ABOUT THE NEED TO WIN THE BATTLE AGAINST HIGH INFANT MORTALITY IN OUR VERY PROSPEROUS COUNTRY. IT IS A BATTLE THAT INVOLVES ALL HEALTH CARE POLICY-MAKERS.

I ASK FOR YOUR FAVORABLE CONSIDERATION AND SUPPORT OF S.902, WHICH IS A STARTING POINT IN OUR STRATEG! TO INCREASE EVERY INFANT'S CHANCE FOR A HEALTHY BIRTH AND A LONG LIFE.

PREPARED STATEMENT OF AARON J. JOHNSON

Mr. Chairman, members of the Committee, I am Aaron Johnson, Commissioner of the Georgia Department of Medical Assistance. I speak to you today as both the Chairman of the National Council of State Human Service Administrators Health Care Committee and Chairman of the State Medicaid Directors' Association. Both these organizations are integral parts of the American Public Welfare Association (APWA).

Let me begin by thanking the Chairman and members of this Committee for providing this opportunity today to discuss children's health. I also want to commend this Committee's leadership in the area of infant and child health, indigent care, and long term care. Members of this Committee have worked long and hard to bring attention to, and resolution of, the plight of those who have inadequate access to the health care system. Those efforts are starting to come to fruition. The American people are more aware of the problems and more willing to accept changes in the system.

I would like to now turn my attention to the issue before us children's health care under the Medicaid program—and to address what I believe to be the key aspects in the various Medicaid bills. Those issues are: program innovation, eligibility, presumptive eligibility, adequate provider reimbursement, outreach and inpatient service limits/payments.

INNOVATION

States strongly support efforts to provide funding for demonstration projects for greater coordination among the various agencies that provide needed services to pregnant women, infants, and children. This will build on many efforts already underway in the states, including improved outreach programs, outstationing eligibility workers, education on the need for early prenatal care and attention to wellness.

States also strongly support authority for demonstration projects to improve provider participation in the EPSDT program. The State Medicaid Directors' Association recently formed a work group, a subset of the Maternal and Child Health Technical Advisory Group (MCH TAG) that will focus on collecting information from the states on their EPSDT programs, review current problems, and develop recommendations for action. I might also add that the MCH TAG, composed of both Medicaid and Maternal and Child Health representatives, has been actively working with the Health Care Financing Administration to address many of the concerns of both Congress and the states regarding infant mortality.

ELIGIBILITY

States have long advocated for breaking the tie between eligibility for cash assistance and Medicaid eligibility to allow more people access to health care services because health care is a very different market good than food, shelter or housing. A first step was taken several years ago under SOBRA. A majority of states (29) have taken up the option to cover pregnant women up to 100 percent of poverty. States then began to advocate for the option to provide coverage for higher income levels among pregnant women and infants, in response to rising infant mortality rates. That option came with OBRA '87, and 12 states have moved to cover pregnant women and infants up to 185 percent of poverty. Virtually all states have responded in some manner to the need for expanded coverage for pregnant women and infants.

I would like to also stress that states have been in the forefront of advocating for the option to expand income-related eligibility for older children, up to the age of 18. State administrators have been among the first to recognize both the needs of older children who do not qualify for cash assistance, and how Medicaid currently cannot address those needs. Thirty-two states now provide optional income-related coverage for children between the ages of two and five.

However, not all states have pursued the new, higher income option up to 185 percent for pregnant women and infants for a variety of reasons. Like the Federal Government, many states find themselves in a period of budgetary constraint. States are concurrently dealing with the substantial budgetary impact of changes to other parts of the program, notably nursing home reform, and the Qualified Medicare Beneficiary provisions of the Catastrophic Care Act. Expanding eligibility for one segment of the Medicaid population has very real implications for other parts of the total Medicaid population. Many state directors, working within constrained budgets, are in the unenviable position of deciding what services to cut back in order to fund other mandated programmatic expansions.

The point here is that the states that have not yet pursued the 185 percent option have valid, and considered, reasons not to do so. A mandate at this time may not be

the most appropriate method by which to address the problem given the competing needs. I would further add that any reductions in Federal funds for the administrative side of the program, in order to enact expanded coverage, is completely unacceptable to the states. This would have a severe impact on the programs we administer. States cannot be expected to bear the total cost of mandated programmatic expansions.

PRESUMPTIVE ELIGIBILITY

There is a growing interest in the Medicaid presumptive eligibility process. State reaction to this option has been mixed. The twenty or so states that have pursued this option have found it useful, however most believe the statute needs some modification. Specifically, the 14-day time limit for a woman to file a formal application has proven to be a barrier to access to care. The woman for whom presumptive eligibility is designed cannot typically jump in a car to visit a physician or the eligibility worker. She often has to arrange child care and or transportation, and do so without sufficient financial resources. Fourteen days is frequently too tight a time frame. States would advocate that the current 14 day time frame be removed completely and that a 45 or 60 day time frame for final determination remain.

Many states have not pursued the presumptive process for a variety of reasons. Many feel that the statutory language defining a qualified provider nets little advantage in the struggle against infant mortality. Essentially, states are limited to defining providers as MCH clinics and health departments. Finally, many states believe that the presumptive process provides no real gain because it is a two step process, whereas, regular eligibility is a one step process.

The fact that a majority of states have not adopted presumptive eligibility does not mean that they have not been addressing the need for a quick turn-around on eligibility determinations for pregnant women. Many states have expedited eligibility processes that will provide a pregnant woman with a medical assistance card in 15 days or less, with eligibility retroactive for 90 days. These systems are working exceedingly well. It is because of states like these, that mandating a national presumptive process would constitute a step backward. A mandate of this nature would effectively limit a state's ability to institute creative alternative strategies for providing expedited access.

I would also like address some of the reasons why several states have neither a presumptive nor an expedited process. In most states, Medicaid eligibility is determined by a worker who also works on AFDC and food stamps. These front line workers, who see great need every day, frequently argue that the need for medical care does not necessarily outweigh the need for food, shelter and clothes. It is this debate that has stymied an expedited process because a separate application for medical assistance that includes no resource test (which is required for AFDC and food stamp eligibility) may slow a woman's eligibility for other services. Further, some have argued that an expedited process for a pregnant woman's Medicaid eligibility ties the hands of eligibility workers to triage the caseload in terms of other clear emergencies. One state has creatively surmounted this very real dilemma by deciding that the pregnant woman must receive a card prior to the date of the next scheduled prenatal care visit, however soon that may be. This has allowed the worker some of the latitude needed to address the variety of needs of diverse populations.

State administrators realize that no course of action is simple and without ramification. I urge this Committee to attempt to address these concerns in the continuing debate on appropriate legislation.

ADEQUATE PROVIDER REIMBURSEMENT

Adequate provider reimbursement, as a function of access to care, is of interest to the states as well as Congress. The question remains, to what extent will the amount of payment increase provider participation? How far do we raise rates before we can discount payment level as a factor in access to care? Many states have undertaken rate increases in the past few years. There are several states where payments are close to the market rate and yet provider participation has not improved commensurate with the rate increases.

What this information signifies is that there are a myriad of other factors that affect provider participation in the Medicaid program. Some of the factors that we have identified include: provider enrollment and reporting; billing complexity; malpractice costs, for the ob/gyn in particular; lack of rural providers; and lack of assured and continued client eligibility so that providers are not at financial risk for provision of services.

States are trying to grapple with these difficult issues. While some initiatives appear promising, no final conclusion can yet be drawn. Mandating adequate reimbursement rates that assume a commensurate increase in access to care, when we are not sure how to define 'adequate' is a highly problematic proposition for state agencies, particularly given the existence of other mitigating factors.

While increasing rates will certainly not harm access, it is not at all clear that access will improve as a result. A more prudent method by which to address this issue would be through demonstration authority aimed at exploring more fully the relationship between access and reimbursement rates. Another option would be to look incrementally at different pieces of the puzzle. Providing funding for states to increase rates in targeted areas, such as rural areas, would give us information upon which to evaluate a future course of action. We may ultimately find that adequate reimbursement means paying above the market to assure a mainstream level of access for the Medicaid client.

States are also concerned about the growing emphasis on increased reporting and data collection. Like Congress, states very much want better quantitative data about access to care. In most cases, however, collecting this information depends on the good will and voluntary participation of the provider. For instance, even state licensing, where a doctor or nurse is asked to declare their specialty certification, is a voluntary self-declaration, which is not verified by the state licensing board. The state licensing board is not under the control of the state welfare or Medicaid agency.

State desire for better information is exemplified by efforts to know more about the effectiveness of EPSDT, and they have tried to collect accurate data. However, tracking the initial health screen often depends on the provider's willingness to use proper billing codes. Associating EPSDT follow-up care and treatment to the initial screen depends on both the provider's awareness of the antecedent to a particular visit and then upon their willingness to fill out the claim form fully with optional information.

Mandating collection of information that is dependent upon provider participation is a tenuous proposition. If we increase provider reporting requirements, we will likely lose another degree of participation in the program. Holding states accountable for information from an essentially voluntary source is particularly onerous. Using data that has a high probability of being incomplete and therefore, inaccurate, is not a practice states can support.

States do not have the information that Congress seeks, not because they don't care, but because they have not been successful in obtaining it.

Collection of data on the timeliness of prenatal care is another issue where states have strong concerns, primarily because state agencies do not currently capture it. In many states, some data is collected by the health department and is often inaccurate because information comes from the delivering provider. The provider who delivered a child may not be the same provider who provided early prenatal care. Or, if the information is to be collected through the MMIS, the woman may not have been on Medicaid early in her pregnancy so any early prenatal care would not be in the system. How are state agencies to overcome these issues in an efficient and consistent manner? It is an issue that must be overcome if approval of state plan amendments and reimbursement rates will become contingent upon this data.

The concept of associating timeliness of care with access to care is also highly problematic. A woman's ability/desire to seek early prenatal care could be affected by: drug dependency, cultural issues, lack of education, even denial of health status in the case of a teenager. States are very concerned about judging access and reimbursement rates by using data that are both incomplete, and without simple or direct correlation.

States want, and need, accurate data. We have not been able to develop comprehensive and proper collection systems, in large part due to the private/public nature of the Medicaid program and the health care system as a whole. Mandating data requirements on the Medicaid agency without resolving some of the inherent problems is strongly discouraged.

A final issue to be raised here is that it is not an easy choice for a state to redirect resources away from client services to administrative needs. Changes in information systems and data collection require substantial allocations of resources, both human and fiscal. States must be provided sufficient time and resources so that any mandated changes can be implemented correctly, thoroughly, and without affecting client services. Information is never free of cost. States believe that recognition must be given to the cost of providing and collecting information, and who is being asked to bear that cost.

OUTREACH

Any effort to provide increased funding for a variety of outreach activities for pregnant women would be welcome by states. Enhanced funding would provide incentive for those states that have not yet undertaken such activities, and would allow the many states that have begun such efforts to build upon, and expand existing programs.

INPATIENT DAY LIMITS/REIMBURSEMENT

I am pleased to say that many states have moved to unlimited inpatient days under Medicaid and have capitated payment systems that account for catastrophic costs resulting from extended lengths of stay, which addresses part of the concerns of disproportionate share hospitals.

States believe disproportionate share payment is an appropriate public policy for hospitals that have a commitment to serving the poor. However, states that continue to have a cap on inpatient hospital days are concerned about efforts to further eliminate that cap for older children served in disproportionate share hospitals. States believe there are equity considerations involved in such a mandate. Eliminating amount and durational limits for one specific subset of the total Medicaid population indicates that one population is more important than another within the same program. There is also concern about the effects such a mandate might have on access to inpatient services in a geographic area. In addition, there are also cost considerations that will impact the program as a whole.

SSI CHILDREN AND MEDICAID ELIGIBILITY

Related to children's health and the Medicaid program is the issue of SSI eligibility. States have a growing concern for SSI children who lose Medicaid eligibility in particular months when their parents may have income in excess of SSI standards due to irregular pay periods. While the children are reinstated in the program several weeks later, this temporary discontinuance of coverage can have substantial adverse impacts. There are also agency administrative considerations involved in removing a child from the rolls, and then reinstating them several weeks later. States fully support any efforts this Committee would undertake to allow consideration of annualized income for SSI eligibility where an irregular pay period would result in temporary termination.

SUMMARY

In summary I would say that states, in general, are equally cognizant of the problems and need for change. States have been making good faith efforts to expand and expedite eligibility, increase outreach, and educate about wellness to combat increased infant mortality. We remain unconvinced, however, that mandating further incremental expansions and reporting requirements at this time constitutes a realistic solution. Further mandates at this time will have significant implications for the whole of the Medicaid population in different states.

The APWA has given the issue of access to health care serious consideration over the past two years and has published a set of proposals for broader reform. We are aware that our proposals do not constitute the ultimate resolution to all the health care problems, but we believe they are a substantive place to start.

I would like to stress that states want to work together with Congressional leaders and their staffs to develop a set of viable proposals based on what we, together, know at this point. It is clear that something needs to be done.

Our system of governance is based on federal/state partnership. That partnership must be evaluated, in the context of the Medicaid program, and built upon in order to turn our nation's health care situation around.

Thank you for the opportunity to testify today.

 PREPARED STATEMENT OF KAY JOHNSON

Mr. Chairman and Members of the Committee: My name is Kay Johnson, and I am the Director of the Health Division of the Children's Defense Fund (CDF). On behalf of the CDF, I want to thank you for this opportunity to testify today regarding programs which promote the health of children. CDF exists to provide a strong and effective voice for the children of America who cannot vote, lobby, or speak for themselves. We pay particular attention to the needs of low income and minority children. For more than 15 years, our efforts to improve programs and policies for

children have included extensive work on reforms in the Medicaid and Title V Maternal and Child Health Programs.

I want to commend you, Mr. Chairman, for holding this hearing today to focus attention on our key publicly funded maternal and child health programs. For millions of low income families, lack of access to adequate needed health care has become a serious threat. Erosions in family income, health insurance, and health status have led to widening cracks in our health care system which the current programs have been unable to fill.

While my written testimony discusses at greater length, the size of this problem and the barriers to health care services which exist for children and families, in the interest of time, I will briefly summarize the recommendations it contains. However, I would like to submit a complete written statement for the record.

I. WHAT IS THE EXTENT OF HEALTH INSURANCE COVERAGE FOR CHILDREN PREGNANT WOMEN?

In recent years, the problem of uninsuredness has been growing. Children are especially likely to be uninsured as a group—representing approximately one-third of the more than 37 million uninsured Americans under age 65.¹ As a result of reductions in coverage under employer-based health insurance plans and reductions in Federal and state public insurance programs for low-income children, fewer children today have health insurance coverage.

Poor children, whose families generally lack the means to pay for health care expenses “out-of-pocket” are among those most likely to be uninsured.

- Between 1980 and 1985, the proportion of children under age 18 covered by employer insurance fell by 6 percent (from 64.6 percent to 60.6 percent). Among poor children under age 18, the proportion privately covered declined by one-quarter, from 16.9 percent to 12.8 percent.²

- In 1986, nearly one out of every 5 children in families over 11 million nationwide—had no health insurance, public or private.³ (Table 1)

- By 1986 nearly one-third of all poor children were completely uninsured. This translates into 4 million poor children nationwide. While an estimated 1 million to 1.5 million children have been added to the Medicaid program since 1986, the remaining 2.5 million to 3 million lack the key to access to health care—insurance.

- In 1986, more than 4 out of every 10 children in employed poor families had no health insurance public or private. (Table 2, Figure 1) These children have traditionally been left outside of the scope of the Medicaid program and, increasingly, their families lack employer-based dependent coverage.

In fact, the absence of health insurance, public or private, is most clearly seen in low income working families. Children in low income working families are less likely to have access to employer-based family coverage, and yet nonetheless are unlikely to be eligible for Medicaid. Many children in such families could be classified as “near-poor” (with family incomes between 100 and 200 percent of the Federal poverty level).

- In 1986, nearly 3 out of 10 children in near-poor families had no health insurance. (Table 2A, Figure 2)

- In that year, just over half of near-poor children had private, employer-based health insurance coverage. Moreover, among this group, the full cost of the children’s premiums was covered by the employer or union in only 32 percent of the cases.

The best way to ensure that a child will begin life as healthy as possible, is to ensure the health of the mother during pregnancy through prenatal care. Women of childbearing age need access to health care, especially during a pregnancy. Yet inadequate health insurance coverage acts as a barrier to health care for women.

- Among women of childbearing age (15-44 years), 9.5 million had no health insurance, public or private, in 1985. If women who have some health insurance but lack adequate maternity care coverage were included, then over 14 million women were completely unprotected against the cost of maternity care in 1985.⁴

While recent Federal changes in Medicaid ensure coverage of all poor pregnant women beginning in 1990, millions of near-poor women continue to be uninsured or underinsured. These women, generally young, married, and in a employed family with an annual income of just under \$20,000, are most typical of those who give birth today.⁵

II. WHAT IS THE RELATIONSHIP BETWEEN INSURANCE STATUS, HEALTH CARE UTILIZATION, AND HEALTH STATUS?

Study after study has shown that health insurance is a significant determinant of health care utilization. The uninsured use substantially fewer services than their insured counterparts, even when health status and the need for services is taken into account.⁶ Research also has shown that even among the poorest families, publicly-funded health care coverage can bring health care utilization up to average levels.⁷

- National survey data reveal that low-income uninsured children have a lower likelihood of, and a significantly lower average of, visits to physicians. When adjusted for health status, uninsured children remain most likely to have no physician visits in a year.⁸

- Even among children with identified disabilities who participate in special education programs, lack of health insurance has been found to be associated with reduced access to necessary health care.⁹

- However, poor children with Medicaid coverage are far more likely than uninsured poor children to have a regular source of health care and to visit a physician in a year. Medicaid recipient children use services in a pattern similar to that of their affluent, privately insured counterparts.¹⁰

- Uninsured low income women are less likely to receive care early in pregnancy and are twice as likely to receive late or no prenatal care.¹¹

At the same time, research indicates the extent to which adequate access to health care is critical to maternal and health and saves money by preventing unnecessary illness, disability, and death.

Maternity care, beginning with prenatal care in the critical first three months of pregnancy and continuing through the birth of a child, can dramatically improve maternal and infant health. An infant born to a woman receiving no prenatal care is more than 3 times more likely to die in the first year of life.¹² Prenatal care can save \$3 for every \$1 invested.¹³ Yet each year, millions of infants are born to women who did not receive early care.

