are programs underway now with the cooperation of Blue Cross and Blue Shield to try and make a dent in that large area of people who fall below poverty but are not eligible for Medicaid.

So subsidized health insurance would be No. 1.

No. 2, I would get a core of block workers. I mentioned before I'd have people going from block to block and making certain that every single person got enrolled in what was currently available to them.

I'd love to have enough money to start the analogous situation to the Peace Corps, but use a mandatory Peace Corps for every one of our American citizens to spend 2 years dealing with the problems of poverty in the inner city.

I would also certainly use some of my money, depending on how much you gave me, to make certain that day care was available and adequate nutrition was available for every American, too.

Ms. ROSENBAUM. I don't have much to add to the list. I just want to note that we recently did some cost estimates for a separate study of what it would cost if we wanted to take the existing Medicaid Program, for example, and amend it so that it provided coverage for families below the Federal poverty level and a subsidized insurance plan for families between 150 and 250 percent of poverty on a sliding premium basis.

For pregnancy alone, it would only cost about $1 1/2 billion to make Medicaid available to any woman with a family income under 250 percent of poverty on a subsidized basis, with the subsidy obviously increasing the lower her income went.

At current Medicaid matching rates, that would be only about $800 million.

Senator SARBANES. Can I interrupt right there? Let me ask the panel this: Are you all satisfied that people with incomes above poverty are coming pretty close to doing all they ought to do with respect to their children, both in pregnancy and post-pregnancy periods, and so forth?

All the focus has been on poverty levels. I understand why it is; obviously, the problem is even more severe there. But how much of a problem is it, or do you see a problem there?

Dr. Oski. I think they have the means to do it. They may not have the priorities. They may have so many other things they want to do with their income.

Senator SARBANES. But society's going to pay a cost if they don't put this priority at the top or near the top of their list.

Ms. ROSENBAUM. I disagree because if you look, there are about 9 1/2 million families of child-bearing age who have no health insurance in the United States. About 5 million have family incomes below the Federal poverty level. The rest are pretty much concentrated into that 100 to 250 percent range.

The average cost of a maternity care package—remember, 250 percent of the poverty level is only about $20,000 a year for a family of four. The average cost of an uncomplicated delivery at this point, including medical and hospital care, is $4,000, and if it's a cesarean section delivery, we're over $5,000 at this point.

For a woman with a family income of $20,000 a year, it's not simply a matter of different priorities. She can't possibly, if she has that kind of family income, afford to pay that. Now she might be
able to pay if off over time. But the problem right now is that, in many areas of the country, because health care is so expensive, in order to get obstetrical services, you must either have insurance or you must prepay your bills. You must pay for your medical bills before the delivery. You must pay a large preadmission deposit just go get into a hospital.

In Texas, for example, hospitals in some parts charge as much as $3,000 for a preadmission deposit. Now, I will tell you that in my family, it would be very difficult if I had no insurance to simply come up with $3,000 to pay for my delivery in advance.

This is not a phenomenon—medical care is so costly, so is food. Food, if you're above the Federal poverty level, you can probably have an easier time coping with food needs. But medical care is not accessible to people without insurance and with family incomes below many hundreds percent of the Federal poverty level.

And until we begin to build on the basic programs and make those basic programs more accessible to near poor or lower income families, we're going to find an enormous band, we're going to continue the old categorical approach in this country of picking off narrow categories of people and leaving a great bulk of Americans who are unable to afford these services with no relief.

And I think the time has come for us to begin acknowledging that, of course, as you're saying, the worst of the problems are concentrated in those families who have nothing to fall back on.

But a woman making $14,000 a year as a secretary, with two children to support, and with a husband who may be unemployed, is in no position to afford maternity care if she needs it. She just is not. And yet, she's not technically poor.

Senator SARBAVES. Dr. Sabin, did you have any comments you want to make, having listened to this panel?

Dr. SABIN. I wonder if I may summarize some of my thoughts after hearing what all these people said.

In the first place, in addressing child health programs in the United States, we are not forgetting, for those who will say that the light is being put in only one corner of the problem, that the vast majority of the children of the United States are better off now than they've ever been before and are getting a great deal of what they need, despite the fact that there are problems.

It's a complex thing. It's not any one thing.

But it is not enough for a rich and compassionate country to sit back and say, now look, by and large, look at the great advantages that we have for our children. A rich and compassionate country has a responsibility to those who cannot make the grade, for whatever reason—it is not enough to say that it is their responsibility, that they are in that state because of what they had done. That is not right.

So out of this discussion have come many aspects of child health that are concentrated among those that are called the poor.

And the issue that arises is, for example, you said, what would additional money do? Well, it's quite obvious, Ms. Rosenbaum pointed out, that we're facing two problems. The immediate one. Well, for the immediate one, you need additional money to do the things that are obviously and, as has been documented, underfunded. No child should go hungry. No pregnant woman should have to
suffer because her husband left her and she has no job, and should have to go without the food she needs for the maternal health care. Immunization programs, sudden infant death, which we haven't mentioned, or battered children, the problems are very, very extensive.

So I think, first of all, you need money to help those who cannot help themselves in essential programs that have been documented.

But then, Dr. Paige made a very important point, which is perhaps not generally thought about, but again, I refer to the Catholic bishops' letter, the headline in the Washington Post 2 months ago was: "Catholic Bishops' Letter Asserts Employment Is a Basic Right."

Now what do you do about a basic right that doesn't exist? Fine, we all agree it's a basic right. But what do you do about it? And what do you do about poverty in certain sectors of the American population? Give them money, as has been suggested by some, as you brought out in a question here, that perhaps everybody should have a certain support, below which, you see, he will not want.

But we're getting now away from the need for immediate attention, and there's a lot of money needed for immediate attention. I would say proper prenatal care, as has been brought out, sufficiently subsidized is absolutely essential.

But employment is the requirement for human dignity to which every person is really entitled. And employment for certain segments of our population cannot be left to the individual alone—you have to do it; it's because you're not trying hard enough; you weren't educated.

That's not enough.

To provide employment for a large section of the population that cannot help itself is a national responsibility.

And how to do that? Are we going to go back to the WPA days of half a century in which I was already an adult and saw things happen? No, I'm not saying that that is the way, but it is a responsibility that requires very careful thought.

In other words, women in the poor segment of the population that have more kids than they can take care of and have no income, to give them some immediate help, good enough. That's absolutely necessary. But there's no reason why there should not be national programs for providing employment, for having children of mothers who cannot work or cannot help themselves in day care centers while the mothers can participate and work and get a wage, and no necessarily say that if they don't do it, they don't get any help, not either/or.

I think employment must become a national responsibility. People who are thrown out of work because of technological or other changes must not be left to just fend for themselves. And particularly for youngsters in poor communities. And we know that unemployment is very high in the black community because of the poverty there. They need to have opportunities for employment.

So I would take up the cudgels that Dr. Paige raised and say that, in the long-term way of dealing with this problem, unless one developed national programs for the unemployed and those who cannot help themselves, poverty will remain a subject for charity. And charity is not enough.
You talk of making sure that a mother, you see, gets enough nutrition while she's pregnant. Well, we all know, and I've been exposed to situations where a mother who gets food, extra food and has three or four children who don't have the food, she gives it to them and not to herself. She's more concerned with the ones who are already here than with the one who's in the incubator.