- In 1986, about one in four babies nationwide was born to a mother who did not benefit from early care. (Table 3)

- In that year, only 68 percent of all births occurred among mothers whose prenatal care could be considered adequate, even in terms of timing and frequency of visits.¹⁴

- That year marked the seventh in a row in which the trend in receipt of late (beginning after the sixth month) or no prenatal care worsened or showed no improvement. In 1986, 70,000 infants were born without benefit of any prenatal care.¹⁵

The Institute of Medicine of the National Academy of Sciences reports that "financial barriers—particularly inadequate or no insurance and limited personal funds—were the most important obstacles reported in 15 studies of women who received insufficient care."¹⁶ From New York City to Oklahoma City, these studies document the financial barriers which keep women from receiving early and adequate prenatal care.

Immunizations, beginning in the first months of life, can eliminate the death and disability that can result from now-preventable, childhood diseases such as measles, mumps, pertussis (whooping cough), diphtheria, tetanus, polio, and meningitis. Childhood immunizations save \$10 for every \$1 invested.¹⁷ Inadequate immunization levels lead to outbreaks of preventable disease. However, between 1980 and 1985, immunization levels for our nation's infants and toddlers eroded substantially.¹⁸ (Table 4, Figure 3)

- In 1985, the proportion of infants younger than one with at least one dose of polio or diphtheria, tetanus, and pertussis (DTP) vaccine was lower than in 1980. Among all nonwhite infants, the proportion receiving at least one dose of polio vaccine fell by more than 20 percent, while the proportion receiving at least one dose of DTP vaccine fell nearly as sharply.

- Because the 1985 DTP immunization status of children who had reached age one showed some improvement, it appears that some families may have delayed immunizations and "caught up" later. This places many infants at unnecessary risk for preventable disease.

- Two-year-olds experienced erosion in immunization status in each vaccine category. The overall pattern indicates a significant decrease in the immunization status of two-year-olds.

Comprehensive primary and preventive care for children can detect and treat a wide range of health conditions before they become serious. Screening for lead poi-

soning, learning disabilities, vision impairments, and dental health needs can reduce the consequences of these health problems. Children who receive comprehensive primary health care have annual health costs 7 to 10 percent lower than those who do not. However, many children do not receive such preventive care.

- In 1986, as a result of inadequate access to health care, poor children were considerably more likely than affluent children to have had a routine physical in the previous year.¹⁹

- National surveys indicate that poor children are at least 3 times more likely than affluent children to have never had a physician visit (5.4 percent and 1.6 percent, respectively).²⁰

We understand how to keep most children healthy. We know that every child needs health care. Good medical care begins before a child's birth with comprehensive prenatal care. It continues throughout childhood, with care for a child's preventive, acute, and chronic health care needs.

No child—whether the need is for immunization, treatment for a strep throat, dental care, hospitalization, medicines, or eyeglasses—should go without health care because a family cannot afford it. No pregnant woman should be denied prenatal care because she does not have enough money to pay for it.

The current gaps in insurance coverage and medical care among children are costly in both human and fiscal terms. Maternity and pediatric services have been found not only to be effective but also to be a remarkably cost-effective type of health care investment. Our highly sophisticated medical system can offer preventive or remedial care for most child health problems. Yet a series of events have left our children vulnerable to preventable childhood disease, disability, and death.

III. WHAT POLICY REFORMS ARE NEEDED TO IMPROVE THE ADEQUACY OF PUBLICLY-FUNDED PROGRAMS FOR LOW INCOME FAMILIES, ESPECIALLY CHILDREN

In recent years, Congress has taken steps to improve access to health care for pregnant women, infants, and children. These preventive investments include changes in key maternal and child health programs such as Medicaid, the Title V Maternal and Child Health Block Grant, Community and Migrant Health Centers, childhood immunization, and health manpower programs. I will discuss reforms in the two programs, Medicaid and the Title V Maternal and Child Health Block Grant, which are of particular relevance to the work of this Committee.

A. Medicaid

For low income children and women, Medicaid is the primary health care financing program.

- In 1987, more than 11.6 million children under age 18 received services paid for by Medicaid. Children comprised 50 percent of all recipients.

- Despite its importance, Medicaid still failed to reach all poor children in 1987. Furthermore, children account for only approximately 15 percent of the total expenditures.

- Medicaid paid for maternity care for approximately one-half million births that year—nearly one in every six U. S. births.

Moreover Medicaid is a unique program in its mission to serve a broad range of medically indigent individuals and families. It is the only publicly funded health program sufficiently elastic to permit the development of both a rationalized maternal and child health system and a basic system of long term care for the elderly and disabled. The most notable aspect of the Medicaid reforms we have witnessed over the past five years is precisely that they have been responsive to the needs of many categories of program beneficiaries, not just one or two. This unified and incremental approach to health policy development is a sound and sensible one. CDF strongly supports this unified approach.

Yet despite recent improvements, the Medicaid program continues to fall far short of fulfilling its mission to address the health care needs of poor Americans. Over 50 percent of all poor Americans, and between one-third and one-half of our poor children did not qualify for Medicaid last year. Strict eligibility rules, difficult enrollment procedures, limitations on benefit packages which vary widely from state to state, and low provider participation levels together create significant barriers to access.

Because of the size and scope of the program, recent reforms in Medicaid have the potential to dramatically affect access to care for low income pregnant women, infants, and the youngest children. However, if we are to ensure health care access even for all poor children and pregnant women, Congress and the states must take

additional steps to improve Medicaid in a number of ways. These include the following:

1. Eligibility Expansions

- Medicaid coverage should be provided to all pregnant women and infants with family incomes below 185 percent of the Federal poverty level. Expansion of eligibility to all pregnant women and infants with family incomes below 185 percent of the Federal poverty level will make coverage available to approximately two-thirds of all uncovered mothers and infants.

- The Medicaid program should be expanded to cover all poor children. There is no magic which protects children over age 6 from acute and chronic health conditions. Currently, millions of school age children are without coverage and are forced to go without needed medical and dental care. This type of neglect can lead to school failure and preventable disability. A phased-in mandatory expansion of Medicaid coverage could lead to a one-third reduction in the number of uninsured children. Moreover, states should be given the option to cover all poor children beginning in FY 1990.

- Medicaid eligibility for near-poor children over age one should be phased-in over the coming years. The families of near-poor children are more likely to be working, but without employer provided coverage and unable to afford private coverage for their children. As a result, these families need access to publicly-funded coverage. Provisions for such coverage are included in S. 339 as introduced by Senator Bradley.

- Allow states the option of extending Medicaid to children in non-federally funded foster care placements with family incomes below 100 percent of the Federal poverty level. Many children in non-federally funded foster care nonetheless receive Medicaid because their incomes and resources do not exceed the AFDC guidelines. However, a handful of children (for example, children receiving Social Security Survivors' benefits) have income slightly over the AFDC eligibility level but under the Federal poverty level. These children currently cannot qualify for Medicaid. States that do not opt now to extend Medicaid to all poor children under 18, nonetheless might elect to provide coverage to this subclass of poor children. S. 949 as introduced by Senator Riegle proposes to extend coverage to this group.

- Prohibit "Section 209 (b)" states from denying medical assistance to SSI qualified children with disabilities. Between 5 and 7 states that are so-called "Section 209 (b)" states presently categorically exclude disabled children from their Medicaid programs, even though they meet SSI standards and would be eligible for coverage as adults. We believe that correcting this problem is virtually no-cost, since so few children are affected.

2. Administrative Reforms

Federal support should be available to states to allow improvement of their Medicaid programs in a number of ways. For example, policies which improve and simplify enrollment procedures or enhance provider participation will allow more pregnant women, infants, and children to receive cost-effective primary and preventive health services.²² Moreover, these are low cost initiatives which make Federal and state eligibility expansions meaningful for families at the local community level.

- Modify resource and asset tests to allow more poor pregnant women and children to become eligible for Medicaid. Low income working families need basic household goods and automobiles which allow them to travel to work. They should not be penalized for having such resources. We support the elimination of punitive resource tests for pregnant women and children in low income families.

- Eliminate the distinction between "qualified" children and "poor" children. As mandatory eligibility for poor children expands, there is little reason to retain a subgroup class of very poor children known as "qualified" children (Section 1905(n)(2)). This situation leads to confusion at the Federal, state, and local level.

- Require states to redetermine eligibility for children enrolled in the program before benefits can be terminated. The Family Support Act of 1988 contains important protections specifying that before Medicaid benefits can be terminated in the case of affected families the eligibility for continued benefits of the children in the household must be redetermined to ensure that they do not remain continuously eligible under another classification. As Medicaid eligibility for children is expanded, the need for redetermination protections also grows.

- Structure an option for guaranteed annual enrollment periods which allow children to be continuously enrolled in Medicaid. The on-again, off-again nature of Medicaid enrollment not only creates a barrier for the family seeking access to preventive and primary health care, it also discourages providers from accepting Med-

icaid program participants. Annual enrollment periods would be a big step toward reducing these barriers.

- **Improvements and expansions to the presumptive eligibility programs.** Currently, states have the option to extend presumptive or temporary eligibility to pregnant women through a network of qualified providers. We recommend expansion of this option to allow infants and children to benefit from such systems. Reports from across the country document the tragedies which have resulted from delays in children's eligibility determinations

- **Provide protections for the disproportionate share hospital providers furnishing extended inpatient services to children.** Consistent with 1988 amendments, which allow an adjustment in payment for hospital services for infants, disproportionate share hospital facilities should be provided with adjustments to reimbursements in the case of children younger than 18.

- **Improve Medicaid reimbursement for providers meeting the requirements of Section 330 and 329 of the Public Health Service Act.** The network of more than 500 federally funded community and migrant health centers who furnish primary care to all poor and publicly insured patients in their communities are now using millions of dollars in scarce Federal discretionary funds to defray the gap between the cost of care furnished to Medicaid beneficiaries and the amount Medicaid actually pays. We estimate that in 1988 this "gap" amounted to about \$45 million—sufficient funding to serve more than 400,000 additional low income persons. Senator Chafee has introduced legislation (S. 1199) with provisions designed to close this gap.

- **Improve the capacity of Medicaid programs to ensure the provision of primary and outpatient treatment services for children with mental or developmental illness or conditions.** Many such children routinely receive services in clinical settings where there is a range of professionals skilled in the diagnosis, evaluation, and treatment of these types of health problems. However current law does not allow a clinic to be reimbursed if it is directed by a non-physician licensed practitioner (such as a psychologist or psychiatric social worker). We recommend that an exception to this rule be made for clinics serving children with developmental or mental health needs.

3. The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program

EPSDT is the most important publicly financed preventive child health program ever enacted by Congress. The benefits it offers are unparalleled. Yet, except for a single sentence, the statute is virtually silent regarding the structure and content of the health benefits included in the program. Moreover, the terminology used in the current definition of EPSDT is extremely outdated.

Mr. Chairman, we appreciate the interest you have shown in improving the EPSDT program through plans for legislation to codify, clarify, and expand the scope and depth of the program. The following elements of EPSDT reform are essential and would remedy problems which have plagued the program for more than a decade.

- **Codification of the current EPSDT regulations.** The Medicaid statute currently only refers to EPSDT in one sentence. This program and the protections it provides are too important to be left to the rulemaking process alone.

- **Clarification of the independent nature of the four basic components of EPSDT.** These include: (1) health and developmental examinations, diagnostic procedures, and treatment; (2) vision examinations and treatment; (3) assessment, diagnostic and treatment services for hearing problems; and (4) preventive and restorative dental care.

- **Expansion of the range of diagnostic and treatment services which may be provided to a child following an EPSDT assessment.** States have long had the option to provide an enhanced benefit package to children with conditions disclosed by an EPSDT assessment. Creating a national benefit package, which would allow providers to deliver a broadened range of diagnostic and treatment services deemed medically necessary through their assessment, would be a giant step forward.

- **Clarification that families can elect to receive either some or all of the components of an EPSDT assessment and treatment program.** There currently is widespread confusion around the issue of whether providers are allowed to provide only a portion of EPSDT screening and treatment. Since few providers are capable of furnishing all elements of the assessment, in many communities no provider is willing to offer EPSDT-quality services. It also keeps out of the program scores of highly qualified providers specialized in one or more aspects of the program. Finally, any other interpretation contradicts years of Federal policy regarding state administration of EPSDT and Federal rulings.

B. Title V Maternal and Child Health Block Grant

For over 50 years, the Title V Maternal and Child Health programs have served America's mothers, infants, and children. As the only Federal health program exclusively focused on maternal and child health, Title V serves as a cornerstone of our public health system. Each year, the program provides maternity care to hundreds of thousands of pregnant women and preventive and primary care to millions of children. In addition, from the beginning, Title V has included in its mission services for children with special health care needs.

However, as with all programs, periodic revisions are necessary to keep the program in step with the times. We hope that this Committee will make improvements to Title V in the following areas:

- **Increased accountability:** Improvements in the planning and reporting processes, as well as creation of a state level advisory board, would allow Title V programs to better document unmet need and program success.
- **Commitment to all three target groups within the programs mission:** Maternity and infant care, primary and preventive health care for children, and services to children with special health care needs are all priorities in maternal and child health. While it may be easier at times to document the problem of infant mortality, children need health care throughout childhood. Moreover, millions of pregnant women, infants, and children live in medically underserved areas where only a publicly funded program like Title V is likely to reach them, even if they have a Medicaid card. It is essential that the program place emphasis on service to all three groups.
- **Flexibility to demonstrate new models of care and replicate models on a nationwide basis:** Title V has a special advantage in that it contains a provision for funding special projects of regional and national significance (SPRANS). The opportunities to test the advantages of home visiting programs, new genetic screening and treatment systems, techniques for better serving children with special health care needs in the community, and other models are essential to the development of a better system of care for all mothers and children.

CONCLUSIONS

We are very pleased that so many members of this Committee, including the Chairman, have made a commitment to improving the health of mothers and children. Likewise, we are pleased that President Bush has made Medicaid coverage for low income pregnant women and children a priority. We know that you believe as we do that society "should ensure that the basic needs of vulnerable Americans do not go unmet;"²³ that we must make preventive investments now to ensure the health and security of our population in the future.

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TABLE 1
Insurance Status of Children Younger than 18 in Families, by Income¹, Race, and
Insurance Status, U.S., 1986

Income as a percent of poverty	All Races			White			Black		
	Less Than 100%	Less Than 200%	All	Less Than 100%	Less Than 200%	All	Less Than 100%	Less Than 200%	All
Children in Families (in thousands)	12,715	26,355	62,745	8,070	18,836	50,934	4,129	6,560	9,606
Percentage of insured children by type of coverage ²									
Medicaid alone or with other coverage	52.3%	30.3%	13.4%	47.2%	25.2%	9.9%	61.6%	43.8%	31.4%
Medicaid only	48.3%	26.8%	11.7%	42.9%	21.7%	8.4%	59.0%	40.7%	28.7%
Employer coverage	11.5%	33.6%	61.4%	13.4%	37.3%	65.9%	7.9%	23.6%	39.0%
VA, CHAMPUS, military ³	2.2%	3.8%	3.9%	2.7%	4.3%	3.8%	—	1.4%	4.1%
Other health insurance	6.0%	7.1%	7.6%	7.7%	8.2%	8.2%	—	2.9%	4.4%
Percentage of children insured	67.6%	69.6%	81.1%	66.3%	69.6%	82.5%	69.9%	69.1%	73.6%
Percentage of children uninsured	32.4%	30.4%	18.9%	33.7%	30.4%	17.5%	30.1%	30.9%	26.4%

¹Income measured as a percentage of the federal poverty level

²Percentages may not equal 100 percent because some children have insurance from more than one source.

³The U.S. Department of Defense covers health care for members of the military and their dependents, including children, at military institutions and at civilian facilities.

SOURCE: Unpublished data from the U.S. Bureau of the Census. Calculations by Children's Defense Fund

TABLE 2.

Percentage of Children in Families with Employer-Based Coverage with All Premiums Paid by Employer or Union, by Income¹, Age, and Race, U.S., 1986

Income Level	Total Number of Children With Employer-Based Coverage (in thousands)				Percentage of Children with All coverage Costs Paid by Employer or Union			
	Less Than 100%	Less Than 200%	Less Than 400%	All	Less Than 100%	Less Than 200%	Less Than 400%	All
All races								
Under age 6	593	3,345	9,571	13,125	28.2%	31.0%	34.8%	37.9%
Ages 6-17	863	5,503	17,610	25,415	26.8%	31.8%	36.1%	38.4%
Total	1,456	8,848	27,181	38,540	27.3%	31.5%	35.7%	38.2%
White								
Under age 6	468	2,773	8,330	11,533	29.7%	31.9%	35.9%	38.8%
Ages 6-17	611	4,256	14,925	22,018	33.4%	35.0%	37.7%	39.7%
Total	1,079	7,029	23,255	33,551	31.8%	33.8%	37.0%	39.4%
Black								
Under age 6	106	479	990	1,177	—	25.5%	26.3%	27.8%
Ages 6-17	221	1,067	2,166	2,567	—	20.2%	26.0%	27.6%
Total	327	1,546	3,156	3,744	—	21.9%	26.1%	27.6%

¹Income measured as a percentage of the federal poverty level.