So that any program, let's say, that would deal with helping a pregnant mother who's poor must consider the children.

I think what has come out of this hearing shows that the picture is so complex and that while you realize that the underlying factor of the worst problems in child health care have to do with poverty, there are also problems in the populations in various ranges of the spectrum that need help.

So what do you do when you have too many problems to deal with? In my mind, the fortunate thing is that there are so many people to deal with them. See? And the assumption that one group must deal with all of these problems is, of course, wrong.

The division of labor is part of a biological law in a highly organized being like the human being. Without division of labor, organized division of labor—not just you do that and I'll do this—without organized division of labor, without organized regulation, we wouldn't have a human being. We wouldn't have a higher being.

So that the same thing, it seems to me, has to be transferred to the social existence organization. I've never seen anything happen really very good without human organization.

And there are so many people who want to help in this country. This is a compassionate country. But unless you provide them a way of doing it, they don't know what to do.

So more organization, more attempts for long-range dealing with providing employment for people who are unemployed because they can't help themselves, but at the same time, immediate attention to the things that need to be done, and that's where you need your money.

Some of the things have been pointed out already, and I wouldn't say three of four things at the top and forgetting all the others. It has to be more or less across the board. And by God, if anybody can afford it, this nation ought to be able to afford it.

Senator SARBANES. A very eloquent statement.

I want to thank the panel. It was a very good panel. And we'll go on to our last panel.

Thank you all very much. We appreciate your testimony.

Our last panel will be; Dr. Tyson Tildon, who is professor of pediatrics and biochemistry at the University of Maryland School of Medicine; Dr. Karen Davis, professor and chairman of the Department of Health Policy and Management at the Johns Hopkins School of Hygiene and Public Health; and Dr. Marvin Kolb, chairman of the Department of Pediatrics of the Fargo Clinic in Fargo, ND.

We're very pleased to have you. I think we'll just start with Dr. Tildon. Dr. Kolb, you've come a long way. We'll save you until last.
STATEMENT OF J. TYSON TILDON, PH.D., PROFESSOR OF PEDIATRICS AND BIOLOGICAL CHEMISTRY, THE UNIVERSITY OF MARYLAND SCHOOL OF MEDICINE

Dr. TILDON. Thank you very much, Senator Sarbanes, for having us. I'm encouraged by your invitation to outline the department's position on Federal funding and to give you some appreciation for what the research community is considering on the effects of Federal cutbacks.

In my remarks, I will try to highlight several items, but in particular, answer some of the questions that you asked, one in terms of where would you focus.

And the second paragraph of my prepared statement really says that. Most academic centers have concentrated their research focus because of research funds on the perinatal period. This would be the fetus before birth and the neonate and the infant during the first early months or life, as has been said by others.

The specific goals of the research efforts related to infants and children have a major thrust toward improving the quality of life and therefore, that is inextricably woven into the fabric of our economy.

There is a concept that I would like to leave here. Because infants and children require care and nurturing, the impact of disease conditions and morbidity in these children multiply several-fold. For example, babies and small children when they become ill in addition to the cost of their illness, mothers and/or fathers must lose time from work.

As a result of the dependency, the economic consequence of disease conditions and poor health status in children have both immediate and long-term effects on our society.

In the interest of time, I would like to say that it should be noted that while our nation is decreasing its emphasis on biomedical research, other nations are increasing their commitment to studies and programs in health sciences.

According to the National Science Foundation, the percentage of the gross national product devoted to civilian research and development for West Germany and Japan is 2.6 percent. But in our country it's about 25 percent less, 1.9 percent.

Taking a page from what Dr. Sabin said, even the developing nation of China has recognized the importance of the health sciences and has targeted health care research for children because it represents that country's most important resource.

But I'm very encouraged by what China has just done and I have the article from the Baltimore Sun papers. It has developed a mechanism for protecting scientists from the economic restrictions of bureaucratic processes. I think that's a very important consideration.

You asked what would be done with the additional money. Let me point out that the major source for funding for research programs in child health is the National Institute of Child Health and Human Development. At the present time, the Institute's budget is about $320 million annually. This translates to less than $5 per family per year.

Yet, for the past 5 years, the National Institute of Child Health and Human Development's ability to fund new grants—these are
new ideas submitted by biomedical or psychological investigators—has declined from 39 percent of the funding to approved grants to 28 percent.

This means that 70 percent of the good ideas do not receive support. That is a place where I would put additional funds.

One of the hallmarks of our society has been the supposition that good ideas shouldn’t get lost. The very success of America has been, I think, its responsiveness to new concepts. We stand on the verge of losing our effectiveness of doing this.

Let me go further and say, most critically, the trend toward decreased support has seriously crippled the effort to develop new physician/scientists. At a time when new technology and excitingly different research strategies are being developed, the Federal Government is decreasing its involvement in biomedical research. And this is sending a very chilling message to young investigators, especially those with medical degrees.

To produce a good physician/scientist requires about 5 to 7 years of intense training after medical school, and it is not difficult for me to understand that we are not going to develop this talent if we cannot assure these scientists that they’re going to have a reasonable opportunity for being supported.

No one is going to spend 5 to 7 years and then have the possibility of not receiving funds to do the research.

At the present time, the paucity of clinical scientists is being offset by the participation of basic scientists like myself in clinical research. But there is a need for physicians because they represent the linkage between the patient and the research activity.

I want to point out that national health, like national defense, is good for everybody and the scope of biomedical research is too large to fit within the confines of the private sector.

I think the Government must provide major funding for pediatric research because it alone has the capacity to take a comprehensive view.

I want to go on, and some of my remarks are in my prepared statement, but it is estimated that for every $1 invested in biomedical research, there is a return of $13 to the community.

I have one copy of an ad hoc report, but I’d be glad to get more copies of this—this is from the Federation of American Societies for Biologists—if you would so desire.

Other studies reveal that the discoveries that are first made in the medical research laboratories provide the basis for non-health-related products—and I want to underscore this—that contribute more than $40 billion annually to the gross national product.

Senator Dirksen says that a billion here and a billion there and sooner or later, you’re talking serious money.

I would think that that is, without a doubt, an indication of what is providing the jobs. And this is what you’re asking about, the economic impact.

When you begin to drain off one area, you decrease its effectiveness in many of the possibilities.

I wanted to talk about my own area, but I’m not going to belabor that. Suffice it to say that I think that an existing area of research is neurobiology. We’re able now to know a lot about how the brain works. But in our own laboratory, we received a grant just this
year for $500,000. And then we were told that we had to reduce that by 12 percent.

This is devastating, as Dr. Felix Heald just indicated. There is an organism. It's just like, again, like Dr. Sabin indicated. We had a certain organization. It was bare bones. If I make an analogy to the human body—which part do I cut off? The hand? The eye? All of that’s less than 12 percent, but you can understand the effect it has.

The cost of doing research also has doubled in the past 10 years. The equipment that cost $10,000 in 1976 now costs $23,000. Chemicals have more than doubled. But now the allocation to NICHD is only increased by 35 percent.

We’re in the midst of an explosion of ideas. This has increased the number of research applications. But the numbers of grants being funded has actually remained unchanged.

I only want to make one other area of consideration and that has to do with the health care of infants and children and the dramatic shifts in the social situation.

More mothers are working. Prenatal and postnatal care is changing. And there is a home-office linkage for caring. But there is no way for us to understand these kinds of problems because we won’t even invest—that is to say, the researchers won’t even invest in this because of the paucity of funds. And I think this is being very penny wise and pound foolish.

I have a statement which has to do with AIDS. I think that, obviously, it has been very well publicized. My only point is I think our inability to really address this issue is a direct outgrowth of our preparedness.

I think that in many cases, immunology could be many steps ahead. Among those 70 percent of our ideas that don’t get funded, probably are many opportunities to address that kind of problem.

Another area, of course, is drug abuse. The impact of using drugs has tremendous implications on infants, toddlers, and adolescents. But we also have to have accurate and reliable tests.

The new and effective techniques using immunoassays and high performance liquid chromatography require refinements that we are not allowing.

In my summary statement, when I shared this with my colleagues, people said, you really aren’t going to say this, are you? And I said, yes.

I think we need to double—that is, two times—the commitment to the National Institutes of Health and the National Science Foundation.

This, if you doubled it, would support about 50 to 60 percent of the ideas that scientists and their peers have agreed are worthwhile. And that additional cost would only be $25 per person.

I think that it goes without saying that the point that I’m making is that this kind of an investment in research is needed. What is needed most is that it would continue to encourage the creation of problem solvers. And this is what I think is being cut off.

Thank you very much.

[The prepared statement of Dr. Tildon, together with the ad hoc report referred to, follows:]
I am J. Tyson Tildon, Professor of Pediatrics and of Biological Chemistry, University of Maryland School of Medicine. I am a member of the American Society for Biological Chemistry and past chairman of the Public Policy Committee of the American Society for Neurochemistry. I am encouraged by the Honorable Senator Paul Sarbanes' invitation to submit a statement outlining the Department of Pediatric's position concerning Federal funding of research.

Across the nation, most academic pediatric centers have concentrated their research focus on health problems that occur in the perinatal period, i.e., the fetus before birth, the neonate, and the infant during its first months of life. These include studies of nutrition, infectious diseases, immunology, growth disorders, birth defects, mental retardation, developmental disabilities, Sudden Infant Death Syndrome, as well as studies of low birth weight and infant mortality.

The specific goals of the research efforts related to infants and children have a major thrust toward improving the quality of life and thus are inextricably woven into the fabric of our total economy. Because infants and children require care and nurturing, the impact of various disease conditions and morbidity are multiplied several fold. For example, when babies and small children become ill in addition to the cost associated with the illness, mothers and/or fathers must lose time from work. As a result of this dependency, the economic consequences of a disease condition and poor health status in children have both immediate and long range effects on our society.
Most of the discussion of public policy issues as it relates to government support of research efforts, ultimately centers on the question of how the benefits are measured. The other factor in the equation, cost, is usually measured in terms of dollars, but we must understand that cost also includes grief, suffering and human misery.

It should be noted that while our nation is decreasing its emphasis on biomedical research, other nations are increasing their commitments to studies and programs in health sciences. According to the National Science Foundation the percentage of the GNP devoted to civilian research and development is 2.6% for West Germany and Japan whereas in the United States that figure is 25% less or only 1.9%. Even the developing nation of China has recognized the importance of the health sciences and has targeted health care research for children because they represent that country's most important resource and it has recently established a mechanism for protecting scientists from economic restrictions by bureaucrats.

The major source of funding for research programs in child health is the National Institute of Child Health and Human Development. At the present time, the Institute's budget is about $320 x 10^6 annually. That is less than $5/family/year. Yet for the past 5 years NICHD's ability to provide funds for new grants submitted by biomedical and psychological investigators has declined from 39% funding of approved grants to a low 28%. This means that more than 70% of the good proposals (i.e., ideas or research approaches that were approved by the peer review system) are not receiving support.

One of the hallmarks of our society has been the supposition that good ideas will not be lost. The very success of America has been its responsiveness to new concepts. We now stand on the verge of losing our effectiveness both in the encouragement of the creative enterprise and the
training of new scientists. Research activity as it relates to child health is not independent of the broader scientific efforts.

The needs are tremendous, and paramount at this time is need for replacement equipment. Most of the equipment was purchased more than 15 years ago. Because of the level of funding of projects, most investigators have been using old and outdated equipment. Because of a lack of commitment to a strong biomedical research program in Pediatrics, we have not been able to periodically update our instrumentation which is a vital part of our ongoing productivity.

Most critically the trend toward decreased support has had a seriously crippling effect on the development of physician/scientists. At a time when new technology and excitingly different research strategies are being developed, the Federal government is decreasing its involvement in the biomedical research effort and it is sending a very chilling message to young investigators, especially those with medical degrees. To produce a good physician/scientist requires 5 to 7 years of intense training after medical school, and it is not difficult to understand that we are not going to develop this much needed talent, if we cannot assure them that they will have a reasonable opportunity of being supported. At the present time the paucity of clinical scientists is being offset by the participation of basic scientists like myself in clinical research. But there is a definite need for physicians with research training because they represent a link to the patient.

National health like national defense is good for everybody and the scope of biomedical research is too large to fit within the confines of the private sector. The government must provide the major funding for pediatric research because it alone has the capacity to take a comprehensive view. The private sector usually focuses on specific areas. It should also be recognized that
in addition to saving lives and improving the health of our nation, the research enterprise provides immediate economic benefits to our community in terms of jobs. Perhaps equally important are the related economic benefits that accrue from the development of new instruments and health care equipment. The private sector is aware that new research strategies results in innovative new technology, but it is often overlooked when we're considering the economic benefits of bio-medical research. Indeed the relationships between the child health scientist and the equipment/instrument supplier has become economically synergistic.

It is estimated that for every dollar invested in biomedical research, there is a return of 13 dollars to the community as a whole. Other studies reveal that discoveries first made in medical research laboratories provide the basis for non-health related products that contribute more than $40 billion annually to the gross national product. In many instances techniques and new advances that are first developed for infants and children are being translated into new industrial advances for manufacturing vaccines against diseases in livestock, or providing genetic techniques for developing better crops.

One of the most exciting areas of research is the new frontier of neurobiology. Our increasing understanding of the normal and abnormal maturation of the brain has greatly enhanced our ability to investigate fundamental questions of mechanisms at the cellular, neurointegrative and socio-behavioral levels of organization. Using state-of-the-art techniques, neurochemists, neurophysiologists, immunologists and neuroanatomists have made great strides in unlocking the secrets of how the brain works. Some of the knowledge has provided immediate benefits like the use of dilantin in the control of seizures or the use of lithium in control of manic/depressive
behavior. Much of the practical outcome has been closely connected to our understanding of how nerve cells "communicate". Our own laboratory is in the forefront of some of these studies and we were recently awarded a grant of $500,000 to continue our programs, but because of fiscal constraints we were told that our budget would be reduced by 12%. This is devastating to a program that was based upon a bare bones budget. Which part of our integrated unit should we cut? If we make the analogy between our program and the human body, then we can appreciate the horrendous decision that had to be made: Do we remove a foot; a hand; an eye or some of the organs? Any one of them would be less than 12% of the total body, but the loss of any of these would seriously cripple the body. Similarly a 12% cut to our program has seriously hampered our research efforts. Benjamin Franklin once said, "For the want of a nail, the battle was lost." We feel the same kind of loss.