SOURCE: Unpublished data from the U.S. Bureau of the Census. Calculations by Children's Defense Fund

TABLE 2A. CHILDREN AGE 0-17 YEARS IN FAMILIES BY INCOME, RACE, AND INSURANCE STATUS, 1986

	ALL RACES				WHITE				BLACK				
	(number)	(numbers in thousands)			(number)	(numbers in thousands)			(number)	(numbers in thousands)			
		(100%	100-200	(200%		ALL	(100%	100-200		(200%	ALL	(100%	100-200
ALL CHILDREN		12,715	13,640	26,355	62,745	8,070	10,766	18,836	50,934	4,129	2,431	6,560	9,606
INSURED CHILDREN BY TYPE OF COVERAGE													
WITH MEDICAID	(number)	6,647	1,351	7,998	8,438	3,808	945	4,753	5,045	2,545	330	2,875	3,013
	(percent of total)	52.3%	9.9%	30.3%	13.4%	47.2%	8.8%	25.2%	9.9%	61.6%	13.6%	43.8%	31.4%
WITH MEDICAID ONLY	(number)	6,145	928	7,073	7,332	3,462	632	4,094	4,260	2,437	230	2,667	2,754
	(percent of total)	48.3%	6.8%	26.8%	11.7%	42.9%	5.9%	21.7%	8.4%	59.0%	9.5%	40.7%	28.7%
WITH EMPLOYER COVERAGE	(number)	1,456	7,392	8,848	38,540	1,079	5,950	7,029	33,551	327	1,219	1,546	3,744
	(percent of total)	11.5%	54.2%	33.6%	61.4%	13.4%	55.3%	37.3%	65.9%	7.9%	50.1%	23.6%	39.0%
WITH VA. CHAMPUS, MILITARY	(number)	274	724	998	2,424	216	589	805	1,916	--	--	94	394
	(percent of total)	2.2%	5.3%	3.8%	3.9%	2.7%	5.5%	4.3%	3.8%	--	--	1.4%	4.1%
WITH OTHER HEALTH INSURANCE	(number)	760	1,118	1,878	4,794	625	922	1,547	4,167	--	--	189	422
	(percent of total)	6.0%	8.2%	7.1%	7.6%	7.7%	8.6%	8.2%	8.2%	--	--	2.9%	4.4%
TOTAL CHILDREN INSURED	(number)	8,600	9,731	18,331	50,882	5,350	7,762	13,112	42,030	2,887	1,643	4,530	7,067
	(percent of total)	67.6%	71.3%	69.6%	81.1%	66.3%	72.1%	69.6%	82.5%	69.9%	67.6%	69.1%	73.6%
TOTAL CHILDREN UNCOVERED	(number)	4,115	3,909	8,024	11,863	2,720	3,004	5,724	8,904	1,242	788	2,030	2,539
	(percent of total)	32.4%	28.7%	30.4%	18.9%	33.7%	27.9%	30.4%	17.5%	30.1%	32.4%	30.9%	26.4%

TABLE 3

CHILDREN'S DEFENSE FUND

CHILDREN'S DEFENSE FUND

United States Fact Sheet, 1986

	White	Nonwhite		Total
		Black	Total	
Births				
To All Women	2,970,439	621,221	786,108	3,756,547
To women age 19 and under	315,335	141,606	156,746	472,081
To women under age 15	4,007	5,877	6,169	10,176
Teen Births				
<i>As percentage of all births</i>				
To women age 19 and under	10.6%	22.8%	19.9%	12.6%
To women under age 15	0.1%	0.9%	0.8%	0.3%
Low-Birthweight Births				
<i>Percentage of births that were low birthweight:</i>				
To all women	5.6%	12.5%	11.2%	6.8%
To women age 19 and under	7.7%	13.3%	12.7%	9.4%
<i>Percentage of all low-birthweight births:</i>				
To women age 19 and under	14.4%	24.1%	22.6%	17.3%
Prenatal Care				
<i>Percentage of Babies Born to Women Who:</i>				
<i>Began prenatal care in the first trimester</i>				
All women	79.2%	61.6%	63.7%	75.9%
Women age 19 and under	55.9%	46.8%	47.1%	53.0%
<i>Began prenatal care in the third trimester or not at all</i>				
All women	5.0%	10.6%	9.9%	6.0%
Women age 19 and under	11.0%	15.0%	15.0%	12.7%
<i>Received adequate prenatal care</i>				
All women	72.6%	50.6%	51.8%	68.4%
<i>Received inadequate prenatal care</i>				
All women	6.3%	15.3%	14.7%	8.0%
Infant Mortality				
<i>Infant Deaths per 1,000 Live Births</i>				
Total infant deaths	8.9	18.0	15.7	10.4
Neonatal deaths	5.8	11.7	10.1	6.7
Postneonatal deaths	3.1	6.3	5.6	3.6

SOURCE: National Center for Health Statistics. Calculations by Children's Defense Fund.

TABLE 4
 Percentage of Infants and Toddlers Who Were Fully Immunized¹,
 by Age and Race, U.S.², 1980 and 1985

Infants		Polio	DTP ³	Measles	Mumps	Rubella
Total	1980	80.0	84.2	These vaccines are not recommended for children of this age.		
	1985	79.6	82.7			
White	1980	80.9	84.9			
	1985	81.5	84.4			
Nonwhite	1980	73.2	79.0			
	1985	58.5	64.8			
Age one		Polio	DTP	Measles	Mumps	Rubella
Total	1980	95.5	76.2	These vaccines are not recommended for children of this age.		
	1985	95.2	78.3			
White	1980	96.2	78.6			
	1985	96.9	80.1			
Nonwhite	1980	89.1	56.5			
	1985	82.3	64.9			
Age two		Polio	DTP	Measles	Rubella	Mumps
Total	1980	80.7	87.0	83.0	83.2	80.2
	1985	76.7	85.8	81.7	77.3	78.9
White	1980	83.0	89.4	84.8	84.4	81.5
	1985	79.5	88.0	82.7	78.6	80.8
Nonwhite	1980	62.8	68.0	69.0	73.4	70.7
	1985	56.5	69.1	74.7	66.9	64.2

¹Dosage levels are approximations of levels needed to fully immunize a child of a given age: younger than age one, one or more doses of polio and DTP; at age one, one or more doses of polio and three or more doses of DTP; and at age two, three or more doses of polio and DTP and one dose of measles, rubella, and mumps vaccines.

²Data are from the U.S. Immunization Survey sample confirmed by parent consultation with an immunization record.

³DTP stands for a combined dose of diphtheria, tetanus, and pertussis vaccines.

SOURCE: U.S. Immunization Survey, Centers for Disease Control.

FIGURE 1

UNINSURED CHILDREN IN EMPLOYED FAMILIES, BY AGE, 1986

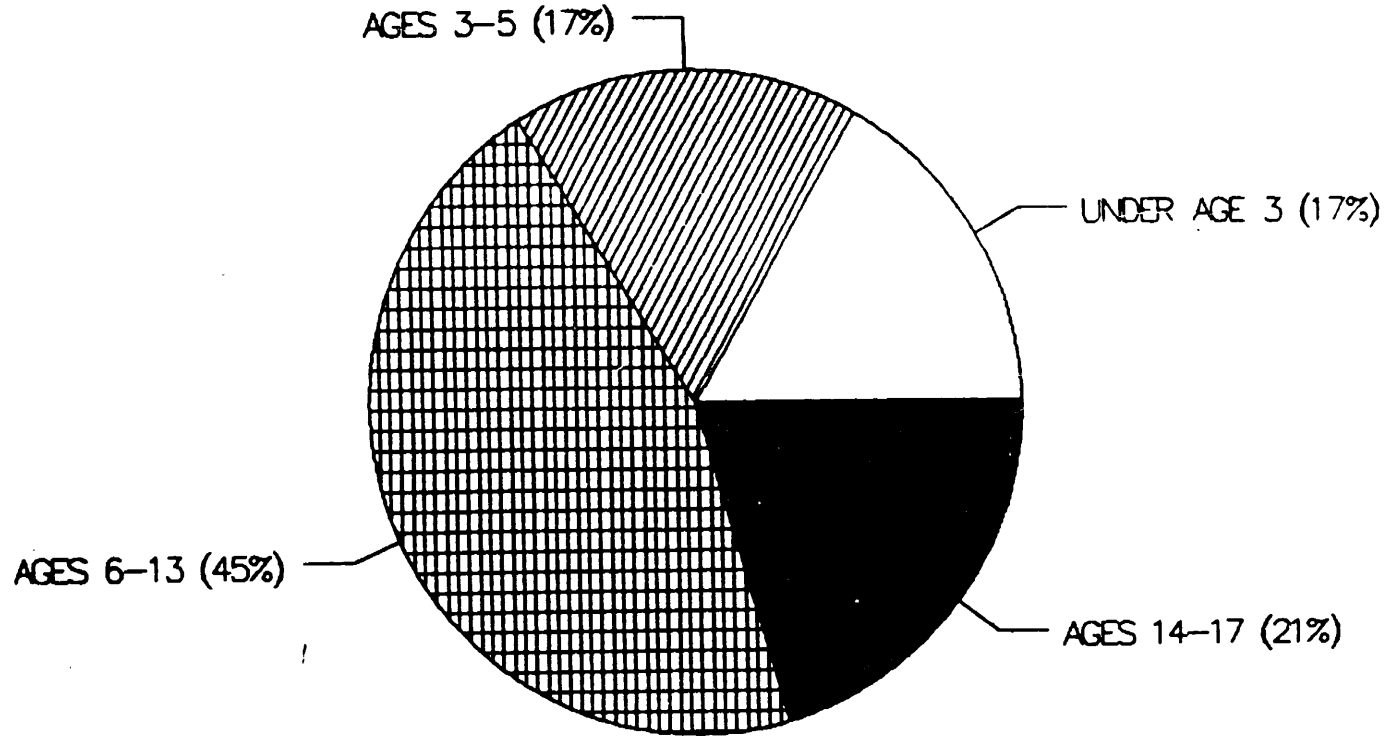


FIGURE 2

UNINSURED CHILDREN IN EMPLOYED FAMILIES BY INCOME, 1986

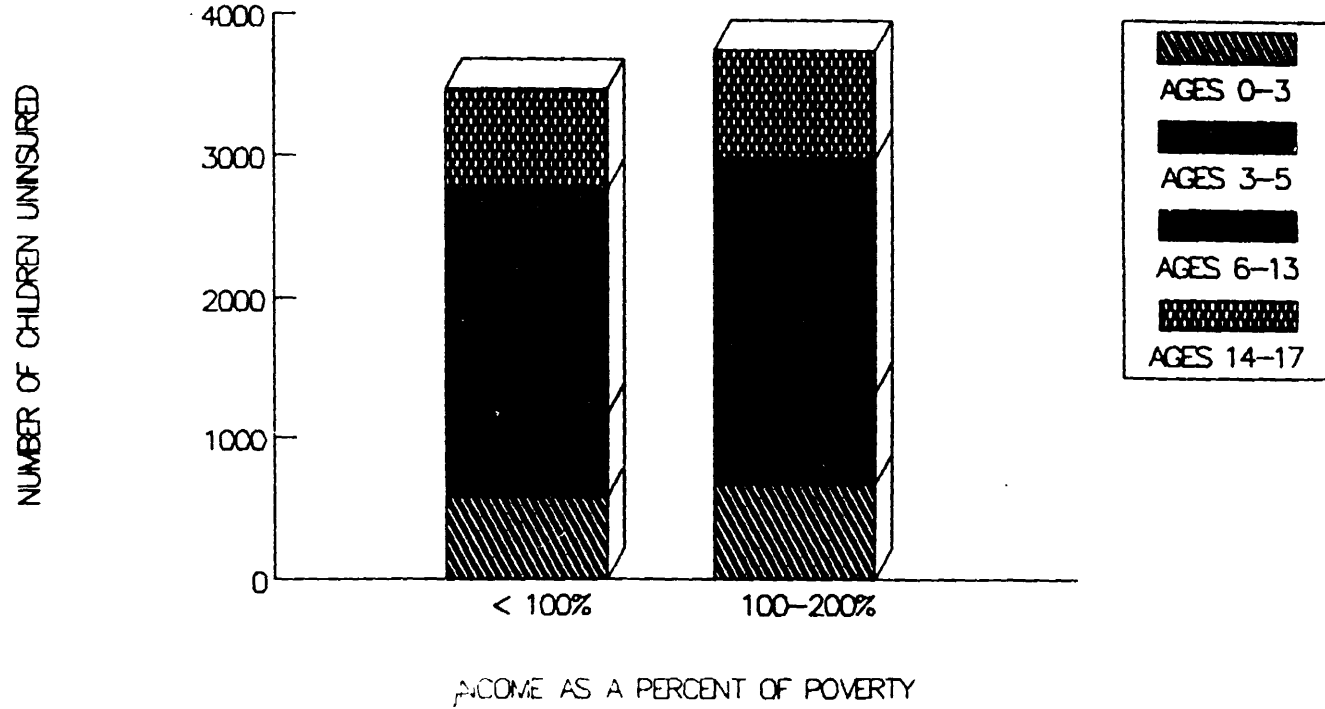
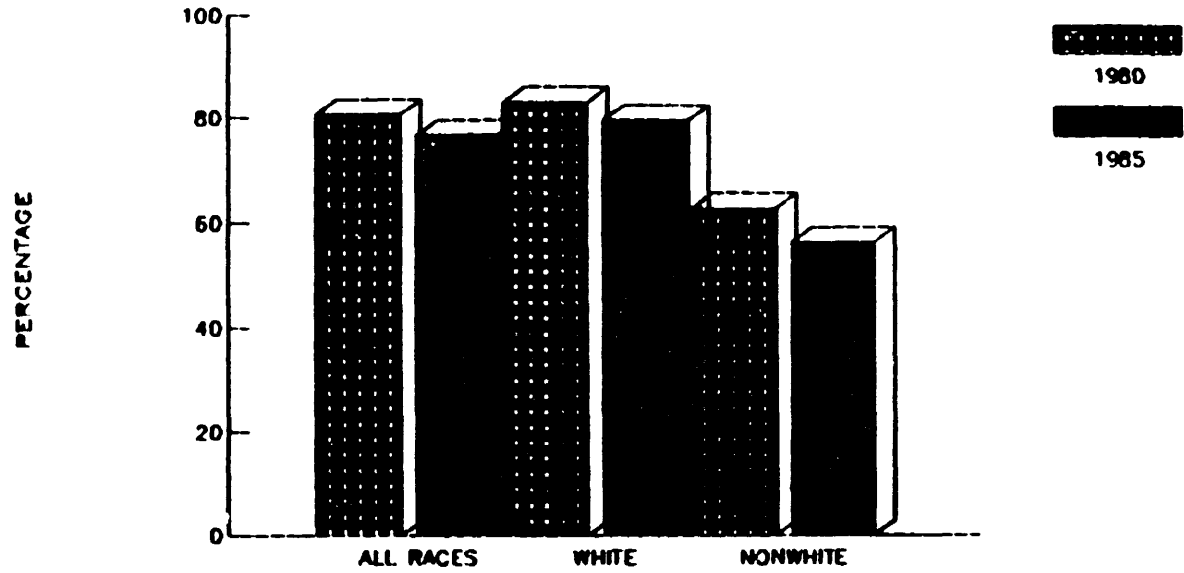


FIGURE 3

POLIO IMMUNIZATION AMONG TWO-YEAR-OLDS,

BY RACE, U.S., 1980 AND 1985



SOURCE: CHILDREN'S DEFENSE FUND

PREPARED STATEMENT OF RICHARD P. NELSON

The Association of Maternal and child Health programs (AMCHP) appreciates this opportunity to provide comments to the Senate Finance Committee today on improving access to maternal and child health care, and the importance of Title V and Title XIX coordination in achieving this goal. We commend the committee's commitment to this goal and applaud current legislative proposals aimed at expanding and improving access for women and children to quality comprehensive health care and supportive services. Our Association represents state Title V program leadership throughout the nation.

Since passage of the Social Security Act in 1935, state Maternal and child Health programs and programs for Children with Special Health Care Needs have been charged with studying and monitoring the health of all women, children and families, planning for effective systems of comprehensive health and developmental services, assuring that needed care is received by those populations and accounting for the quality and results of our health care investments.

Title V programs remain a vital source of health care to the one in four women of childbearing age and the one in five children who are uninsured. State and local programs funded by Title V have been shown to be effective in reducing infant mortality and low birthweight, delivering cost-effective pediatric care and immunizations and mitigating the effects of chronic illness and disability through coordinated diagnostic, medical, and support services. Title V programs are commonly a major source of care for Medicaid eligible women and children living in areas where few Medicaid providers are available.

Title V also has a responsibility to assure standards for the quality and content of maternal and child health care and to evaluate services and outcomes. MCH agencies are uniquely placed to determine if services are available, accessible, affordable, comprehensive, coordinated, and responsive to family health needs. The specific means by which each state assures care for mothers, children, and families varies due to differences in state needs, agency structures, and resources. However, the role of MCH programs is critical in every state. We would like to share with you some example which the Association gathered through a 1988 survey of state Title V Programs.

- Title V programs assess the adequacy of health care systems and identify funding and advocacy priorities for effecting system improvements. Our 1988 survey documented statewide needs assessments of service needs, using vital statistics, census data, Medicaid data and hospital discharge reports, and specially designed consumer and provider surveys. In nineteen states, Title V and Title XIX programs were successfully linked their data to develop a comprehensive picture of patient characteristics, services, health outcomes, and costs in both programs.

- Title V programs are key players in planning and coordinating implementation of health and related services system-wide. For example, over two-thirds (72%) of the states reported Title V program involvement in Medicaid SOBS expansion, described their roles as "collaborative" or "lead." Twenty state programs reported involvement in Medicaid waiver programs and forty-one indicated involvement in implementation of EPSDT services, ranging from consultation to direct administration. In 1987, one-half of state MCH Program Units were administering the WIC program. In forty-one states, Title V program personnel served on P.L. 99-457 Interagency Coordinating Councils.

- Title V programs also have been active in developing and monitoring standards of care for public and private providers and payors. Our survey results show that forty-seven state Medicaid programs have adopted MCH/CSHCN standards in at least one program area. A committee of Title V and Medicaid directors has distributed model maternal and infant health guidelines which were derived from standards of care developed in 19 state MCH programs, and is now planning to develop similar guidelines for EPSDT services.

- Nearly all Title V programs reported providing information, outreach, training, and assistance to families and professionals on areas such as preventive health care, support of children with special health care needs, and effective use of existing services.

- Title V programs also provide direct care services otherwise unavailable through other public or private providers. In many states, Title V programs remain a major service resource, especially in medically underserved areas. In 1987, nearly all states invested MCH funds in maternity services, and MCH programs' pediatric services reached as many as 42% of one states' age eligible child population.

- Title V programs provide or arrange case management or care coordination for families to assist them in integrating health, welfare, social service, and educational

programs for their special needs children. Fifty-one state programs are providing or planning case management (care coordination) services for at least one sub-group of women or children. Many of our programs have assumed responsibility for Medicaid case management for pregnant women, for children served by EPSDT, and for children with chronic illnesses or disabilities.