The cost of doing research has almost doubled in the past ten years. An instrument that cost $10,000 in 1976 now costs $23,000. Chemicals have more than doubled during that period; however, the funds allocated to NICHD only increased about 35%. We are in the midst of an explosion of ideas and this has increased the number of research applications, but the actual number of new grants funded has remained essentially unchanged over the last five years.

Another major consideration of health care to infants and children is the dynamic shifts in social situations. More mothers are working. Prenatal and postnatal care is changing. The home-office linkage for caring has become an important factor. The increased use of outpatient facilities requires much more attention to prevention. However, we do not have the capacity to address these new public health concerns because of the imposed austerity. When we look at the small size of the investment compared to the benefits, we are being very penny-wise and pound-foolish.
I would be remiss if I didn't include in this statement some reference to the problem of AIDS. This is a grave public health problem and the news media has helped to create extensive public awareness around the issues. However, more than anything, the problem of AIDS has made us in the scientific community very aware of what we don't know about basic immunology. It can easily be proposed that our inability to treat and arrest this disease is a direct outgrowth of our lack of preparedness.

Drug abuse testing programs are gaining wide acceptance in today's society. The impact of the use of drugs has tremendous implications for infants, toddlers, and adolescents as well as the unborn fetus. The accuracy and reliability of these testing efforts will be a direct reflection of our technology. New and efficient techniques such as immunoassays or high performance liquid chromatography require continuing research refinement.

In summary, I simply recommend a doubling of funding for the National Institutes of Health and the National Science Foundation; this would result in the support of about 50 to 60% of the ideas that scientists have agreed are very worthwhile. The additional cost to the taxpayer would be less than $25/person, but the benefits would be enormous. If the return on the dollar is even one-fifth of the return that we have been experiencing, then it would be well-worth it.
Open Heart Surgery

"Replacement of damaged heart valves and coronary artery bypass surgery are now possible due to state-of-the-art surgical technologies developed in part through NIH-funded research."

A Proposal for Fiscal Year 1987
The Ad Hoc Group for Medical Research Funding

United by their concern for the vitality of the biomedical and behavioral research enterprise, a large and diverse group of organizations recommends that appropriations for health science be increased reasonably above Fiscal Year (FY) 1986 in the coming fiscal year. This document presents the rationale for this group's budget proposal for FY 1987.

Today, because there is a direct causal relationship between the work done in the nation's research centers and better health care, and because the Congress has recognized the benefits of increased investment in research, there is a revolution in the biological and medical sciences that is leading to the prevention and cure of countless previously intractable conditions. The pace of progress has placed the United States at the forefront of biomedical and behavioral research. Congress has demonstrated, through support of the NIH and ADAMHA, an acute understanding of the pace of research and the importance of a balanced research program.

In addition, the spinoffs of medical research are promising dramatic economic growth with concomitant benefit to the federal budget, the foreign trade balance, and the employment outlook. Biotechnology provides advances in human health, extraordinary possibilities for the industrial community, and the promise of reduced health care costs.

Yet this nation is confronted with a growing budgetary crisis engendered by years of deficit spending and the growing federal debt. Scientists join all other segments of our society in their concern that these trends be reversed. However, we do not believe that sharply decreasing our nation's investment in research and development is the way to accomplish this goal. R&D investment fuels our economy, provides goods and products that are urgently needed to reverse the recent decline in the U.S. trade balance for high technology products, trains the scientists who will provide the new ideas in the next generation, and improves the health and job productivity of the American people. The means must be found to permit our nation to balance its budget while continuing its R&D investment in our future.

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Photo courtesy of National Institutes of Health
America's World Leadership in Medical Research and Biotechnology is No Longer Assured:

West Germany and Japan continue to have the highest percentage of GNP devoted to national civilian R&D expenditures. For 1985, the R&D/GNP ratio for both West Germany and Japan was 2.6 percent, for the United States, 1.9 percent.

Federal funds available for the purchase of academic research equipment and instrumentation declined 78 percent between 1966 and 1983.

From 1973–1982, the U.S. proportion of science and technology in U.S. trade remained constant; its share of science and technology in clinical medicine and biology steadily declined.

The Japanese government has targeted biotechnology as a key technology of the future.

The U.S. trade surplus in high technology products, measured in constant dollars, fell by over 40 percent between 1980 and 1982.

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Figure 1: Estimated ratios of non-defense R&D expenditures to gross national product (GNP) for selected countries.

Figure 2: U.S. trade balance in high-technology and other manufactured product groups.
The National Institutes of Health
50 Years and $50 Billion

- sulfa for the treatment of streptococcal infections
- routine use of insulin for diabetes
- discovery of 8th factor in human blood, its role in infant deaths and Rhogam therapy to prevent hemolytic disease of newborns
- penicillin as the first practical powerful antibiotic
- streptomycin to treat and often cure tuberculosis, followed by stronger drugs
- synthesis of quinine to treat malaria in WWII
- discovery of the role of Vitamin K in preventing or treating excessive bleeding
- identification of Vitamin D deficiency as the cause of rickets, leading to its prevention by supplementing milk with Vitamin D
- cortisol for control of rheumatoid arthritis and a host of other immune diseases
- the heart lung machine, which made open heart surgery possible
- the birth control pill
- cigarette smoking identified as the cause of 85 percent of lung cancers
- development of the Salk anti polio vaccine
- liver extract to treat pernicious anemia and later discovery of its active ingredient, Vitamin B12
- discovery of the role of DNA as the molecular basis of inheritance
- use of laser devices in human surgery
- the artificial heart and heart valves
- the development of knowledge and techniques that permit transplantation of the heart, lung, kidney, liver and pancreas
- use of beta blocker and calcium channel blocker drugs to relieve angina
- influenza vaccines
- the advent of genetic engineering, which enables us to produce human gene products in the laboratory
- the development of coronary bypass surgery for atherosclerotic heart disease
- systematic vaccination of children against diphtheria, whooping cough, tetanus, mumps, measles, rubella, haemophilus meningitis and polio
- effective treatment to cure early syphilis
- adaptation of sonography from submarines to medical diagnosis, especially of fetuses
- dialysis to compensate for previously fatal kidney failure
- the use of radiation and drugs as well as surgery to cure cancer
was Established in 1937. has Produced:

- Surgical and bioengineering technology enable us to provide freedom of movement for 200,000 bedridden or chairbound Americans each year through implanting new hips, knees, shoulders, wrists, elbows, and ankles.
- The death rate from bacterial infections has been reduced from 25 percent to less than 3 percent.
- Electronic pacemakers have been developed which control heart beat, preventing fatal arrhythmias, control breathing in persons with diaphragm paralysis, and may soon be able to control bladder function in 25 million paralyzed Americans.
- Insulin deficient diabetics can be treated with pure human insulin produced with recombinant DNA techniques. Insulin can be administered continuously through a portable pump, transplantation of healthy pancreatic tissue to restore insulin production is being tested, and the relationship of viral infection to pancreatic destruction is being unraveled and may lead to a vaccine to prevent diabetes.
- Mental illnesses, once poorly defined and somehow shameful, have been recognized as real illnesses that can be treated with a modern armamentarium of psychoactive drugs, bringing immense relief to individuals suffering from these diseases.
- Over 200 of the 3000 described genetic diseases can now be treated because we understand their basic cause and can compensate for the damaged gene product.
- New epidemics of infectious diseases such as Legionnaire's Disease, Toxic Shock Syndrome and AIDS have been discovered, their causative agents rapidly identified, and for each in turn an effective prevention or treatment has been rapidly devised and made widely known.
- Modern medical techniques permit us to open clogged arteries with balloon catheters, reattach retinas with lasers, repair knee joints through tiny incisions using the arthroscope, dissolve kidney stones with sound waves, reattach severed limbs, and maintain human life in the face of failure of any organ except the brain.
- More than half of burn victims suffering 60 percent body burns now survive because of careful management of fluid loss and infections and the recent development of artificial skin.
- The biologic and genetic basis of addictive disorders such as alcoholism, smoking, and drug abuse is being clarified and will lead to the development of effective therapies to release people from the bondage of addiction.
- Treatment of breast cancer has progressed from mutilative surgery as the only option to the use of limited surgery plus radiation. At the same time, chemotherapy has increased the survival rate for the 34,000 women afflicted yearly with this common female cancer.
Premature Infant

The outlook for a premature baby born in the 1980s has dramatically improved compared to a premature baby born 50 years ago. Life-saving medical research and technology not only can help the newborn infant survive the first crucial months of life, they also allow him to grow to maturity and lead a healthy, prolonged life.
Why Federal Investment in Medical Research Must Be Increased

- 855,000 Americans are diagnosed each year as having some form of cancer, about half will die of the disease
- 3.5 million Americans are disabled by stroke or other injuries to the central nervous system
- 2 million elderly Americans are affected by Alzheimer’s disease
- 60 million people suffer from cardiovascular disease
- 16 million Americans have developed osteoarthritis
- 11 million people in this country are diagnosed as having diabetes
- 100 million Americans suffer from some form of digestive disorder each year.
- One of three babies born in 1985 will develop cancer during its lifetime
- 100,000 Americans will die this year as a result of allergic and infectious diseases
- 2,5 million new cases of gonorrhea and over 80,000 new cases of syphilis develop each year in the United States
- 62,000 people each year become blind. At any one time there are over a half a million blind people in America.
- 24 million Americans in any given month are affected by psychiatric disorders
- 4,000 infants died in 1981 in this country as a result of respiratory distress syndrome
- 7 million visits to physicians’ offices due to blood diseases were made in 1979 alone.
- 15 million Americans suffer from chronic lung disease
- Over 200 million Americans have at some time contracted a dental disease
- About 2 million children in this country have mental disorders so severe they require immediate care.
- 17 million hearing impaired persons live in the United States
- 300 million people worldwide are afflicted with malaria, each year 1 million will die of the disease.
- Each one of the approximately 240 million Americans will at one time or another suffer a disorder of the endocrine system. Endocrine diseases range from osteoporosis to diabetes and include hypertension, hormonal dysfunction, growth and development disorders.

"if you are looking about for examples of things that government can do, and do beautifully well, rest your eyes on the NIH. The existence of this institution in its present form owes much to the political leaders in and out of Congress, whose wisdom and statecraft put it in place.”

Lewis Thomas, M.D
Lasker Foundation Awards
1986
Ad Hoc Group for Medical Research Funding: A Proposal for the National Institutes of Health

<table>
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<th>FY 1986 Congressional Appropriation</th>
<th>FY 1987 Current Services</th>
<th>Ad Hoc Group FY 1987</th>
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<tbody>
<tr>
<td>$5.493 billion</td>
<td>$5.993 billion</td>
<td>$6.079 billion</td>
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This proposal brings the increase for the NIH into line with those requested by the President for science support in other agencies, excluding the larger increase for the Department of Defense (see Figure 3). It provides very modest program growth of about $86 million or 1.4 percent over a current services budget (which includes $156 million for nursing programs recently transferred to NIH).

The FY 1987 Ad Hoc Group proposal for NIH provides funds sufficient to support research activities at levels provided for by the FY 1986 congressional appropriation, with modest increases for a variety of important programs. Our proposal emphasizes the need for program balance at NIH with a diversity of support mechanisms and recognizes the multifaceted mission of the agency— to conduct basic and applied research, train qualified promising investigators, and speed the transfer of life prolonging and life-saving research and technology to the public. Our proposal also emphasizes the high degree of flexibility required in the management of NIH for the greatest effectiveness in the use of research funds, considering the substantial variations in the pace of research in different fields supported by the various institutes.

The Ad Hoc Group's proposal for NIH has been severely tempered by the stark realities of the current federal budgetary imbalance. The proposal does not, therefore, advocate optimal funding for NIH; substantial additional funds could be efficiently deployed immediately over a wide range of activities.

The Ad Hoc Group proposal for FY 1987 provides for:

- A current services dollar level for full funding at study section recommended levels of competing and non-competing research project grants (approximately $3.4 to $3.6 billion)
- Some growth in research career awards and funds sufficient to raise the current level of research trainees to that recommended by the National Academy of Sciences
- Needed upgrading and renovation of primate centers and outmoded and inefficient research laboratories
- Some additional funding for General Clinical Research Centers (GCRCs) to facilitate the conduct of clinical research projects and trials
- A slight increase in the number of research centers specialized in biotechnology, etc.

For the remainder of NIH's research activities—contracts, biomedical research support grants (BRSGs), minority biomedical research support, intramural research and full-time equivalent (FTE) personnel—we propose maintenance levels as established in the FY 1986 congressional appropriation.
Ad Hoc Group for Medical Research Funding:
A Proposal for the Alcohol, Drug Abuse, and Mental Health Administration*

<table>
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<tr>
<th>FY 1986 Congressional Appropriation</th>
<th>FY 1987 Current Services</th>
<th>Ad Hoc Group FY 1987</th>
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<tr>
<td>$366 million</td>
<td>$405 million</td>
<td>$465 million</td>
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The proposal for ADAMHA reflects the magnitude of the Agency’s mission by providing necessary program growth over the FY 1986 level of effort. Our recommended funding levels are consistent with the recommendations of the Institute of Medicine of the National Academy of Sciences for a doubling of the ADAMHA research budget over the 1986 to 1991 period. This increase is necessary to achieve catch up growth in the funding of mental health and addiction research. The FY 1987 current services budget of $405 million merely restores ADAMHA purchasing power for research and training to the constant dollar level of 1974.

The FY 1987 Ad Hoc Group proposal for ADAMHA allows funding sufficient to conduct biomedical and behavioral research activities at levels only slightly in excess of the FY 1986 congressional appropriation, with necessary increases for an array of critical programs. Our proposal emphasizes the need for program balance and recognizes the multifaceted missions of the agency—to conduct basic and applied research, train qualified promising investigators, and to transfer life prolonging and life saving clinical knowledge and technology to the public. Our proposal also stresses the high degree of flexibility required in the management of ADAMHA for the greatest effectiveness in the use of research funds, given its diverse research funding mechanisms. We urge ADAMHA to continue to use its multiple support mechanisms in recognition of the many ways in which excellent research can be organized.