• States are also responding to the 1986 amendments to Title V which provided additional funds earmarked to improve access to primary health care for children and case management and community based services networks for children with special health care needs. In Texas these funds have been used to promote utilization of child health services in 20 counties by children enrolled in WIC. Data from 9 of these counties indicates that 973 additional children received care in 1988 as a result of these expansions. New Mexico used earmarked funds to establish Teen Wellness Centers located at four high schools. 2541 teenagers received direct health services at these centers in FY 1988. Ohio's program for children with Medical Handicaps utilized earmarked funds to develop care coordination services for children with spina bifida. Since these services became available, 570 children have benefited.

Titles V and XIX are complementary commitments to the health of America's children and young families. Title V was written into the original Social Security Act, assuring a public health approach to the needs of our children. Title XIX was added in 1965, in the belief that the nation had an obligation to provide health care coverage to indigent children, as well as the elderly, blind and disabled.

The statistics of the 1980's underline the continuing need for these two programs and verify their interdependence. Children's health and development is not what it should be today, especially when compared to that of other nations which have universal access to health care. Although the mandates and resources of Titles V and XIX together address many of the health needs of women, children, and children with special health needs, they are insufficient to the task. As more young families slip into poverty and isolation, both programs must be strengthened. As MCH leaders, we believe that expanded coverage to pay for needed health services is critical for our nation's children. Medicaid represents the nation's largest financial investment in children's health and clearly has improved many poor children's access to health services. Unfortunately, Medicaid does not cover all low-income children, and also suffers from eligibility and service inconsistencies from state to state, problems of low provider participation, a general lack of outreach and marketing, and the stigma of association with welfare programs.

Moreover, we all know that coverage does not assure care and that medical care does not assure health. Title V programs play their most important roles in the assurance of care and the development of services and policies that will protect the health and development of children. MCH agencies are at the forefront of developing expanded maternity care to reduce infant mortality, have created models for effective case management and care coordination, especially for children with special needs, and have been leaders in making expanded Medicaid coverage work for families. MCH agencies also have sponsored much of the evaluation of these investments.

Title V has been an important, effective, and enduring mechanism in the distribution of resources and support, planning, leadership, program development, establishment of standards, and evaluation of maternal and child health programs. It places authority and flexibility at the state level, where the "fit" with other programs and data on local needs is best. It integrates information, programs, and care for families. It adds state, local, and in-kind resources to very modest Federal investments. Although the Title V formula has often been debated, it does assure that a population-based allocation of funds goes to every jurisdiction, avoiding the "rich get richer" phenomenon and other problems associated with competitive grants and similar mechanisms. Most important, in most jurisdictions Title V has effectively engaged all levels of public and private sector leadership in maternal and child health activities.

The Association strongly supports congressional action to improve and expand both Title V and Title XIX. Until there is national consensus for more fundamental reform in our nation's fragmented system of health care delivery and financing, these two programs will continue to serve as the major vehicles for assuring the health of women and children. Our Association supports and will actively participate in efforts to develop proposals for more universal and comprehensive systems of health care services and coverage. For the immediate future, we believe that improvements in Title V and Title XIX, including closer collaboration between the two programs, will result in improved access and health status of women and children. We believe that legislation enacted this year should include the following elements:

For Title V:

1. Strengthen requirements for accountability, including:

- State maternal and child health plans that include: needs assessment of women and children, including children with special health care needs; goals and objectives to address the identified needs which also are linked to relevant national health objectives for the Year 2000; and strategies and services necessary to achieve the objectives.
- Annual state reports which assess progress in meeting goals and objectives, and which include measures of key indicators that will enable the Secretary to prepare annual national reports on maternal and child health status and services.
- Public processes which encourage and enable collaboration with other public agencies, providers, professionals and consumers in developing, implementing and evaluating plans for maternal and child health.

2. Increase the resources allocated directly to the states to:

- Further the development of coordinated, comprehensive systems of reproductive and maternity care at the community level required to address the problems identified in numerous state and national studies of infant mortality, particularly the National Commission to Prevent Infant Mortality and the Institute of Medicine.
- Continue and strengthen state efforts to ensure access to comprehensive preventive and primary care services for children and adolescents in order to promote health and development and prevent the major causes of death, disease and disability for school-aged children.
- Promote the optimal development of children with special health care needs and support their families by addressing the U.S. Surgeon General's recommendations for services necessary to assure family-centered, community-based coordinated systems of care.
- Support increased state capacity for effective needs assessment, planning and reporting.

3. Strengthen the mandates for program and agency coordination, particularly with Medicaid, P.L. 99-457, P.L. 94-142, WIC, family planning and community and migrant health centers.

For Title XIX—

1. Further expansions of eligibility to eventually include all pregnant women and children through the age of 21 with incomes below 185% of the Federal poverty line.

2. Further reforms to facilitate early and continuous participation of pregnant women and children in Medicaid, including mandatory presumptive eligibility and simplified applications.

3. Further reforms to increase provider participation, including reduced administrative complexity and increased rates of reimbursement.

4. Greater consistency across the country in ensuring comprehensive benefits for preventive, primary, specialty and support services necessary to improve and maintain the health of women and children.

5. Requirements for coordination with the state Title program including:

- Participation of the Title XIX agency in development of the state Title V plan, including participation in the state's advisory council.
- Review recommendations from the Title V agency on the Title XIX state plan.
- Consultation and assistance from the Title V agency in development of provider certification, and recruitment, standards of care, quality assurance, and evaluation.
- Consultation from Title V in development and revision of policies, procedures and forms governing client and provider participation.
- Collaboration in developing systems of care coordination or case management, including consideration of Title V administration of care coordination services.
- Collaboration in development of benefit packages for enhanced services for pregnant women, and protocols, periodicity schedules, and treatment services under the EPSDT program.
- Collaboration in development of information, education, outreach and referral mechanisms for women and children.
- Collaboration in needs assessment and evaluation including data collection, matching and analysis.

Senator Bentsen's Title V proposal, which we have had to opportunity to review, addresses our recommendations for improved accountability, including establish-

ment of an advisory council, stronger emphasis on needs assessment and planning, and more consistent state and national reporting. The proposal offers significant new resources directed primarily to ongoing state programs, and would assure a minimal level of investment in services for children with special health care needs. We have urged Senator Bentsen to ensure that the proposal also address congressional expectations for continued development of preventive and primary care services to prevent infant mortality and promote the health of children and adolescents.

Senator Bentsen's amendments for Title XIX would achieve a number of important objectives in improving the Medicaid program to ensure more consistent, comprehensive and continuous coverage of low income women and children. In addition to supporting these proposals, we urge committee consideration of confirming amendments to Title V and XIX to further interagency collaboration in ensuring that increased coverage results in improved services and health status outcomes.

In conclusion, the Association would again express our appreciation for this opportunity to comment and for the Committee's proposals for strengthening Title V and Title XIX to achieve improved access to comprehensive care for low income women and children.

PREPARED STATEMENT OF SENATOR JOHN D. ROCKEFELLER IV

Over the past few years, the Federal Government and the states have been working together to provide essential health coverage to poor pregnant women and children.

States have risen to Congress' Medicaid challenges.

West Virginia has been especially strapped for funds over the past few years. In spite of this, West Virginia has made substantial improvements in their Medicaid program, especially for pregnant women and children.

I am extremely proud of the important gains they have achieved—many times surpassing what States are required to do by law.

As of July 1, 1990, States will be *required* to cover pregnant women and infants up to 100% of the poverty level. Last July, West Virginia expanded Medicaid eligibility for pregnant women and infant to 150% of the Federal poverty level.

West Virginia met the challenge and went beyond it.

Currently states have the *option* to provide Medicaid coverage for a pregnant woman 60 days after the birth of her child. West Virginia continues coverage for 60 days.

West Virginia does not apply an assets test to pregnant women and children up to 8, and they adopted a simplified Medicaid application form for pregnant women and children.

In addition to these significant achievements—at the other end of the spectrum—West Virginia has enrolled over 3,000 senior citizens in the new Medicaid buy-in program mandated in the Medicare Catastrophic Act—this does not include the over 20,000 SSI-individuals that were automatically enrolled in the new "QMB" program.

The West Virginia Department of Human Services has made important strides. With few resources to spare, West Virginia has moved in concert with Congress to strengthen the Medicaid safety net.

Senator Bentsen has crafted a comprehensive package of child health initiatives that provides important directions and goals for the states.

Senator Bradley has been a "model" of incrementalism—but taken all together—he has achieved significant reforms of the Medicaid program.

I am looking forward to hearing today's witnesses.

PREPARED STATEMENT OF WILLIAM V. ROTH, JR.

Mr. Chairman, I too commend you for holding this hearing. The health of the nation's children is of paramount importance to a successful next generation. Infants and children AFE the future and we should not forget that they are particularly vulnerable to deficiencies in the health care system. The hearing today will focus on a population that has never voted for any one of us . . . YET.

Reducing the rate of infant mortality is a goal we should continue to aim for. I remember a hearing held last year before this committee on Children's Primary Care and Chronic Health Care Issues. Senator Lawton Chiles also testified then, and I was struck with his description of the child health care program in Japan. He told us that after World War II, Japan made babies THE national priority. Japan established a preventive health care system where pregnant women were given a "pass-

port" which showed them what care was available to them. Today, Japan has one of the lowest infant mortality rates—still almost half of ours.

While Japan may be ahead of us now in reducing its infant mortality rate, we have also made improvements in recent years. Since 1980, my home state of Delaware has reduced the black infant mortality rate by 37% and the total infant mortality rate by 17%. Part of this improvement has been accomplished through awareness campaigns and expansions in Medicaid. Governor Castle made infants and pregnant women a State priority and stressed preventive care. There have also been improvements nationwide.

In part, due to Congressional mandates and optional expansions in the Medicaid program, the percentage of children covered under Medicaid has been increasing in recent years. Today, over one half of American children in poverty are covered by Medicaid. In fact, by July 1, 1990, States will be required to cover low income infants and pregnant women up to 100% of the Federal poverty level. Another important program for low income children and pregnant women is the Women, Infants and Children nutrition program. I have supported WIC in the past because I believe it provides a thriving start on life through good nutrition. Studies even show that for every dollar spent for WIC, three dollars are saved later. This program makes CENTS—C-E-N-T-S!

The tragedy of a baby born with the virus which causes AIDS, a baby born addicted to drugs, or a baby born with extreme low birthweight—is an even greater tragedy when simple preventive steps are available. I am well aware of these sad situations, and, I am well aware of the situation of fiscal constraint we find ourselves in when faced with the current Budget Deficit. Just reducing the infant mortality rate in this country is a challenge we must meet, and with a private sector partnership, we just may reach that goal.

PREPARED STATEMENT OF RAYMOND C. SCHEPPACH

Good morning Mr. Chairman, members of the Committee. I appreciate the opportunity to appear before you on behalf of our nation's Governors regarding legislative initiatives to combat infant mortality and improve children's health. These issues have been a priority for the Governors, and with continued Federal support, we will continue to make progress.

Last year, Governor Ray Mabus of Mississippi testified before this committee and gave a complete review of state activities to assist pregnant women, infants, and children. I would like to quickly update the committee on actions states have taken to improve the health of these populations. To date, 44 states have taken advantage of the option to provide Medicaid eligibility to pregnant women and infants with family income below the poverty level. In addition, 15 of these states have elected to cover pregnant women and infants with incomes up to 185 percent of the poverty level. Only 10 of these states still use an asset test; the others have dropped such a requirement. Twenty-three states are providing coverage to all children below poverty up to age three, and nine states are enrolling all children below poverty up to age eight. I would also point out that 20 states are using presumptive eligibility as a way of expediting the enrollment of pregnant women.

So you can see that states have actively taken advantage of new options enacted by this committee and the Congress over the past two years. Almost all of these actions were taken before the mandates on eligibility were enacted last year.

The Governors are very proud of the work they have done in helping these populations. Beyond simply expanding Medicaid eligibility, states have been working to streamline the eligibility process, improve outreach efforts, and increase the participation of physicians in the program. States have also wanted to coordinate the activities of the Medicaid program with other programs serving the same population, such as the maternal and child health programs and the supplemental food program for women, infants and children (WIC). The common thread to these efforts is bringing down barriers, which, have been created over time. Facilitating improved access to health care for populations at risk is our goal.

The committee now has before it several bills intended to further direct, and increase support for, the activities I have just mentioned. Rather than comment on the specific bills, I would like to provide you with the National Governors' Association's position on the most significant proposals that are contained in one or more of the bills being considered.

The National Governors' Association is opposed to any further mandated eligibility requirements in the Medicaid Program.—Individual states are in the best position to decide how Medicaid funds should be spent to assist citizens who are in need. In

addition, because of the variety of populations we serve under the program, it is important to maintain some latitude in how a state structures its program. This concept is at the heart of the federal-state partnership upon which Medicaid is based.

This is not to say that these populations are not in need. Quite the contrary, the extensive action by states to enhance coverage of pregnant women and children illustrates our commitment to this population and to meeting their needs. But by enacting new mandates, Congress is failing to recognize the fiscal environments in which states operate. Despite continued growth in the economy, few states are in a positive fiscal situation. In 1990, states will face their lowest year ending balances since the recession of the early 1980's.

The Medicaid program will consume 11 percent of state expenditures in 1989. In 1981, it constituted only 7 percent of those expenditures. Even with no further program changes, the National Association of State Budget Officers has estimated that by 1995, health care cost inflation will mean that Medicaid will account for 15 percent of state expenditures. Trying to deal with such a large and growing program expense at the state level, where budgets must be balanced each year, is not an easy task. The task becomes much more difficult if the flexibility in program design is taken out of the states' hands.

In the last year and a half, this committee and the Congress passed sweeping changes to the Medicaid program that altered the way care is provided and evaluated in nursing homes, and significantly expanded benefits to the elderly on Medicaid or with incomes near poverty.

These have been the biggest changes in the program since 1981. These changes, while benefiting thousands of elderly persons, cost a great deal of money. Once fully implemented these changes will cost the states in excess of \$1 billion a year.

The states are just beginning to feel the fiscal impact of these changes. While the Governors are not suggesting repeal of these initiatives, they do want you to know that such changes mean that less money is available for other programs. Less money for all programs, but in particular, less money for the other human service programs. For these reasons, we ask the committee to forego any new mandates on Medicaid eligibility.

Having said that, I want to emphasize NGA's support for proposals that would allow states to provide Medicaid eligibility to all children below the poverty level up to age 18. We have long held the position that states should have the opportunity to provide health care coverage to low-income children of all ages, not just the youngest.

There are several proposals before the committee that address the need to make the eligibility process more efficient and to encourage outreach efforts by the states. Governors support any initiatives that can assist them in their effort to bring down barriers that keep women and children out of America's health care system. I would, however, like to express a note of caution. We are still learning a great deal about which outreach efforts work and which do not. We are also learning which initiatives work in particular settings, for example rural areas, but not in others. States need to have the freedom to design their programs so they can appropriately respond to the needs of their citizens. Mandating certain procedures that have helped in some instances may cause harm in other areas.

I particularly want to express our concern with the proposal to mandate presumptive eligibility. This process, as you know, has been used successfully to provide services quickly to pregnant women. Presumptive eligibility allows for a quick eligibility review at the time the pregnancy is determined by the provider of service. The women must then go to the local welfare office to undergo a standard eligibility determination. By getting women into the program immediately, program participation and access to services is significantly increased.

Mandating this process, however, would be a mistake. Several states have taken action to streamline their standard eligibility process so that it is as effective, or more effective, than presumptive eligibility. A recent NGA report, *Reaching Women Who Need Prenatal* details these initiatives. Placing eligibility workers in clinics, shortening eligibility forms, and expediting eligibility determinations have all led to much faster eligibility determinations. Forcing such states to put in presumptive eligibility would be detrimental. It would actually increase the effort involved to enroll in the program. Presumptive eligibility is a two-step process, while standard eligibility is a one-step process. States should continue to be encouraged to streamline their eligibility processes, but mandating presumptive eligibility is the wrong approach.

I would like to address one final issue regarding the Medicaid proposals before the committee. Some of these bills would codify current regulations regarding provider reimbursement. That requirement says, basically, that Medicaid must reimburse physicians a fee that will provide Medicaid recipients with the same access as the

general population. It is not realistic to try to achieve this goal through reimbursement alone. In a recent NGA report, *Increasing Provider Participation*, the reasons obstetricians and gynecologists give for not participating in the Medicaid program were outlined. They included:

- Medicaid fees that are below the community average;
- growing malpractice costs;
- the high-risk nature of serving low-income populations; and
- the burden of administrative procedures in Medicaid.

Some of these are beyond the control of state Medicaid programs. States have acted to increase access through higher fees and improved administrative process. Between 1985 and 1987, three-quarters of the Medicaid agencies and three-fifths of the maternal and child health programs raised their fees.

Other factors, however, cannot be controlled by the state. Beyond the general malpractice problem and its impact on providers, many physicians believe that low-income persons, and Medicaid recipients in particular, litigate more often than the rest of the population. While the research has not supported, and often refutes, this assumption, it still affects participation. Other negative perceptions of Medicaid recipients are brought on by language and cultural barriers, and these too are beyond the control of the state.

For these reasons, we believe that it would be inappropriate to require fee increases as the sole method of bringing about equal access. States are moving to improve fees and should be encouraged to continue to do so as part of a much broader strategy for increasing provider participation. Simply increasing fees alone will not resolve the problem, and in some cases will not increase provider participation at all.

I would hope that in the context of all the changes that have already occurred in the Medicaid program, that this committee and the Congress will consider a period of slowing down or limiting the amount of changes. States need time to implement changes already enacted and further mandates will make the job that much more difficult and jeopardize the success of initiatives already undertaken.

One final comment regarding the Maternal and Child Health Block Grant. The Governors are opposed to any net requirements that direct states to set aside a given portion of the grant for specific services or populations. The intent of the block grant is to allow states to efficiently direct the funds to those in need of assistance. The Governors and their administrations are in the best position to make those decisions. Federally prescribed set-asides lessen Governors ability to serve the needs of their states' citizens. The states have been very pleased with the block grant as it is currently structured and do not want to change it into a de facto categorical grant program.

Thank you again for allowing me to appear before me. The Governors and their staffs look forward to working with you as these legislative initiatives are developed.

PREPARED STATEMENT OF DONALD W. SCHIFF

Good Morning Senator Bentsen, Members of the Senate Finance Committee. I am Don Schiff, president of the American Academy of Pediatrics and a pediatrician in private practice in Denver, Colorado. The Academy represents over 38,000 pediatricians dedicated to improving the health and welfare of our nation's infants, children, adolescents and young adults.