The Ad Hoc Group proposal for FY 1987 provides for:

- necessary expansion in the level of competing and non-competing research project grants with full funding at study section recommended levels (approximately $243 million)
- critical growth in research centers (including sufficient funding for competing renewals), Research Scientist Development Awards (which particularly focus on establishing a pool of talented young investigators), and funds sufficient to raise the number of research trainees to that recommended by the National Academy of Sciences
- needed renovation of outmoded research laboratories and equipment
- necessary funds for the intramural programs to provide for replacement of obsolete equipment and to regain lost positions

This proposal recognizes the extraordinary contributions of ADAMHA supported research and would hasten the growth and refinement of new knowledge and clinical applications

*Research and Research Training only
Figure 3
Federal Support for Research and Development
Percentage Increases
Fiscal Year 1987 vs. 1986
Obligations

-5 5 10 15 20 25
Percentage

Government-wide (+17%)
National Science Foundation (+13%)
Department of Defense (+25%)
National Institutes of Health (-10%)
Alcohol, Drug Abuse and Mental Health Administration (-6%)

Source: Budget of the U.S. Government, FY 1987 Special Analysis 5. Adjusted data allowed to include Community Programs as consistent with stated congressional preference.

Figure 4
Percentage of Grant Applications
Recommended for Approval by Council
and Percentage Awarded, NIH, 1972–1986

72 73 74 75 76 77 78 79 80 81 82 83 84 85 86

Recommended for Approval by Council
Awarded

Percentage
Figure 5
Paylines* for Funding Approved New and Competing Research Projects
FYs 1979-1987

- ADAMHA
- NHI

Ad Hoc Group Recommendation

President's Request

Fiscal Years

*In the NHI and ADAMHA peer review systems, the best proposals receive the lowest scores, and funds are awarded based on their priority score. The "Payline" is the cutoff score of ending at which funds available for the fiscal year are exhausted.

Figure 6
Award Rates* for Funding Approved New and Competing Research Projects
FYs 1976-1987

- ADAMHA
- NHI

Ad Hoc Group Recommendation

President's Request

Fiscal Years

*Award rates are the number of projects actually funded as a percentage of those approved and therefore eligible for funding.
Small Scale Chromatography

A scientist uses small scale chromatography, in which a protein produced by recombinant DNA technology is run through small columns of densely packed materials especially designed to purify the desired protein.
Reasonable Funding of Medical Research Would Enable Pursuit of Opportunities Such as:

- Further study of the body's main defense mechanism against disease, the immune system. Diseases of the immune system occur in allergic diseases, certain forms of arthritis, multiple sclerosis, chronic infections, blood disorders, and other diseases, and are believed to occur in over 30 million people at some time during their lives.
- Evaluation of LAK cell and interleukin II therapy of solid tumors. Early trials have shown promising results against such treatment-resistant metastatic cancers as melanoma and colon cancer.
- Efforts to develop effective vaccines against AIDS.
- Studies using a newly developed model of Parkinson's Disease in primates to devise new and more effective therapies for this movement disorder affecting 1 in 600 older Americans.
- Research to identify biologic clues in depression and mania, disorders which affect between 10 and 14 million people at any one time. Biologic clues are potential keys to explaining causes of depression, distinguishing among depressive patients, and selecting treatments best suited to their needs.
- Development of antibodies against the principal bacteria responsible for dental plaque and tooth decay. Although the incidence of tooth decay is declining, the average American child develops 11 cavities by age 17.
- Understanding how the clotting enzyme thrombin interacts in patients, which would provide important information on how the early events in clotting take place. This work has important implications for heart attacks, stroke, and other abnormal clotting situations.
- Understanding how embryonic development is controlled genetically, which will provide valuable information on birth defects and malformations and perhaps how to prevent them.
- Use of monoclonal antibodies to treat cancer and to produce immune suppression for transplant recipients.
- Testing of plasmapheresis for treatment of Guillain-Barré syndrome, a form of ascending motor paralysis which follows viral infection in 2 per 100,000 persons.
- Development of drugs that might interfere with the release of cholesterol into the blood stream, thus reducing coronary atherosclerosis and the risk of heart attacks.
- Trials of an experimental herpes vaccine which has been successful in preventing development of latent herpes infection in mice.
- Development of effective prenatal diagnosis of cystic fibrosis based upon use of the genetic markers which have recently been identified near the cystic fibrosis gene on chromosome 7.
- Identification of the mode of genetic transmission in schizophranias and affective disorders.
- Continued long-term testing of hundreds of new drugs and chemicals introduced into our bodies and the environment annually.
- Identification of the biological mechanisms involved in susceptibility to alcohol addiction.
- Research to identify further causes of low birth weight, which is associated with higher infant death and developmental disability rates and occurs twice as frequently in blacks as in white infants.
An overwhelming majority of Americans believe that "government ... as for basic research should be increased by a sizable amount—even in this era of tight federal budgets and soaring deficits."

— Louis Harris Poll Quoted in Science December 1983

- Total health care costs in the U.S. for 1985 are estimated at $456.4 billion. Federal investment in medical research is only 1.2% of this figure. Health care now consumes 10.8% of the GNP.

- The annual expenditure on health care in the United States is $2,000 per person. The annual federal investment in medical research to reduce this cost is only $25 per person.

- Studies show that the rate of return on every $1 invested in medical research is $13. Between 1900 and 1975, benefits exceeded the federal investment by some $300 billion in constant dollars, a seven-fold return.

- Over $40 billion is contributed annually to the GNP from medical research discoveries that are now used in non-health related products. This is more than the total federal investment in life sciences basic research over the past 50 years.

- More federal dollars are spent on the defense R&D budget in 15 months than the total spent on biomedical research since the establishment of NIH ($50 billion since 1937).

Figure 7
Mortality rates for the United States, for all causes of death, and for four major causes of death, 1950–1984
Ad Hoc Group Proposal for the Year 2000

The NIH and ADAMHA are the flagships of our nation's biomedical and behavioral research effort. They are unique in the world. They provide leadership and quality control as well as funds for scientists in universities and independent laboratories throughout the nation, and their own laboratories produce some of our finest research. Their administration is non-political, professional and dedicated. To maintain this world leadership and to continue to pursue the goal of advancing knowledge to alleviate human suffering, federal support for biomedical and behavioral research must have three characteristics:

- It must be on a stable base of federal funding which enables scientists to plan for the future so that they can pursue long-term basic research projects. Such projects are high risk, without clear immediate payoff, but they have the highest likelihood of ultimately improving health.

- It must provide a stable program for research training to ensure that we continually invest in those superb young people who will provide the creative ideas for the next generation of research. The time line is long for the advanced training necessary to equip a scientist for the sophisticated research of the year 2000.

- It must provide program flexibility. Scientific activity continually identifies the next attainable horizon, as research proceeds from one discovery to another. The focus of support should be on talent and creativity rather than rigid priorities and precise directions, which must always be limited to what is already known.

A stable base of funding will be achieved when we have assured a steady supply of new creative researchers who enter productive careers, supported the best ideas they propose, as judged by merit review and award of the top 50 percent of approved grant applications, insured that retiring scientists are replaced to achieve a steady state; and provided proper equipment and facilities for this cadre of scientists to pursue their proposals. It is estimated that an optimal steady state will be achieved when the federal research effort is one quarter to one third larger in constant dollars than at present. Federal funding policy should be to increase the annual appropriations for both NIH and ADAMHA by 2-3 percent in real growth above the current services budget base for that year. Thus, the constant dollar budget base for each agency would be 25-35 percent greater by the year 2000 than at present. In this way we will fully unleash the creative potential of the biomedical and behavioral research enterprise.

Our reward will be the good health of not only our citizens but those of all the world, a vigorous industrial base in biomedical science and technology, increased productivity due to improved health of our workers, and the maintenance of our preeminence in health research.
Sickle Cell Anemia

Pictured above are abnormal elongated sickled red cells blocking the flow of blood in a capillary (normal red blood cells appear round). In recent years NIH has undertaken important research initiatives to develop prenatal diagnosis and effective treatment for sickle cell anemia.
Senator SARBANES. Thank you very much.
Dr. Davis, please proceed.

STATEMENT OF KAREN DAVIS, PH.D., PROFESSOR AND CHAIRMAN, DEPARTMENT OF HEALTH POLICY AND MANAGEMENT, THE JOHNS HOPKINS SCHOOL OF HYGIENE AND PUBLIC HEALTH

Dr. DAVIS. Thank you, Mr. Chairman, for the opportunity to appear today to discuss the long-term consequences of a reduced Federal commitment to child health programs, and the research necessary to guide public policy affecting the health of children.

You’ve heard excellent testimony this morning on the problems of health-poor children and pregnant women and particularly the problems of low-income children and pregnant women. So I think what I would like to focus on in my oral statement are two points. First, the importance of the Medicaid program in improving access to health care for low-income children and pregnant women, and second, the need for research on the health services, not so much the biomedical research that Dr. Tildon has touched on, but on the economics, the financing, the access to care, the efficiency of care for the services that are provided.

Medicaid has been instrumental in improving access to care for millions of poor and near-poor children and mothers. We have about 8 million children and about 800,000 pregnant women who are covered under Medicaid. This is a program that came in the mid-1960’s and, since that time, we have seen a halving of the infant mortality rate, even though in the decade before Medicaid came in, there was actually no change in the infant mortality rate.

We know that this program has been very important in improving access, particularly to physician services, that it has greatly increased the access to physician care among low-income children.

It’s also increased the proportion of pregnant women that get care early on in their pregnancy.

When we look at statistics today, we see that children who are covered under Medicaid fare much better with regard to access to health care services than do poor children left out of Medicaid.

And the main point I want to stress is that Medicaid simply does not cover all low-income children and pregnant women. In fact, it covers only about 40 percent of the poor. There are only 6 million children in families with incomes below the poverty level who do not have Medicaid.

We have these gaps in coverage really for two reasons. The Medicaid program only covers certain types of low-income people. So it’s a very rare situation where you’d have two-parent working poor that would get covered under Medicaid. And the other reason is that each State sets their own income eligibility level. And that varies tremendously. There are really only 12 States that have an income eligibility level for AFDC and thus, for Medicaid, in excess of 60 percent of the poverty level.

In Maryland, it’s 43 percent of the Federal poverty level and in Alabama, it’s 15 percent of the Federal poverty level.
So you can have an income of $120 a month for a family of three in Alabama and not be considered poor enough to warrant coverage under AFDC or under Medicaid.

As Ms. Rosenbaum pointed out, the early 1980's have been a period of rapid increases in poverty among children, but a time of cutbacks in insurance coverage. There has been a cutback in private insurance coverage because of the recession in the early 1980's and the high unemployment and also because of the trend toward increased payments by employees that employers require.

But there's also been the cutback in Medicaid that came in 1981, with the dropping of many of the working poor from AFDC. I intended to give you a figure, and I'll make sure you have it, that shows this tremendous spread between 1980 and 1984 in the number of poor children and the number actually covered by Medicaid.

In 1984, you had about 17 million children with incomes below 125 percent of the poverty level and only 9 million covered by Medicaid.

But Congress has taken a couple of important steps to expand Medicaid coverage and I think that's particularly gratifying. We found in the Deficit Reduction Act of 1984 and the Consolidated Omnibus Budget Reconciliation Act of 1986 that it mandated coverage of pregnant women, infants, and children up to the age of 5 eventually in families with incomes below State income standards.

So with these new provisions in the 1984 and the 1986 legislation, every State will be required to cover all pregnant women and eventually all children up to age 5 if their incomes are below the State income level; that is, the 43 percent of poverty, for example, in the State of Maryland.

So that it's no longer a function of whether you're on welfare or not on welfare, a two-parent family or a one-parent family.

But there's an extremely important provision currently before Congress. The Senate Finance Committee, as part of this current budget reconciliation bill, has provisions that would, on a voluntary basis, permit the States to cover any pregnant woman or any child up to the age of 5, or any elderly or disabled person whose incomes are below the Federal poverty level.

So this would get at the issue of inadequate income standards at the State level for Medicaid, that it would be up to the State's discretion. But under this new provision, if it's enacted by the Congress, and as I say, it has been reported out by the Senate Finance Committee and also by the House Energy and Commerce Committee, would permit the States to cover every pregnant woman, every child up to age 5, up to the Federal poverty level. And they could do this without being required to extend AFDC or welfare support. It would give them the health insurance coverage under Medicaid.

I think that's a very important provision and I hope the Congress will move forward with that.

The final comments I wanted to make had to do with the need for research funding.

Dr. Tildon has very eloquently addressed the problems of biomedical research funding through the National Institute for Child Health and Human Development. But we also have a problem with inadequate funding for health services research.
It has been very important to have this kind of research to form the basis for the kinds of legislative changes, the swings back in the pendulum, that have occurred in the last few years. Many of the panelists this morning have cited the Institute of Medicine study finding that you save $3.40 in the first year of life for every dollar that you put into prenatal care.

The Southern Governors had a task force on infant mortality and drew on some of these research results to come out in favor of this type of legislative provision that the Senate Finance Committee has reported out.

So it’s this type of research documenting the extent of the problem, what the consequences are, that has helped form the basis for these new legislative initiatives and, in fact, that led to having Medicaid and some of the other programs we’ve discussed like WIC exempt from the Gramm-Rudman-Hollings budget cuts because it was recognized that these programs are so important.

And I think it’s very important that we continue this type of research funding to do further analyses of the impact of governmental programs such as Medicaid, the title V maternal and child health programs, and primary care centers on child health, to continue to analyze gaps in access to child health services and, in particular, to make sure that we have current data.

A lot of the data we use come from 1977 surveys and we simply can’t get any defined or disaggregated data on what’s happening to people with all the changes in the health care market place lately.

We also need more research on cost-effective ways of caring for children and more research that would look at measures of childhood functioning beyond just mortality. I think we focus on infant mortality and low birthweight because we have the data for those. We don’t have data as readily available on various measures of morbidity, such as uncorrected vision, hearing loss, other types of conditions in childhood.