The Academy has appeared before this Committee numerous times in the past two years, talking about access to care for children; uninsurance and underinsurance; the needs of children with special health care needs and the role of the Maternal and Child Health (MCH) Block Grant and the Medicaid program. I am particularly pleased to be here today, Mr. Chairman, because I believe we are making headway evidenced both by new relationships being forged by state MCH and Medicaid programs and by the potential roles for these programs suggested in your legislation and those introduced by other members on this Committee. The Academy strongly applauds the direction for the Medicaid and MCH Block envisioned by your proposals. As you are aware, the Academy and a number of child advocacy organizations developed a series of recommendations to improve and enhance the Maternal and Child Health Block Grant program. Many of our concerns are considered by your legislation. Requirements for enhanced state assessments of maternal and child health needs, improved annual reports, the creation of a state-level health advisory board and a system for care coordination are all essential to crafting an effective child health system at the state level. Indeed, the single most important point I

will make today is the need to fashion a comprehensive system to meet the needs of children and pregnant women. Title V and Medicaid should not be viewed separately. Rather, we need to focus broadly on how maternal and child health programs will interlock to establish a coordinated system of child health care. Your proposals are clearly a strong step in that direction. My specific comments follow.

I. MATERNAL AND CHILD HEALTH BLOCK GRANT

As you know, the Maternal and Child Health Block Grant (Title V of the Social Security Act) is the only public health service program which is devoted exclusively to meeting the needs of mothers and children. As such the MCH Block is a unique and important program whose efforts and initiatives must be strengthened and reinforced.

The purpose of the MCH Block is to enable each state to assure mothers and children access to quality health services, reduce infant mortality and incidences of preventable diseases and handicapping conditions among children, provide rehabilitation services for blind and disabled children under the age of 18 and provide otherwise unavailable services for children with disabilities and chronic illnesses. As such, the Block has a dual focus—to serve the primary and preventive care needs of all children and mothers and also to help children with special health care needs. Clearly, these are worthy goals.

The Title V program recently celebrated its 50th anniversary. It is appropriate to look at the direction we must take over the next 50 years. Indeed, the medical environment has changed dramatically since the enactment of this block, both in areas of medical technology and treatment and financing for an array of needed services. It is important that we examine the design and ability of this program to meet the complex needs of today's children and their families—needs that involve a range of services from health, education, social services and other areas. The block must be assessed with respect to its responsibility for children and families for preventive, sick and catastrophic care coordination.

As I noted previously, a number of these issues are addressed by proposals before this committee. In particular the Academy believes the strengthening of the statewide needs assessments, creation of a state child health advisory board, a plan for meeting the needs of children with special health care needs and annual reporting requirements are crucial.

A clear definition of the needs of pregnant women and children is essential. At a minimum we believe these assessments should: (1) identify the unmet health needs of pregnant women and children; (2) identify availability of resources for unmet needs; (3) determine children's access to care, including the types of services they are receiving and the payment vehicle; (4) set specific and measurable goals for improving services and health outcomes; (5) define steps to be undertaken to attain these goals; and (6) specify steps to coordinate efforts among providers and relevant federally supported programs, such as the MCH Block, WIC, EPSDT, family planning, P.L. 99-457 and Medicaid.

The statewide needs assessment should include specific information on maternal and infant care, such as immunization status, as well as the needs of all children, not just mothers and infants. Particular attention should also be given to be given to children with special health care problems.

The Academy also strongly supports the requirement for state annual reports. The information included in these reports should reflect the data collected as part of the statewide needs assessment. For example, these reports should include information on the number of women, infants and children served; an account of how they were served; and what services were provided. Information on statistics related to birth weight distribution should be linked to demographic characteristics and utilization of services. The numbers and types of chronically ill children served, and the ways in which they are served, should also be designated. There ought to be a reporting system for children with special health care needs.

We further applaud the requirements for developing a statewide system for planning and development of care coordination services for children with special health care needs and the creation of a state maternal and child health advisory board. In addition to assisting with the development and review of the state plan, this advisory board should be used to improve the coordination of this program with all other state child health programs, including Title XIX, Title X, the lead agency under PL 99-457, SSI and WIC to name a few.

In addition, we support strengthening the accountability provisions in the block—where dollars are being spent and who is receiving services.

II. MEDICAID

While the incremental enhancements in allowable Medicaid benefits and eligibility over the past years have helped, the enormous variations and limitations in state coverage have resulted in a nonexistent or ineffective program for many children. The present system, which offers different health care coverage to a child based on where he lives, is inequitable and discriminatory.

Although they vary, a number of proposals are pending before this Committee which would mandate extending Medicaid eligibility. While the Academy supports mandating a phase in of all children up to age 18 and pregnant women up to 185% of the Federal poverty level, we do realize the economic implications of such a recommendation. Implicit in each of these proposals is the recognition that the variation in state programs is intolerable and we support this committee's efforts to mandate improved uniform eligibility. In this same light, we encourage you to address the variations in the state benefits packages. Children are clearly being discriminated against in receiving necessary benefits by virtue of where they live. All children must have access to the comprehensive range of benefits. While the Medicaid package may appear ample in writing, many children do not receive the services to which they are entitled. Moreover, limitations in amount, duration and scope of services makes the program ineffective in a number of states.

I also want to express the Academy's support for a number of provisions in the Chairman's Medicaid proposal. Changes to the asset test—requiring presumptive eligibility for pregnant women, adjustments in payments for hospital services to low income children, expansion of home and community based services to children who have acquired immune deficiency syndrome or who are ventilator dependent are extremely important and should be enacted. Several other provisions of this legislation deserve additional comment.

1. Annual Report on the Health Status of Children

The Academy strongly supports the requirement for an annual report on the Health Status of Children which would include statistics on infant mortality, the number of children participating in EPSDT, the delivery of prenatal care, child morbidity, health insurance and health care utilization. No comprehensive report currently exists on the health of children, either on their unmet needs or on the discrepancies of the current health care delivery system. At a minimum such information will give us a clear picture as to the state of our nation's children's health and hopefully help to plan more effectively for ways to address their needs. In addition, we recommend the Secretary provide a summary of all efforts taken by the Administration to address areas covered by the report and that priority areas for future initiatives, including budget requests, be determined based on this information. Each year the Secretary should set specific and measurable goals for improving services and outcomes and steps to attain these goals.

2. Definitions of a Model Health Benefit Package for Pregnant Women and Children

The Academy strongly endorses the requirement that the Secretary develop a model health benefit package for pregnant women and children through age 18.

As you know, a crucial shortcoming of our current health insurance system for children is the inadequacy of coverage. Primary care, preventive services, and services for children with special health care needs are either completely uncovered or subject to inappropriate limits.

Children are not just small adults—they differ not only in size, but also in chemistry, immunity, neurologic maturity, digestive ability, emotional maturity and more. Children are constantly growing, developing and changing. They have specific health care needs to enable them to become productive adults. Nevertheless, health insurance plans continue to cover adult needs (hospitalization) and exclude children's needs (preventive services/ambulatory care).

While most American children have been immunized by the time they enter school, there are still millions of others including one third of poor pre-school children—who do not receive protection against measles, rubella, mumps, polio, diphtheria, tetanus, and pertussis. Immunizations are not generally covered by private health insurance even though a bipartisan study released by the House Select Committee on Children, Youth and Families—as well as previous reports on the same subject—indicates that immunization programs save \$10 for every dollar spent. Preventive care is not generally covered, even though for each dollar spent on screening Texas children for congenital malformations, eye and ear problems and preventive dental care, \$8 was saved in long-term costs and income loss.

In addition, all children must have access to a full range of benefits, including emergency care, hospital care, outpatient diagnostic care, medical devices, home

health care, medical and social services to evaluate and treat suspected child abuse and neglect, transportation, respite care, mental health services, substance abuse treatments and care coordination for children with special health care needs. These plans must be based on the child's needs.

Indeed, the Academy has developed such a package, including a catastrophic provision as part of our efforts to develop an access proposal for children and pregnant women. We would be interested in sharing this information and working with the Secretary in developing such a model.

3. Reimbursement

Although eligibility expansions for Medicaid is perhaps the most important factor in improving access to care, other barriers, including impediments to physician participation, must be removed to assure that Medicaid children have access to comprehensive continuing medical care.

The Academy supports the provisions in both Senator Bentsen and Senator Bradley's legislation to make reimbursements to providers of pediatric and obstetrical care more appropriate and to assist providers with administrative problems. Although pediatricians have the highest participation rate among physician groups, the rate of participation is declining.

In 1978, 85 percent of all pediatricians had some Medicaid participation with a decline to 82 percent in 1983. More notable is the trend in the number of pediatricians who limit their participation in the Medicaid program. In 1978, 26 percent of the pediatricians had some restriction on the number of Medicaid recipients that they would treat, but this percent grew to 35 by 1983. Thus in 1983, the last year for which we have a national survey, 50 percent of pediatricians either did not participate at all or limited their participation. We have reason to believe that nonparticipation and limited participation are increasing. This year we are about to conduct another national survey of pediatrician participation in Medicaid.

Regulations implementing previous legislation state that there must be "enough providers so that services under the plan are available to recipients at least to the extent that these services are available to the general population." The American Academy of Pediatrics strongly supports the intent of the regulation but suggests that further Federal action is needed. For the Medicaid program to live up to its promise, there must be participation by competent physicians, and, particularly, by pediatricians since half of all Medicaid recipients are children.

We strongly support the provision in Senator Bradley's Infant Mortality Initiative which would require states to submit annually a plan which specifies payment rates for pediatric procedures. If implemented appropriately, this requirement should lead to a more equitable fee schedule. Although an important first step, the only way to verify the impact of reimbursement reform is through actual increases in pediatrician participation. Therefore, we recommend that Congress and the Administration establish physician participation targets for the states, with penalties for failure to achieve targets or bonuses for reaching targets. States could be allowed to phase in their efforts as long as evidence of progress is verified through achievement of previously established interim targets. Fundamental to the process of setting physician participation targets is definition of "participation." States should not be able to count as participators those physicians who provide occasional emergency room care, those who accept only limited numbers of Medicaid children, or those who will not accept new Medicaid patients. From true physician participators, Medicaid eligible children should receive comprehensive, continuing care in a medical home, as do children in more favorable financial circumstances. Such care can offer appropriate parenting, promote disease prevention, provide care early in the course of an acute illness before it reaches a life threatening stage, and give the family confidence and security that there is a physician who truly cares about their children and whom they can feel free to call for advice.

In addition we recommend the report of timeliness of payments under Medicaid not be limited to providers of obstetrical care, but to all health care providers through the Medicaid program. This is a barrier which affects all providers under the program.

CONCLUSION

As several members of this Committee are aware, the Academy has designated ensuring access to quality health insurance for all children and pregnant women as the organization's main priority for the next several years. To that end we are in the process of drafting a proposal to restructure the current financing system for these populations. Indeed, we have come to believe that despite all of our best efforts, attempts to weave together a coherent system from a patchwork of programs

will never succeed. Nevertheless, we continue to support expansions and enhancements to the MCH Block and Medicaid program which will serve as the basis for our future efforts. We look forward to working with you as the Committee refines these proposals to further enhance this important program.

PREPARED STATEMENT OF RICHARD H. SCHWARZ

Mr. Chairman, Members of the Committee I am Richard H. Schwarz, MD, an obstetrician-gynecologist from New York City and Vice President of the American College of Obstetricians and Gynecologists (ACOG). I am also Chairman of the Department of Obstetrics and Gynecology at the State University of New York Health Science Center and Chief of Obstetrics at Kings County Hospital. These institutions deliver 7,000 babies a year, of which 5,600 are covered by Medicaid or have no insurance coverage at all. I am delighted to be here today testifying on behalf of ACOG, which represents more than 28,000 physicians specializing in the delivery of health care to women. One of the most important issues to ACOG is getting children off to a healthy start. One of the best ways to do this is to assure that all pregnant women have access to prenatal care. In these days when we are forced to make difficult choices because of budget constraints, this choice is an easy one. It is simply a question of whether we invest now or pay later.

I have been practicing medicine for 34 years and have witnessed tremendous advances in the field of obstetrics. Ultrasound, electronic fetal monitoring, neonatal intensive care these are just a few examples of the exciting new technologies we employ to care for pregnant women and their infants.

But despite the technological advances, the prescription for delivering a healthy infant has changed very little in my lifetime. It is really very simple: all pregnant women need good prenatal care beginning early in pregnancy; they need adequate nutrition; and they need readily available services to plan their pregnancies and to treat any complications that may arise.

The relationship between prenatal care and the prevention of infant mortality was well documented in the 1985 report of the Institute of Medicine (IOM) *Preventing Low Birthweight*. The IOM found "the overwhelming weight of evidence is that prenatal care reduces low birthweight," a condition associated with two-thirds of the deaths in the neonatal period and 20% of postnatal deaths. Moreover, the IOM reported that "a major theme of virtually all the studies reviewed is that prenatal care is most effective in reducing the chance of low birthweight among high-risk women, whether the risk derives from medical factors, sociodemographic factors, or both."

Do all pregnant women uniformly receive good prenatal care? Unfortunately, the answer is no and the evidence is seen daily in the neonatal intensive care units of hospitals throughout the country. There has been no progress since 1979 in getting more women into early prenatal care with the number of women who obtain late or no prenatal care actually increasing since 1982. In 1986, the latest year for which figures are available from the National Center for Health Statistics, 24.1% of mothers failed to begin prenatal care in the critical first trimester of pregnancy. Five percent of white women and 10.6% of black women received late or no prenatal care at all. The data shows that those states with increases in the proportions of mothers receiving late or no care substantially outnumber states with declines.

MEDICAID ELIGIBILITY

Medicaid is the single most important source of care for low-income pregnant women and their children. Yet, a major problem is that far too few of the poor qualify for Medicaid. During the past several years, Congress has taken significant steps to address the infant mortality problem by expanding Medicaid eligibility for maternity care to more low-income pregnant women. Studies show that women of child-bearing age and children are the most likely to be uninsured for medical care. Fully 15% of the 3.7 million women who give birth each year have no insurance, private or public, to pay for maternity care. Raising the Medicaid income ceiling further could greatly reduce the number of women who are without maternity care. Even for families with incomes above the poverty level, the cost of maternity care can be prohibitive. The Health Insurance Association of America (HIAA) estimated that in 1986, the total medical cost, including hospital care, of having a baby was \$2,560 for a normal delivery and \$4,270 for a caesarean delivery.

ACOG fully supports efforts to further expand Medicaid eligibility to pregnant women and children with family incomes up to 200% of the Federal poverty threshold. We also strongly support the proposal, included in the FY 1990 Budget agree-

ment, to require states expand Medicaid eligibility to low-income pregnant women and children with incomes up to 185% of the poverty level. Medicaid expansion will go a long way towards assuring that no pregnant woman lacks prenatal care because she cannot afford to pay for it. The logic behind this step is irrefutable; prenatal care is not only effective in reducing low birthweight and infant mortality, it is cost effective. The IOM report concluded that for every dollar spent for prenatal care among a targeted population, \$3.38 could be saved in the total cost of caring for low birthweight infants requiring expensive medical care.

AVAILABILITY OF CARE

ACOG also urges you to address the issue of the availability of pregnancy related care to Medicaid recipients. Pregnant women who are eligible for Medicaid services often have difficulty obtaining prenatal care, in part because a number of physicians in private practice are unwilling to accept Medicaid patients. Changes in the law expanding eligibility, while positive, have not addressed the problems created when there are not enough providers in the Medicaid system.

Studies of participation in Medicaid by obstetrician-gynecologists, which rely on self-reported data, show participation rates ranging from 46% in 1983 of obstetricians in private practice (the Alan Guttmacher Institute, 1985) to 72.2% in 1984 of all obstetricians (OTA 1988). Data from a survey conducted in 1987 by ACOG's Standing Committee on Health Care for Underserved Women, showed that 64% of obstetrician-gynecologists sampled, who provided obstetric care, did so for Medicaid patients. The obstetricians surveyed listed low reimbursements, slow payments, denial of eligibility after the patient has been in care, and a belief that Medicaid patients are more likely to sue as the main reasons for nonparticipation.

In many states the reimbursement rate for total obstetric care is well below half the prevailing charge for obstetric care. In 1986, ACOG found the medical charge for total obstetric care nationwide to be \$1,000. For that same year the General Accounting Office (GAO) reported the national average reimbursement rate under Medicaid was \$473.11. In some states payment rates have not been updated in more than a decade. For example, for complete obstetric care including all prenatal visits plus attendance at delivery, the GAO reported that New Hampshire reimburses \$214, West Virginia \$255, and Pennsylvania \$312.

Professional liability concerns also discourage physician participation. The cost of liability insurance may constitute a large portion or actually exceed the reimbursement rate for obstetric services from Medicaid. In New Hampshire the average cost of liability insurance in 1987 was \$154 per delivery, \$273 in West Virginia, and \$203 in Pennsylvania. Increasingly, we are noting a decline in access to obstetric services in rural and economically depressed communities as obstetricians, and family practitioners confronting the reality of high insurance premiums and low reimbursement from public programs give up the practice of obstetrics.

Bureaucratic problems present in the Medicaid program are a major factor in slow payments. The State of California provides several examples that are representative of problems faced throughout the country. The average period of time between submission of a claim and reimbursement is 3 months in California. This is in a state that requires payment within 45 days.

One reason that claims take so long to be processed is that they are singled out for special review. While this review takes place, the 45 day rule does not apply. And this review process can take more than a year. To make matters worse, claims for reimbursement for certain services are always singled out for this special review. For example, all claims involving a caesarean delivery or sterilization receive this special treatment. We are not suggesting that claims should never be reviewed, but certainly it is unacceptable that every single claim by every physician for a specific service regardless of the medical indications requires review. And the length of delays when this review occurs are excessive.

Another problem is a sequential review process which upon identification of the first error immediately rejects the claim and sends it back to the physician. The result is that the same claim can be rejected several times, even though each time the identified error is corrected. For example, if an error is identified on line 6, the form is returned to the physician. This error is corrected and the claim resubmitted. When processing begins again an error is identified on line 8, and once again the claim is rejected. This can happen a number of times, which greatly adds to the time required for payment.

Reviewing the forms that must be submitted makes it easier to understand the problem. A copy of the California Medi-Cal sterilization form is attached. And, this is the simplified version designed by a group that included representatives from ACOG's California District, the California Medical Association, the California De-

partment of Health, the fiscal intermediary and the HCFA regional office. A California physician reported that Medi-Cal bill collection is so much more difficult and complex than other insurers that his billing service charges him \$4 for processing a regular bill and \$15 for a Medi-Cal bill. After reviewing this form, this difference is not surprising.

ACOG believes that the Federal Government should establish Medicaid demonstration programs, such as the proposal included in the Infant Mortality and Children's Health Act (S. 339), to find ways to improve access to needed physicians' services by pregnant women and children. Specifically, states should be encouraged to try innovative approaches to increasing provider participation. These should include:

- improving compensation, expediting reimbursement, and using innovative payment mechanisms including global fees for maternity and pediatric services with guaranteed periodic payments;
- assisting in securing, or paying for, medical malpractice insurance or otherwise sharing in the risk of liability for medical malpractice;
- decreasing unnecessary administrative burdens in submitting claims or securing authorization for treatment;
- guaranteeing continuity of coverage, and expediting patient eligibility determinations; and,
- covering medical services to meet the needs of high-risk pregnant women and infants.

Research indicates there is a positive response on the part of physicians in states which have increased reimbursement rates and made improvements in claims processing, eligibility determinations, and scope of services. A demonstration program may well show it is possible to improve access to prenatal care to Medicaid recipients and may ultimately reduce the rate of infant mortality. We urge the Committee to look favorably at the various programs included in legislative proposals currently before you.

LIABILITY ISSUES

Liability coverage and the cost of liability coverage is an acute problem and it affects access to care by all women, not just those who are insured through public programs. We are experiencing a virtual exodus from obstetrics of many bright, skilled, dedicated professionals who are being pushed out because of professional liability. Family physicians as well as obstetrician-gynecologists are giving up caring for pregnant women. If we are going to address access to obstetric care for the Medicaid population, we must encourage family physicians and obstetrician-gynecologists to continue the practice of obstetrics.

The cost of liability coverage is often greater if one provides obstetric services. One insurance company in Florida charges rates more than double for those who provide obstetrics than those who only provide gynecologic services, going from \$77,000 to \$186,000 in some parts of Florida and from \$90,000 to \$217,000 in another. Similar situations exist in other states. For example, rates vary from \$37,000 to \$60,000 in Georgia, from \$33,000 to \$56,000 in Michigan; and from \$24,000 to \$48,000 in California. (These rates are from one company in each state. Other companies may charge significantly different rates. Also, the limits of coverage may be different so comparisons between states cannot be made.)

Twelve percent of obstetrician-gynecologists surveyed by ACOG in 1987 had quit delivering babies because of the risk of malpractice. An even greater percentage of family physicians—who are an important source of care in rural areas—no longer practice obstetrics. A shocking trend uncovered in ACOG's 1987 survey was that many obstetricians are limiting the high-risk portion of their practice. In 1985, less than 2% of our members devoted a nominal 10% or less of their practice to high-risk care. But in 1987, 45% restricted their high-risk practice to that extent. This is a finding that does not bode well for high-risk patients.

Liability poses a serious threat to women's health care and there is an urgent need for action to resolve this problem. Health care will become unaffordable and unavailable if we allow escalating liability insurance premiums to drive out dedicated professionals. As fewer physicians deliver babies, access to obstetric care for poor women in particular will become even more limited. The problem is national in scope. For example, the number of physicians delivering babies in Oregon has declined by 25% since 1984. In Iowa, 31% of all physicians who provided obstetric services since 1981 have now quit. In Georgia, 67 counties have no obstetric care provider.

The list goes on, but the point is clear, we need Federal action to resolve the problem. For years, Federal legislators have responded to problems in professional liability by saying that the crisis must be addressed in areas traditionally left to the states—establishing rules for tort actions and regulations of insurance. Many states have enacted changes in their tort laws over the past decade, but their success in stemming the crisis in this report has been limited. It is time for national leadership to assert its role and address the tremendous liability problems facing us. ACOG looks to the Congress to develop model solutions aimed at solving the recurrent liability insurance crisis and the resulting threat to access to high quality maternity care for all of the women of this country.

In particular, we would encourage the members of this Committee to consider the Medical Offer and Recovery Act, which would provide for prompt and fair resolution of medical malpractice claims. The current system for resolving medical malpractice claims is too expensive and takes too long for injured parties to obtain compensation. Currently, it takes an average of three and a half years to resolve a claim. Recent ACOG claims data indicate that 26% of obstetric and gynecologic claims take five or more years to close. As little as 28% of the premium dollars paid by physicians are used to compensate injured patients. There must be a better way! The Medical Offer and Recovery Act holds promise of prompt payment to injured parties with a significant reduction in the costs associated with settling claims. By eliminating the necessity for an adversarial relationship between physicians and patients, it would also reduce the tension between them. We believe it would lead to greater predictability for insurance carriers and reduce the pressure to increase premiums to cover unpredictable losses. A summary of the bill is attached.

While we understand that enactment of a broad proposal like the Medical Offer and Recovery Act would take significant study, a proposal that could have an effect on the willingness of physicians to provide obstetric care will soon be before this Committee—that is how to include the costs of liability coverage in the new Medicare reimbursement rates under the Resource-Based Relative Value Scale. It has been suggested that a per procedure amount should be determined based on a premise that the elderly sue less frequently than others. This proposal, if enacted, would actually encourage physicians to stop providing obstetric care. Frequently obstetrician-gynecologists and family physicians can drastically reduce their liability payments by dropping obstetrics. If Medicare bases its payment on only the liability costs directly attributable to the elderly, physicians providing both obstetrics and gynecology will receive much less than a fair amount based on what they must pay for liability coverage. Surely, it makes little sense to sabotage one program, through the policies of another. The liability problem has variously been attributed to lawyers, insurance carriers, bad doctors, or to public expectations or perfection. It is a complex problem, and no one group is to blame. The solution requires that everyone be willing to give a little. As long as we allow liability to force providers out of obstetrics, the access problem, which is so critical to a reduction in infant mortality, will remain unsolved. Access will be difficult for those whose health care is unfunded or underfunded. The National Commission to Prevent Infant Mortality recognized this problem in their publication "Malpractice and Liability: An Obstetrical Crisis." We would encourage you to look at alternatives to the tort system for resolving malpractice claims and at interim steps which will enable public programs to deal with the crisis.

CONCLUSIONS AND RECOMMENDATIONS

ACOG would like to commend this Committee, and particularly its Chairman, for holding this hearing and for all the efforts you have made on behalf of pregnant women and children. Much progress has been made and much remains to be done. In addition to supporting efforts to expand Medicaid eligibility, address the Medicaid liability issue, and promoting demonstration programs encouraging innovative methods to increase the availability of services to Medicaid beneficiaries, ACOG makes the following recommendations:

1. Congress should require continuous eligibility throughout pregnancy and the postpartum period. This would assure that pregnant women have coverage during the entire course of pregnancy and would encourage providers to participate by assuring payment. In addition, implementation of a required presumptive eligibility component could reduce the delays that Medicaid beneficiaries experience in obtaining prenatal care.

2. Congress should increase funding for the Maternal and Child Health Block Grant. Like community health centers, clinics funded through MCH block grant funds, coupled with state and local dollars, are a critically important source of pre-

natal care for poor women. The block grant is an important resource for states and a source of care for women who would otherwise fall through the cracks because they don't qualify for Medicaid.

3. There are a number of social factors that affect our nation's infant mortality rate that must also be taken into consideration. Substance abuse can have determinantal effects on the outcome of pregnancy. It is clear that obstetrician-gynecologists play an important role in identifying and educating patients as to the negative effects of substance abuse. The Federal Government must also play a role by; educating the public on the harmful effects of substance abuse, particularly during pregnancy, increasing the availability of drug treatment centers and health care workers trained to counsel, educate, and treat individuals who abuse drugs, and by increasing funding for basic medical research on the effects of substance abuse. More research is needed on cocaine abuse and pregnancy and on the long-term effects of such abuse on infants.

4. When addressing the need for AIDS education and research, Congress should also take steps to help prevent the perinatal transmission of AIDS or the spread of the HIV infection from the mother to the infant. We must work effectively and compassionately to help the infants who are already infected with the AIDS virus. Education about the risks associated with AIDS and pregnancy is vitally important if we are to give infants a fighting chance.

5. Congress should increase the cigarette excise tax. Smoking during pregnancy increases the risk of miscarriage, premature delivery, and stillbirth. Newborns of smoking mothers weigh on the average 200 grams less than babies born to mothers who do not smoke. Smoking is thus an important and preventable contributor to low birthweight. And of particular importance, we find that more teenage girls now smoke than boys. Despite the well documented health risks to children from maternal smoking during pregnancy, smoking by women in the childbearing years persists. The cigarette excise tax is an effective deterrent to smoking. Studies show a 9% increase in the cost of cigarettes produces approximately a 4% decrease in smoking among adults and a much greater effect—a 14% decrease in smoking among teenagers.

Thank you for the opportunity to testify. I will be happy to answer any questions you may have.

INSTRUCTIONS FOR STERILIZATION CONSENT FORM

ALL ENTRIES MUST BE LEGIBLE

1 Prestamp, type or print physician name. Entries must be identical.

6 Enter the words "Tubal Ligation" (or Vasectomy). Entries must be identical. OK to prestamp.

3 Birthdate, month, day and year **MUST** match birthdate on claim, master file and treatment authorization.

4 Patient's name should be identical in all 3 places.

7 Patient's signature **MUST** be entered.

8 Date of patient's signature. Patient **MUST** be 21 or older on date form is signed. Claim will be rejected if patient signs this form before 21st birthday.

10 Complete only if there was an interpreter. If any entry is completed, all three (10, 11, 12) must be completed.

15 Name of physician or office staff person. **MUST** include date consent obtained.

20 Date of sterilization only. (No need to enter name of procedure on following line.)

22 If 22 applies, 23 and 24 **MUST** be scratched out.

23 If item 23 applies, scratch out paragraph 22 **AND** check the applicable block (24, 25 or 26).

CONSENT FORM

YOUR DECISION AT ANY TIME NOT TO BE STERILIZED WILL NOT RESULT IN THE WITHDRAWAL OF WITHHOLDING OF ANY BENEFITS PROVIDED BY PROGRAMS OR PROJECTS RECEIVING FEDERAL FUNDS

CONSENT TO STERILIZATION

I have asked for and received information about sterilization from _____ When first asked for information I was told that the decision to be sterilized is completely up to me. I was told that I could decide not to be sterilized. If I decide not to be sterilized, my decision and not of fact my right as future care or treatment. I will not lose any help or benefits from programs receiving Federal funds, such as A.F.D.C. or Medicaid that I am now getting or for which I may become eligible.

I UNDERSTAND THAT THE STERILIZATION MUST BE COMPLETELY PERMANENT AND NOT REVERSIBLE. I HAVE DECIDED THAT I DO NOT WANT TO BECOME PREGNANT AGAIN.

I was told about these temporary methods of birth control that are available and could be provided to me which will allow me to bear or father a child in the future. I have rejected these alternatives and chosen to be sterilized.

I understand that I will be sterilized by an operation known as _____ The doctor's name and birthdate and sex, such as the operation have been explained to me. All my questions have been answered to my satisfaction.

I understand that the operation will not be done until at least thirty days after I sign this form. I understand that I can change my mind at any time and that my decision at any time not to be sterilized will not result in the withholding of any benefits or medical services provided by federally funded programs. I am at least 21 years of age and was born on _____

My consent is given by _____

My consent expires 180 days from the date of my signature below.

I also consent to the release of this form and other medical records about the operation to _____ Representatives of the Department of Health, Education and Welfare or Employees of programs or projects funded by that Department but only for determining if Federal laws were observed. I have received a copy of this form.

Signature _____ Date _____

You are requested to supply the following information, but it is not required:

Are you ethnic (designate race):

American Indian Black (not of Hispanic origin)

Alaska Native Asian

Asian White (not of Hispanic origin)

Pacific Islander Other _____

INTERPRETER'S STATEMENT

If an interpreter is provided to assist the individual to be sterilized:

I have explained the information and advice presented orally to the individual to be sterilized by the person of _____ I have also read him/her the consent form in _____ the best of my knowledge and he/she understands the operation.

Signature _____ Date _____

STATEMENT OF PERSON OBTAINING CONSENT

I, _____ signed the consent form prepared to further the nature of the sterilization operation. _____ the fact that it is intended to be a final and irreversible procedure and the doctor's name and birthdate presented with it.

I consented that individual to be sterilized that operation is permanent that sterilization is different because it is permanent. I informed the individual to be sterilized that he/she cannot be sterilized at any time and that he/she will not lose any health services or benefits provided by Federal funds.

To the best of my knowledge and belief the individual to be sterilized is at least 21 years old and appears mentally competent. He/she knowingly and voluntarily requested to be sterilized and appears to understand the nature and consequences of the procedure.

Signature of person obtaining consent _____ Date _____

PHYSICIAN'S STATEMENT

I certify before I performed a sterilization operation that _____ I am a duly licensed physician.

I am licensed to perform the sterilization operation. _____ the fact that it is intended to be a final and irreversible procedure and the doctor's name and birthdate explained with it.

I counseled the individual to be sterilized that operation is permanent that sterilization is different because it is permanent. I informed the individual to be sterilized that he/she cannot be sterilized at any time and that he/she will not lose any health services or benefits provided by Federal funds.

To the best of my knowledge and belief the individual to be sterilized is at least 21 years old and appears mentally competent. He/she knowingly and voluntarily requested to be sterilized and appeared to understand the nature and consequences of the procedure.

Reasons for use of alternative third paragraph: Use the first paragraph below, except in the case of premature delivery or emergency abdominal surgery where the sterilization is performed less than 30 days after the date of the individual's signature on the consent form. In those cases, the second paragraph below may be used. Cross out the paragraph which is not used. (At least thirty days have passed between the date of the individual's signature on the consent form and the date the sterilization is performed.)

This sterilization was performed less than 30 days but more than 72 hours after the date of the individual's signature on the consent form because of the following circumstances which applicable here and fill in information requested:

Premature delivery

Individual's unexpected date of delivery

Emergency abdominal surgery

(Describe circumstances) _____

Signature _____ Date _____

24 If "Premature Delivery" is checked, date delivery was expected must be entered on line 25.

26 If applicable, enter name of operation.

27 Physician signature - must be entered after the sterilization operation by the actual surgeon.

28 Date of signature **MUST** be entered.

The Medical Offer and Recovery Act

The Medical Offer and Recovery Act is designed to serve as model legislation for the states. In states that do not implement similar reforms for all medical malpractice cases by January 1, 1988, the provisions will apply to injuries resulting from the provision of health care paid for by the federal government, including Medicare and Medicaid.

How the Process Works

- o Either the patient or the health care provider can activate the system to promptly resolve an incident resulting in personal injury to the patient.
- o Within 180 days of an incident resulting in personal injury, a health care provider can agree to pay the patient's net economic loss.
- o In the case of injury to a newborn, informed consent or failure to diagnose, the 180-day period would run from the date of a claim against the health care provider since the provider might not be aware of the injury at the time of treatment.
- o This bill does not apply to injuries intentionally caused by the provider or "wrongful death" cases.
- o If the provider makes an offer, the patient could not sue for the same injury under the tort system.

Payments Under the System

- o All of the patient's net economic loss must be paid as costs are incurred, thus assuring benefits as long as they are needed. Net economic loss includes the cost of continued medical and hospital care, rehabilitation, nursing care, wage loss, the cost of a housekeeper and adapting the patient's house and car, as well as reasonable attorney's fees in advising the patient.
- o Payments from collateral sources such as private health insurance and workers compensation are mandatorily offset from the amount owed by the provider.
- o The payments would be made periodically as the patient's economic loss accrues. Parties can agree to a lump sum settlement if net economic loss is less than \$5,000.

Use of Binding Arbitration

- o In the event that a provider does not choose to make an offer, a patient who believes he or she has been injured by malpractice can, within 90 days, request that an expeditious arbitration proceeding be conducted to determine if the provider was at fault. If the arbitrator finds the provider was at fault, the patient will be awarded compensation for net economic loss as if the provider had voluntarily made the offer.
- o Binding arbitration would be used for disputes relating to the actual payment of net economic loss or to the amount of the payment.
- o The provider making an offer may require other parties (potential defendants) who may be responsible for the injury to join in the offer. Other parties may request on their own to participate. Any disagreement between the joined parties will be settled by binding arbitration.

Patient Assurances

- o Physicians are required to carry sufficient malpractice insurance or post bond in order to participate in the program.

February 1989

COMMUNICATIONS

STATEMENT OF THE MARCH OF DIMES BIRTH DEFECTS FOUNDATION

The March of Dimes Birth Defects Foundation is pleased to have this opportunity to share our views on the Medicaid program and the Maternal and Child Health (MCH) Block Grant with the Senate Finance Committee. We commend the members of the Committee for the leadership they have demonstrated by introducing and supporting legislation to expand and improve Medicaid and the Maternal and Child Health Block Grant. We are heartened as well by the President's initiative to increase Medicaid income eligibility for pregnant women and infants. We hope that the concern demonstrated here will lead to improved access to preventive health care services for the nine million women of reproductive age and 12 million children who are uninsured.

We are seeing progress in our effort to ensure access to health care for mothers and their children. The Alan Guttmacher Institute estimates that 361,000 newly eligible infants and pregnant women will be covered by Medicaid in 1990 as a result of recent incremental expansions. Concerned legislators and organizations have worked consistently and effectively over the last few years to greatly improve access to prenatal and infant health care, and we should soon be seeing improvements in key indicators of maternal and child health.

The March of Dimes is concerned that the growing problem of substance abuse during pregnancy will lead to increased maternal and infant death and disability. Pregnant women who abuse drugs or alcohol expose their babies to a high risk of being born too small, too soon or with birth defects. In addition, women who abuse drugs are at risk for sexually transmitted diseases, including AIDS, which also can be passed on to the baby before or during birth.

A recent telephone survey of hospitals in large metropolitan areas conducted by the Select Committee on Children, Youth and Families indicates that there may well be a significant rise in maternal mortality and morbidity and infant mortality and morbidity as a result of increased substance abuse during pregnancy. Experts estimate that each year up to 375,000 babies may be exposed in the womb to illicit drugs.

This threat to the health of our nation's mothers and children can be alleviated if we can provide prenatal care to all pregnant women and if we can assure the availability of substance abuse treatment for all pregnant women who need it. The March of Dimes views pregnancy as an opportune time to break the grip of substance abuse. At this time, many women who abuse drugs and alcohol may be receptive to education regarding the hazards of substance abuse to their fetus, and to treatment to halt the abuse. It is a time to reach the fathers—many of whom are addicts—and other family members to help keep the family together. Follow-up programs for infants born exposed to alcohol and other drugs can render medical and social services to the entire family, thereby providing the healthiest environment for the infant. Comprehensive prenatal care that includes drug and alcohol treatment as well as family support services is necessary.

We can address the threat posed by substance abuse during pregnancy by expanding existing treatment services and coordinating maternal and child health programs with treatment services. We also would like to see states include drug and alcohol abuse treatment included in the pregnancy-related services offered to pregnant women receiving Medicaid.

The March of Dimes recommends that the following components be included in legislation to improve Medicaid and the MCH Block Grant:

MEDICAID

- Require coverage for all pregnant women and infants living in families earning less than 185 percent of the Federal poverty level, and for children living in poverty.
- Require presumptive and continuous eligibility and eliminate the assets test for pregnant women and infants.
- Assure adequate provider participation in the program.
- Include treatment for substance abuse in the definition of "comprehensive prenatal care."
- Encourage states through an enhanced Federal matching rate to implement "outreach" services to bring pregnant women into the Medicaid program.
- Encourage coordination between Medicaid, WIC, MCH, community and migrant health centers and providers of substance abuse treatment, and other social services.

MATERNAL AND CHILD HEALTH BLOCK GRANT

- Increase the authorization level from \$568 million to \$711 million.
- Improve accountability by strengthening state planning and reporting procedures.
- Continue the set-aside for sickle cell screening and other genetic services.
- Improve participation by eligible women and infants by instituting home visiting and co-location of services.
- Establish statewide, governor-appointed advisory boards to ensure coordination of services in each state.

In summary, we would like to emphasize that federally funded programs for mothers and children have been and continue to be effective. We must continue our commitment to preventive health services that benefit our nation's future generation.

CRS ISSUE BRIEF

MEDICAID: FY 90 BUDGET AND HEALTH INITIATIVES

ISSUE DEFINITION

Medicaid is a Federal-State matching program providing medical assistance to a projected 25 million low income persons in FY89, at a total Federal cost of \$34.5 billion. The FY90 budget resolution approved by the Congress provides a \$200 million increase in Federal Medicaid funding over current law levels, and permits further expansions if offsetting savings can be found in other programs. There are a variety of proposals to use the additional funds to extend Medicaid eligibility to larger numbers of pregnant women and children and to take other measures to improve access to prenatal and early childhood health care.

BACKGROUND AND ANALYSIS

Description of Medicaid

Medicaid, authorized by Title XIX of the Social Security Act, is a Federal-State matching program providing medical assistance to a projected 25 million low income persons in FY89. FY90 program expenditures under current law are expected to reach \$67 billion, of which the Federal share will be \$38 billion. Although Federal funds account for 56% of total program expenditures, each State designs and administers its own Medicaid program, setting eligibility and coverage standards within broad Federal guidelines. Thus, there is considerable variation among the States in terms of eligibility requirements, range of services offered, limitations placed on those services, and reimbursement policies.

Every State except Arizona participates in the Medicaid program, as do the District of Columbia, American Samoa, Guam, Puerto Rico, the Virgin Islands, and the Northern Mariana Islands. (Arizona currently provides federally funded medical assistance through a demonstration program that has received waivers of certain Medicaid requirements.) At the State level, Medicaid is administered by a designated single State agency. Federal oversight of the Medicaid program is the responsibility of the Health Care Financing Administration (HCFA) within DHHS. HCFA also administers the Federal Medicare program for the aged and disabled.

The Federal share of expenditures for Medicaid services is tied to a formula inversely related to the square of a State's per capita income. For FY89, the Federal matching percentages range from 50% to 79.8%. The matching rate for administrative costs is generally 50% for all States. Higher matching, at levels ranging from 75% to 90%, is available for certain management and control activities. The remaining costs of the program are paid by the State; in some States local governments may also contribute.

Eligibility

Eligibility for Medicaid benefits has traditionally been linked to actual or potential receipt of cash assistance under either of two programs: Aid to Families with Dependent Children (AFDC), and Supplemental Security Income (SSI) for the aged, blind, and disabled. Recently States have been given the option to extend

Medicaid to other low-income groups. Coverage of some of these new populations was made mandatory by legislation enacted in 1988.

All States must cover the **categorically needy**. These include all persons receiving AFDC and, in most States, persons receiving SSI. States have the option of limiting Medicaid coverage of SSI beneficiaries by using more restrictive standards for Medicaid, if those standards were in effect on Jan. 1, 1972 (before implementation of SSD). Fourteen States continue to use more restrictive standards. States must also cover as categorically needy a number of groups that are not receiving AFDC or SSI. The following are among the more important of these groups:

- Certain persons whose family income and resources are below AFDC standards but who fail to qualify for AFDC for other reasons, such as family structure. These include pregnant women, as well as children born on or after Oct. 1, 1983, to age 7.
- Families losing AFDC benefits as a result of increased employment income or working hours or increased child or spousal support payments. States must continue coverage for these families for various periods, depending on the reason for the loss of AFDC benefits.
- Persons who have been receiving both Social Security and SSI benefits and who become ineligible for SSI because of increases in their Social Security payments.
- Certain disabled people who lose SSI after returning to work but who remain disabled and who could not continue working if their Medicaid benefits were terminated.

In addition to the mandatory groups, there are several optional groups that States may elect to treat as categorically needy for Medicaid purposes. These include families with unemployed parents and "Ribicoff children" in families with income below AFDC standards; these are children whom the State is not required to cover but who are under a maximum age set by the State, which may be 18, 19, 20, or 21. States may also cover persons in institutions who meet a special institutional financial standard set by the State; this standard may not exceed 300% of the SSI payment level. Finally, States may cover disabled children who are not in an institution but who would be eligible if they were in an institution.

Thirty-nine States and other jurisdictions also provide Medicaid to the **medically needy**. These are persons whose income or resources exceed the standards for the cash assistance programs but who meet a separate medically needy financial standard established by the State and also meet the non-financial standards for categorical eligibility (such as age, disability, or being a member of a family with dependent children). The separate medically needy income standard may not exceed 133.3% of the maximum AFDC payment for a household of similar size. Persons may qualify as medically needy after their incurred medical expenses are deducted from their income or resources. This process is known as "spenddown." It is a frequent route to Medicaid eligibility for persons in nursing facilities.

Finally, beginning with the Omnibus Budget Reconciliation Act of 1986 (P.L. 99-509), Congress has permitted States to extend Medicaid coverage to certain **target populations**, using eligibility standards which are not directly linked to those used in the cash assistance programs. The Act allowed States the option of covering pregnant women and young children and/or aged and disabled persons meeting State-established income standards as high as 100% of the Federal poverty level.

The Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360) converted the options to mandates for several of the target groups. States must phase in coverage of pregnant women, infants under 1 year old, and aged and disabled persons eligible for Medicare with family incomes below 100% of poverty. Lower mandatory income thresholds will be in effect during a transitional period for each group. For pregnant women and infants, States must reach full coverage by July 1, 1990. The transition period for the aged and disabled ends Jan. 1, 1992, or Jan. 1, 1993, in 209(b) States. Coverage for the aged and disabled may be restricted to Medicare premiums and cost-sharing amounts and prescription drugs up to the new Medicare drug deductible. States may still choose to extend coverage to these groups faster than the timetable requires. They may also choose to cover older children with family incomes below 100% of poverty. This option is being phased in on a timetable that ends Oct. 1, 1990, at which time States will be able to cover children through age 7.

Finally, the Omnibus Budget Reconciliation Act of 1987 (P.L. 100-203) further expanded States' options by allowing coverage, beginning July 1, 1988, of pregnant women and children up to age 1 with incomes less than 185% of the Federal poverty level. The State may impose a premium for this coverage, equal to no more than 10% of the amount by which the family's income exceeds 150% of the poverty level.

Services

All States must cover a minimum set of services under Medicaid and may at their option offer additional services. The minimum service requirements differ for the categorically needy and the medically needy. For the categorically needy, the State must provide inpatient and outpatient hospital services, physician services, laboratory and x-ray, family planning, skilled nursing facility (SNF) services for those over age 21, and home health care for persons entitled to SNF care. The State must also provide early and periodic screening, diagnosis, and treatment (EPSDT), a preventive health program for persons under 21. If the State covers the medically needy it must provide, at a minimum, ambulatory care for children and prenatal and delivery services for pregnant women. States may limit coverage for the mandatory services in a variety of ways. They may impose ceilings on the number of inpatient days or physician visits that will be reimbursed, require prior authorization or second surgical opinions, and deny coverage for services deemed to be experimental.

Among the additional services that States may choose to provide are prescription drugs, dental care (some dental coverage is mandatory for children under EPSDT), eyeglasses, and care in inpatient psychiatric facilities for persons under 21 or over 65. In terms of overall expenditures, the most important optional Medicaid service is care in intermediate care facilities (ICFs). All of the States and the District of Columbia cover ICF services, and every State except Wyoming also covers services in an ICF for the mentally retarded, or ICF-MR.

Whatever services the State chooses to cover, it must offer them uniformly throughout the State and must, with minor exceptions, offer comparable coverage to all persons in the categorically needy groups. Finally, beneficiaries must generally be allowed to obtain services from any qualified provider. All three of these requirements -- statewideness, comparability, and freedom of choice -- may be waived under circumstances to be described below.

Payment for Services

States are generally free to develop their own reimbursement methodologies and levels for covered services. Specific payment rules or limits are established by law only for three types of service: rural health clinics, hospices, and laboratories. There are general guidelines for certain other services, but only two rules applying to every service type. First, providers must accept Medicaid payment as payment in full and may not seek to collect from beneficiaries. Second, Medicaid pays only after any other insurance or third party payment source available to the beneficiary has been exhausted. In particular, when beneficiaries are eligible for both Medicaid and Medicare, Medicare pays first for the services it covers. Medicaid pays what would ordinarily be the beneficiary's share (deductible or coinsurance) and covers services not available under Medicare.

For institutional services, including hospital inpatient and nursing home care, payment rates must be "reasonable and adequate" to meet the costs of "efficiently and economically operated" facilities. For hospital inpatient care the rates must also be sufficient to assure reasonable access to services and must include adjustments for hospitals serving a high proportion of low-income patients. States use two basic payment methodologies for institutional care: retrospective and prospective. In a retrospective system, payment amounts are determined after services are rendered and are based on the actual costs incurred by the provider in furnishing those services. In a fully prospective system, payment amounts are determined in advance. The provider receives a specified rate for each defined unit of service, such as a day of care or a total hospital stay, regardless of whether the provider's actual costs are more or less than that rate. States are increasingly shifting towards prospective systems for both hospital and nursing facility care.

For services of physicians or other individual practitioners, payment amounts are usually the lesser of the provider's actual charge for the service and a maximum allowable charge established by the State. In setting these maximums, some States use methods comparable to those used by Medicare in establishing reasonable charges for physician services. Other States have developed fixed fee schedules, specifying a flat maximum payment amount for each type of service; the maximum may be unrelated to actual provider charges.

Alternative Delivery Systems

States are permitted to develop alternative ways of providing Medicaid benefits, through a variety of structured systems. Use of some of these alternatives is wholly at the State's option; others require waivers of Federal requirements approved by the Secretary.

First, States may contract with health maintenance organizations (HMOs), or other prepaid health plans for the enrollment of Medicaid beneficiaries. For each beneficiary enrolled in a plan, the State issues a fixed monthly premium payment, out of which the plan provides all covered services.

Second, States may obtain waivers of freedom of choice and other requirements to restrict the providers from whom beneficiaries may obtain services. Some States have used this option, established by Section 2175 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35, OBRA81), to enter into selective contracting arrangements. The State may, for example, choose participating hospitals through a system of competitive negotiation. The more common use of the 2175 waiver authority is to establish primary care case management programs. Beneficiaries are required to select a single primary care provider. Except in an emergency, care from other providers must be authorized by the primary care physician.

Finally, States may obtain waivers, authorized by Section 2176 of OBRA81, to provide home and community-based services to persons who would otherwise require continuing care in hospitals or nursing homes. The waivers allow the State to design a comprehensive package of medical and social services to allow a target population, such as the frail elderly or the mentally retarded, to remain in the community.

FY90 Budget

Each of the last four budget reconciliation acts has provided for expansions of the Medicaid program, chiefly by providing for optional or mandatory coverage of additional groups of women and children. Partly as a result of these expansions, Medicaid expenditures have recently been growing more rapidly than anticipated. In its FY88 budget, the Administration projected that Federal outlays would grow from \$25 billion in FY86 to \$28.2 billion in FY88, for a 2-year growth rate of about 13%. Instead, FY88 outlays rose to \$30.4 billion, nearly 22% above the FY86 level. The Administration's original FY89 projections assumed further growth, under current policy, of 6.5%. However, current projections are that FY89 Federal expenditures will reach \$34.3 billion, 12.8% above the FY88 level.

Medicaid expenditures under current law are expected to continue to rise faster than medical care inflation, largely as a result of further program expansions that will take effect over the next several years. These include the phased extensions of coverage in the Medicare Catastrophic Coverage Act and the Family Support Act of 1988. State costs for nursing home care are also expected to rise in response to new quality of care mandates included in the Omnibus Budget Reconciliation Act of 1987.

President Reagan's FY90 budget included legislative and regulatory proposals intended to reduce Federal Medicaid outlays from a projected \$37.6 billion to \$36.0 billion. President Bush's revised proposal, presented to Congress on Feb. 9, 1989, retained only one of the proposed legislative changes, a reduction in Federal funds for State administrative costs. Savings would have been used to finance the Federal share of costs for expanded services to pregnant women and children. The net effect of this proposal was to maintain FY90 Federal spending at current law levels, with costs for Medicaid eligibility and service expansions to be borne by the States.

The Bipartisan Budget Agreement accepted by the President and congressional leadership in April 1989 provided for FY90 Medicaid funding at current law levels. As passed by the House, H. Con. Res. 106, the FY90 budget resolution, provided for a \$200 million increase over current law levels. This would be used to fund new initiatives in the area of infant mortality and child health, expanded community services for the frail elderly and the mentally retarded, as well as to make coverage of hospice services mandatory. As amended by the Senate, the budget resolution provided for Medicaid funding at current law levels, with any program expansions to be funded through offsetting savings in Medicaid or other programs. The conference agreement follows the House provision, allowing a \$200 million increase for program expansion. It also permits further expansion if the committees of jurisdiction can achieve offsetting savings in other programs.

Maternal and Child Health Initiatives

The last three Congresses have gradually expanded both mandatory and optional Medicaid coverage for pregnant women and children. At least two major factors have contributed to congressional interest in Medicaid expansion. The first is growing concern over the incidence of infant mortality and other unfavorable outcomes of pregnancy. The United States had an infant mortality rate in 1986 of 10.4 deaths per thousand live births, higher than that of many other major industrial nations. Rates are higher for minorities and residents of inner cities. Beyond the children who die, there are many more low birth-weight infants and others with preventable problems that are costly to treat and that can result in lifelong disabilities. There is evidence that access to prenatal and well baby care is an important factor in these outcomes.

A second source of interest in Medicaid expansion has been the growth in the number of Americans without health insurance coverage. The proportion of the population without insurance has been going up in this decade, from about 14.6% of the non-elderly in 1979 to 17.5% in 1986. In that year, 37 million persons lacked coverage; of these 12 million were children under age 18. More than half of these children were in families with incomes below the Federal poverty level. In 1987, Medicaid covered only 53% of children in poverty. Many poor children were excluded because Medicaid maximum income standards in most States were well below the poverty level, while others were excluded on categorical grounds, such as restrictions on enrollment of two-parent families with an employed parent. Recent changes in Medicaid eligibility standards, both financial and categorical, are often spoken of as having severed the traditional link between Medicaid and the welfare programs. These changes are only beginning to be implemented, and their impact cannot yet be measured. However, they are expected to reach only a fraction of uninsured children.

The 101st Congress is considering a variety of proposals for further expansion of Medicaid eligibility for pregnant women and children and for initiatives to address other factors in access to care, such as availability of health care providers and coordination of services. The Bush Administration proposal to finance expanded coverage through a reduction in Federal matching for administrative costs has been

introduced as H.R. 2216/S. 902. Other congressional proposals include broader expansions, affecting other Federal programs as well as Medicaid.

Further expansion of the Medicaid program could take the form either of new mandates, coverage requirements that all States would have to meet, or of new options, additional populations or services that a State could offer at its discretion. The expansions in recent years have been enacted in a stepwise fashion: a new option established by one year's budget legislation is made mandatory in a later year, at the same time that still more options are offered. Many of the proposals in this Congress follow the same pattern, adding new options while mandating State adoption of options established by the 100th Congress. This approach is facing increasing opposition from State governments. Although many States initially supported the flexibility provided by new coverage options, they object to the conversion of these options into mandates at a time when some of which are currently facing revenue shortfalls.

Eligibility for Pregnant Women and Children

Proposals in the 101st Congress would raise the optional or mandatory maximum income standards for pregnant women and children and would also address other potential barriers to Medicaid coverage for these groups, such as limits on allowable assets, delays in the application and eligibility determination process, and discontinuous eligibility.

Income Standards

Pregnant women and infants. Under current law, States must cover pregnant women and infants under 1 year old with family incomes up to 75% of the Federal poverty level by July 1, 1989, and up to 100% of the Federal poverty level by July 1, 1990. States may, at their option, establish a higher maximum income standard for pregnant women and infants, up to 185% of the Federal poverty level. As of January 1989, 12 States had adopted standards above 100% of the poverty level. H.R. 800/S. 339 would phase in mandatory coverage of pregnant women and infants up to 185% of the poverty level by July 1, 1993. H.R. 1573 would phase in mandatory coverage up to 200% of the poverty level over the same period, and would permit States to raise their standards to 200% of poverty beginning in July 1990. H.R. 2216/S. 902, the Administration proposal, would mandate coverage up to 130% of the poverty level by April 1990; it would remove the requirement that income standards reach 75% of the poverty level by July 1989.

Children over 1 year old. States have the option of providing Medicaid to children aged 1 through 7 who were born after Sept. 30, 1983, and whose family incomes meet a State-established standard no higher than 100% of the Federal poverty level. H.R. 833/S. 339 would mandate coverage of children under age 18 and born after Sept. 30, 1983, with incomes up to 100% of the poverty level. H.R. 1573 would mandate coverage of 1 through 7 year olds with incomes below 100% of 1 through 5 year olds by Oct. 1, 1992. S. 440 would phase in mandatory coverage up to 100% of poverty through age 18 by FY94. Under each of these proposals, States would have the option of accelerating coverage (covering older children or setting higher income standards before the deadlines for mandatory coverage). S. 949 would leave coverage optional, but would allow States to cover 8 year olds and would raise

the maximum permissible income standard for 1 through 8 year olds to 135% of the Federal poverty level. S. 949 would also allow States to cover foster children and children in group homes through age 20 with incomes below 100% of the poverty level.

General expansion. Several other bills include expansions of Medicaid eligibility for all low-income persons, rather than just mothers and children. H.R. 1845, which would mandate that employers provide health benefits to their employees, also expands Medicaid to cover persons not eligible for an employer plan. States would have to cover all persons with incomes below the Federal poverty level by Jan. 1, 1991, all those below 185% of the poverty level by Jan. 1, 1996, and all persons not otherwise insured by Jan. 1, 1999; States could charge an income based premium to enrollees above the poverty level. (The companion bill in the Senate, S. 768, imposes the same timetable but does not refer to the health plan to be offered by the State as "Medicaid." However, it provides for Federal matching payments to each State's program using the current Medicaid formula.) H.R. 950, a general rural health care bill, includes a requirement that State Medicaid programs cover all persons with incomes below 100% of the Federal poverty level by Jan. 1, 1991.

Other Eligibility Standards

In establishing Medicaid eligibility for pregnant women and children, a State must determine income using the same methodology used in the State's AFDC program. States have the option of applying a resource standard (a limit on allowable family assets), but are not required to do so. H.R. 800, H.R. 833, H.R. 1573, and S. 339 would allow States to use an income determination methodology less restrictive than that for AFDC. All of these bills, along with S. 440, would forbid the use of a resource standard for mandatory coverage groups of pregnant women and children. Under H.R. 1573 and S. 440, States could continue to apply a resource standard for optional coverage groups.

H.R. 800/S.339 and S. 949 would temporarily exempt State determinations of eligibility for pregnant women and children from the Medicaid Quality Control system, under which States may suffer Federal financial penalties for excessive errors in eligibility determination. H.R. 800 would also exempt pregnant women from the current requirement that they cooperate with the State in establishing paternity and securing support payments for their children.

Presumptive Eligibility

To insure early access to prenatal care, States have the option of establishing "presumptive eligibility" for low-income pregnant women. Qualified providers (such as Federally funded clinics, providers participating in a State perinatal care program, or Indian Health Service facilities) may make a preliminary determination that a pregnant woman seeking treatment is potentially eligible for Medicaid. The woman may then receive ambulatory prenatal care for up to 45 days or until the State completes an eligibility review, whichever is earlier. Even if the woman is ultimately found to be ineligible, the provider may be reimbursed for services furnished during the presumptive eligibility period. However, if the woman fails to apply for Medicaid within 14 days, presumptive eligibility ceases. As of January 1989, 20 States provided for a presumptive eligibility period.

H.R. 800/S. 339 and H.R. 1573 would require all States to implement the presumptive eligibility option, effective Jan. 1990, and would eliminate the 45 day limit; eligibility would continue until the State had completed its review of the Medicaid application. H.R. 2216/S. 902 would mandate presumptive eligibility effective Oct. 1989, and would extend eligibility for 60 days even if the woman is determined ineligible before that date. Qualified providers could accept a food stamp card as evidence of presumptive eligibility. (The maximum income level for food stamps, 130 percent of the Federal poverty level, is the same as that established for Medicaid for pregnant women by H.R. 2216/S. 902.) S. 440 and S. 949 would allow States to establish presumptive eligibility for children, through age 17 under S. 440 and through age 20 under S. 949.

Continuation of Coverage

Beginning July 1, 1989, States have the option of continuing coverage for a pregnant woman through the end of the second full month beginning after the end of the pregnancy, even if the woman would otherwise become ineligible during that period. H.R. 800/S. 339 and H.R. 1573 would change this option to a mandate, effective Jan. 1990, and would also require continued coverage of infants through the first year of life; S. 440 would mandate continuation of coverage for pregnant women only. H.R. 833/S. 339, S. 440, and S. 949 would also permit, but not require, extended coverage for older children. Eligibility could be deemed to continue for 1 year from the date of the last previous determination of eligibility.

Other Medicaid Child Health Proposals

Although congressional interest has centered on financial eligibility for medical care, there are concerns that mere extension of Medicaid coverage may not ensure that all mothers and children will receive appropriate services. Low-income people may face other barriers to access. First, not all providers of care will accept Medicaid reimbursement, largely because of low Medicaid payment rates. Second, some low-income mothers may be unaware of the availability of Medicaid benefits or may need help in applying for them. Third, there may sometimes be insufficient coordination between the Medicaid program and other medical and social services available to mothers and children. Medicaid proposals in the 101st Congress seek to address each of these problems. There are also proposals to modify Medicaid to address another child health concern, declining rates of immunization for certain diseases.

Medicaid Provider Participation

Low rates of provider participation, and especially physician participation, have been a historic problem under Medicaid. Surveys of physicians have generally found that low Medicaid reimbursement, relative to the physicians' usual charges, is an important factor in the decision to refuse Medicaid patients.

Federal regulations require that a State's Medicaid payment rates "must be sufficient to enlist enough providers so that services under the [State Medicaid] plan are available to recipients at least to the extent that those services are available to the general population." (42 Code of Federal Regulations 447.204.) H.R. 800, H.R.

833, H.R. 1573, S. 339, S. 440, and S. 949 would all incorporate this rule in the Medicaid statute and would require DHHS to determine the adequacy of States' payment rates for obstetrical and/or pediatric services. (S. 440 would require a review of hospital payment rates as well.) Each bill except H.R. 833 also includes new State data reporting requirements intended to facilitate DHHS rate review. States would have to report on the extent to which providers participated in the program, the relative proportions of Medicaid and non-Medicaid patients receiving prenatal or pediatric care, and the difference between Medicaid payment rates and those offered by other payers. S. 721 focuses on the availability of obstetrical care in rural areas. It would raise the Federal matching rate to 90% for pregnancy related services in rural health manpower shortage areas if the State's Medicaid rates for these services were equal to at least 80% of the rates paid by the health insurance plan offered to State employees.

Several bills would expand current provisions under which States are required to give special treatment to hospitals serving a disproportionate share of low-income patients. Currently, State Medicaid programs must provide increased inpatient payment rates to such hospitals for all inpatient services, make extra payments for infants with very long stays or high costs and must waive any durational limits on covered services for infants. H.R. 800/S. 339 would extend these provisions to all children under age 18, while S. 949 would require higher payment rates to disproportionate share hospitals for outpatient as well as inpatient care.

Some providers may be deterred from accepting Medicaid patients, not just by Medicaid payment rates, but because of problems in dealing with State Medicaid agencies and delays in receiving Medicaid payment, or because of concerns about potential malpractice liability. Several bills, including H.R. 800, H.R. 833, S. 339, and S. 949, would provide grants to States for demonstration projects to test innovative ways of overcoming barriers to provider participation, such as expedited reimbursement, changes in burdensome administrative requirements, or sharing in the cost of malpractice insurance. Federal funding for the projects would be available at enhanced matching rates.

Outreach and Application Assistance

Some mothers may be unaware of the importance of prenatal and well baby care or the availability of Medicaid to pay for that care; others may find the application process difficult. Several proposals would provide for outreach services, to locate potentially eligible mothers or families, educate them about available benefits, and/or assist in filing applications. H.R. 800/S. 339 and H.R. 2216/S. 902 would require outreach activities, while S. 430 would merely permit States to claim Federal matching for such activities. The bills differ in the amount of Federal funding they make available. H.R. 800/S. 339 treats outreach as a service, subject to matching at the individual State's Medicaid percentage (50% to 79%). H.R. 2216/S. 902 treats outreach as an administrative activity, subject to 50% matching. Finally, S. 430 creates a new 75% matching rate for outreach services.

Some proposals would also simplify the process of applying for Medicaid. H.R. 833/S. 339 and H.R. 1573 would require States to process applications at sites other than welfare offices, such as hospitals or clinics. "Outstationing" of eligibility workers could be included as an optional outreach service under S. 430. H.R. 1573

would also require DHHS to develop a uniform application for programs serving children under 6, including Medicaid, the MCH block grant, Head Start, and the supplemental food program for women, infants, and children (WIC).

Coordination with Other Programs

Several proposals seek to improve the coordination between Medicaid and other programs, such as the supplemental food program for women, infants, and children (WIC), which is designed to prevent medical problems due to inadequate nutrition. H.R. 800/S. 339 would require States to make information about WIC available to all eligible Medicaid beneficiaries. S. 949 would fund State demonstration projects to improve the coordination of Medicaid, WIC, the MCH block grant program, and other services. The Administration has proposed similar demonstrations, to be funded at \$40 million over a 2 year period. (This initiative was not included in the Administration Medicaid bill, H.R. 2216/S. 902, but might be undertaken under the Secretary's general authority to conduct Medicaid demonstration projects.)

Childhood Immunizations

Overall immunization rates for children have improved in recent years as a result of requirements that children be immunized for certain diseases before entering elementary school. However, immunization rates in the pre-school population have declined for certain diseases, such as polio and diphtheria/tetanus/pertussis. The Administration's Medicaid proposal (H.R. 2216/S. 902) would require States to cover immunizations for children under age 6 who are receiving food stamps, regardless of whether these children were otherwise eligible for Medicaid. It would also require a State to pay for an immunization furnished to a child by any Medicaid provider, even if the child could have obtained the service from some other provider at no charge. (H.R. 1573 would provide supplementary funds for childhood immunization through the Public Health Service Act.)

Related Non-Medicaid Initiatives

In addition to proposals for changes in Medicaid, proposals in the 101st Congress would establish new Federal programs or expand existing ones to provide medical and related social services to pregnant women and young children.

H.R. 1117 would establish a new Public Health Service (PHS) program targeted specifically at teenage mothers and their children. Grants would be made to public and private nonprofit entities to provide medical care to mothers and children under 6, along with outreach, education, and related social services. Authorized funding levels would be \$60 million in FY90, \$65 million in FY91, and \$70 million in FY92.

Several bills would expand the current Maternal and Child Health (MCH) Block Grant program authorized by Title V of the Social Security Act. This program provides grants to States for a variety of health programs, including direct provision of preventive and primary care services to mothers and children, health screenings, immunizations, and rehabilitation services for children with special health care needs (formerly referred to as crippled children). The permanent authorization for the MCH block grant program is \$561 million per year; the appropriation for FY89 is \$554 million. Of this amount, approximately 84% is allocated to States; the rest is

retained by DHHS to support "special projects of regional and national significance" and to conduct research, training, and genetic disease screening programs.

H.R. 1710/S. 708, would increase the permanent MCH authorization to \$661 million; any appropriation in excess of \$561 million would be used for grants to States for comprehensive infant mortality initiatives, which would include home visits by nurses or social workers and a "one-stop shopping" application process for government medical and social programs. States would also be required to disseminate a new maternal and child health handbook to be developed by DHHS and to operate a toll-free information and referral line. (S. 339 would require DHHS to establish a national MCH information line.) H.R. 1568/S. 1053 would also provide a \$661 million authorization, but appropriations in excess of \$561 million would be distributed in the same manner as the current MCH funds and would be used for general maternal and infant care programs, with DHHS retaining 15% percent for special projects.

H.R. 1584 would increase the MCH authorization to \$612 million. Any appropriation beyond the FY89 funding level of \$554 million would be used for grants to States for education and outreach programs designed to promote participation in the Medicaid, AFDC, food stamps, and WIC programs. Activities would include outstationing of eligibility workers, education about preventive services, and home visits to infants. H.R. 1573 would increase the MCH authorization to \$661 million in FY90, \$711 million in FY91, and \$761 million in FY92 and later years. Funding in excess of \$561 million would be allocated to States for perinatal services to low-income women in areas with high rates of infant mortality and inadequate maternity and infant care. This proposal would include direct payment for medical care, as well as the outreach and social service activities included in the other MCH expansion proposals.

H.R. 1573 would also authorize expansion of another existing program, the infant mortality initiative conducted by PHS under the Community and Migrant Health Centers programs. Under this initiative, Federally funded clinics receive supplemental grants to develop coordinated systems of care for pregnant women and infants. Authorized funding for this initiative is \$32 million per year; the FY89 appropriation is \$20.6 million. The Administration has requested an FY90 appropriation at the full \$32 million level. H.R. 1573 would increase the authorization to \$80 million for FY90, \$90 million for FY91, and \$100 million for FY92 and later years.

LEGISLATION

Note: The provisions of the following bills are discussed in detail in the preceding text. The following discussion includes only provisions not discussed above.

H.R. 800 (Rep. Leland et al.)

Medicaid Infant Mortality Amendments of 1989. Expansion of Medicaid for pregnant women and infants under 1 year old. (S. 339 includes similar provisions, along with provisions similar to those of H.R. 833.) Introduced Feb. 2, 1989; referred to Committee on Energy and Commerce.

H.R. 833 (Rep. Waxman et al.)

Medicaid Child Health Amendments of 1989. Expansion of Medicaid for children aged 1 through 17. (S. 339 includes similar provisions, along with provisions similar to those of H.R. 800.) In addition to provisions discussed above, provides for an optional extension of welfare transition coverage, under which Medicaid is continued for families losing benefits after the principal earner re-enters the workplace. Introduced Feb. 2, 1989; referred to Committee on Energy and Commerce.

H.R. 1117 (Reps. Leland and Waxman)

Adolescent Pregnancy and Parenthood Act of 1989. New grants to States under Public Health Service Act. Introduced Feb. 27, 1989; referred to Committee on Energy and Commerce.

H.R. 1568 (Rep. Kennelly et al.)/S. 1053 (Sen. Riegle et al.)

(S. 1053 only entitled Title V Infant Mortality Reduction Act of 1989; otherwise similar to H.R. 1568.) Expansion of MCH block grant. H.R. 1568 introduced Mar. 22, 1989; referred to Committee on Energy and Commerce. S. 1053 introduced May 18, 1989; referred to Committee on Finance.

H.R. 1573 (Rep. George Miller et al.)

Child Investment and Security Act of 1989. In addition to provisions relating to the Medicaid, MCH, and Community and Migrant Health Center programs, the bill includes expansions of the WIC and Head Start programs. Introduced Mar. 22, 1989; referred to Committees on Energy and Commerce and Education and Labor.

H.R. 1584 (Rep. Synar et al.)

Maternal Child Health Improvement Act of 1989. Expansion of MCH block grant. Introduced Mar. 23, 1989; referred to Committee on Energy and Commerce.

H.R. 1710 (Reps. Rowland and Tauke)/S. 708 (Sens. Bradley and Durenberger)

Healthy Birth Act of 1989. Expansion of MCH block grant. H.R. 1710 introduced Apr. 5, 1989; referred to Committee on Energy and Commerce. S. 708 introduced Apr. 5, 1989; referred to Committee on Finance.

H.R. 2216 (Rep. Michel et al.)/S. 902 (Sen. Dole et al.)

Medicaid Pregnant Women, Infants, and Children Amendments of 1989. (Administration proposal.) Funds provisions relating to expanded Medicaid eligibility and childhood immunization programs by reducing Federal matching payments for administrative costs. Matching percentages for the following activities would be reduced to 50% on a timetable ending Sept. 30, 1994: compensation or training of skilled professional medical staff, nursing home pre-admission screening and resident review, nursing home survey and certification, contracts with utilization and quality control peer review organizations (PROs) or similar entities, and immigration status verification. The current 90% matching rate for family planning services would be retained, but the rate for administrative costs associated with those services would be reduced to 50%. H.R. 2216 introduced May 3, 1989; referred to Committee on Energy and Commerce. S. 902 introduced May 3, 1989; referred to Committee on Finance.

S. 339 (Sen. Bradley et al.)

Infant Mortality and Children's Health Act of 1989. Includes provisions similar to those of H.R. 800 (pregnant women and infants) and H.R. 833 (older children). Does not include the provision of H.R. 800 exempting pregnant women from the requirement that they cooperate in establishing paternity and obtaining support for their child, or the provision of H.R. 833 permitting optional extension of welfare transition coverage. S. 339 contains one provision not included in either H.R. 800 or H.R. 833, the establishment by DHHS of a toll free maternal and child health information line. Introduced Feb. 2, 1989; referred to the Committee on Finance.

S. 430 (Sen. Daschle et al.)

Optional Medicaid coverage of outreach services. Introduced Feb. 22, 1989; referred to Committee on Finance.

S. 440 (Sen. Biden)

Health Care for Children Act of 1989. Medicaid expansions for children aged 1 through 18. Introduced Feb. 23, 1989; referred to Committee on Finance.

S. 721 (Sen. Baucus et al.)

Rural Obstetrical Care Access Act of 1989. Medicaid reimbursement increases. Introduced Apr. 6, 1989. Referred to Committee on Finance.

S. 949 (Sen. Riegle et al.)

Medicaid Children's Health Improvement Act of 1989. Medicaid expansion for children aged 1 through 20. Introduced May 9, 1989; referred to Committee on Finance.

CONGRESSIONAL HEARINGS, REPORTS, AND DOCUMENTS

- U.S. Congress. House. Committees on Education and Labor, and Energy and Commerce, and the Senate Special Committee on Aging. Insuring the uninsured: options and analysis. Oct. 1988. Education and Labor Serial No. 100-DD. Energy and Commerce Serial No. 100-BB. Special Committee on Aging Serial No. 100-O. 212 p.
- U.S. Congress. House. Committee on Energy and Commerce. Subcommittee on Health and Environment. Nov. 1988. House Energy and Commerce Committee Print 100-AA. 501 p.