So when you asked the panel to set priorities, one doesn’t know in detail the kinds of health problems that children ages 5 to 18, for example, are having. We just don’t have those as well documented.

Finally, we don’t have good research or statistics on a State level basis. These new provisions in Medicaid, if they get adopted by the Congress, will permit the States to expand coverage up to the Federal poverty level, but it will be a legislative issue in each and every one of these States, and you do need data for each State on how many people are left out, what would be the consequences, what would be the costs, what would be the health impact of having this expanded coverage.

But the funding for health services research that looks at these types of issues has even been more hit by budget cuts than the National Institutes of Health.

There are really two basic places that fund this kind of research. There’s the National Center for Health Services Research and then the Health Care Financing Administration has an office of research and demonstrations.

Between those two places, they, in 1985, in money terms, spent $50 million on research.
Now we know from the statistics last week, that we're spending $425 billion on health care in this country. And to think that we're only spending $50 million on this kind of research for all of the Medicare, Medicaid access and financing issues just shows how inadequate it is. That's been cut in half in real terms over the last 5 years.

So the National Institutes of Health has managed to stay about even with inflation. But these sources of funding health services research have really dropped in half in terms of what the money will cover.

And I think that this is a period of such rapid change in the health care system, with the growth of HMO's, preferred provider organizations, prepaid managed care systems, cutbacks in insurance coverage under Medicare and under employer plans, that we simply have to have timely research on the consequences for health and health care of vulnerable population groups in a decent magnitude.

So I didn't try to estimate whether we need to double that or triple that, but it's certainly clearly inadequate. We just need some increased awareness of the importance of this type of research to provide information on our Nation's progress toward achieving health goals in this era of change and scarcity.

Thank you very much for the opportunity to participate.

[The prepared statement of Dr. Davis follows:]
PREPARED STATEMENT OF KAREN DAVIS

CHILD HEALTH AND RESEARCH FUNDING

Thank you, Mr. Chairman, for this opportunity to appear before you today to discuss the long-term consequences of a reduced Federal commitment to child health programs, and the research necessary to guide public policy affecting the health of children.

Today, I will review some of the evidence on the importance of health care services for children, identify the major unmet health needs of mothers and children, briefly discuss the importance of Medicaid coverage for access to health care for poor children and pregnant women, and outline major areas of research that need to be pursued to investigate the consequences of inadequate access to health care and the most effective approaches to improving child health.

The Health of Low Income Children

Over the years, the United States has made significant strides in improving the health status of mothers and children. Much of this improvement can be attributed to better nutrition, sanitation, and general living conditions as well as increased access to more effective medical care. Infant mortality, one of the most easily measured indicators of health status, has
steadily improved over the past decades. In 1955, 26 infants died in the first year of life for every 1,000 babies born. In 1965, the year in which Medicaid was passed, the infant mortality rate stood at 25 deaths per 1,000 live births. By the early 1980s, that rate had been cut in half to 11 deaths per 1,000 births. Much of this progress directly parallels efforts to expand financial access to health care under Medicaid and to improve provision of care under the maternal and child health programs.

However, despite these gains, we remain a nation of contrasts. As the life span of the average American increases, some infants continue to die within the first year of life at inordinately high rates. As we develop increasingly sophisticated medical technologies, many children fail to receive the most basic preventive services. As we debate ways to contain health care costs, millions of children and pregnant women lack adequate financial resources to purchase care.

In 1980, one birth in 20 was to a mother who received prenatal care after the seventh month of pregnancy or in some cases who delivered without any prenatal care at all. Women in low income families are 50 percent more likely to receive no prenatal care or late prenatal care than their more affluent peers. Teenage mothers are less likely to get care early in pregnancy than older mothers. Delay in obtaining prenatal care is also more common among blacks than whites; in 1980 77 percent of white pregnant women and 59 percent of blacks received
prenatal care in the first trimester of pregnancy.

The proportion of low birth weight babies is much higher for mothers who do not receive prenatal care. Nearly 7 percent of all births are low birth weight babies weighing less than 2500 grams. For women without prenatal care, 22 percent of all babies born are low birth weight with 7 percent of babies to women without prenatal care weighing less than 1500 grams. Black infants are twice as likely to be born with low birth weight as white infants. A recent Institute of Medicine report found that for every $1 invested in prenatal care for poor women, $3.40 of savings were generated in the first year of the infant's life from reduced hospitalization costs.

These statistics are especially troubling since we know the health care received during pregnancy and early childhood influences the child's health throughout life. Early prenatal care is essential so that conditions such as hypertension, diabetes, and iron deficiency anemia can be diagnosed early and brought under control. Without such intervention, premature births with resultant mortality or physical and mentally handicapping conditions will occur with high frequency. Adequate medical care in the first year of life is also important to provide prompt medical attention for gastrointestinal, respiratory, or other disorders that can be life threatening for vulnerable infants.

Throughout childhood, low income youths continue to face health problems, some of which may result from inadequate
prenatal and infancy care. Poor children are more likely than nonpoor children to suffer from low birthweight, congenital infection, iron deficiency anemia, lead poisoning, hearing deficiencies, functionally poor vision, and a host of other health problems amenable to medical intervention. Poor children are more likely to become ill, more likely to suffer adverse consequences from illness, and more likely to die than are other children.

The National Health and Nutrition Examination Survey shows the proportion of children with significant abnormal findings on examination increases as family income decreases. Children who are poor are 75 percent more likely to be admitted to a hospital in a given year and when admitted, stay twice as long as nonpoor children. These medical limitations also affect other aspects of poor children's lives. Poor children have 40 percent more days lost from school than children in non-poor households.

**Medicaid Coverage for Poor Children**

Medicaid has been instrumental in improving access to care for millions of poor and near poor children and mothers. In 1982, 8 million children and 800,000 pregnant women received needed health care services as a result of Medicaid coverage. Through Medicaid, more of the poor receive medical care early in pregnancy. In 1963 prior to enactment of Medicaid, only 58 percent of poor women received care early in pregnancy. By 1970,
71 percent of poor women received early prenatal care.

The best single measure of the extent to which the poor have gained access to care under Medicaid is the utilization of physician services. That is, to what extent has Medicaid enabled the poor to see physicians as frequently as the average American with similar health problems? Dramatic gains in access to physician services by the poor have been made over the last 20 years. In 1964, the poor saw physicians an average of 3.9 times per year while the nonpoor visited physicians 4.8 times per year despite the fact that the poor were sicker and needed more health care than the nonpoor.

By 1977, this situation had been radically altered. The poor with insurance, notably Medicaid, saw physicians 4.2 times per year compared to 3.8 visits per year for the nonpoor. The uninsured poor, however, still lag considerably behind with 2.3 visits per year. Uninsured minorities fare the worse with only 1.5 ambulatory visits per year. However, when visits for the insured poor are adjusted for health status, even the insured poor have fewer visits than their nonpoor counterparts.

Thus, poor children, particularly those not eligible for Medicaid, still receive less care than nonpoor children. Sick day for sick day, poor children have fewer medical visits, but poor children with Medicaid coverage are better off than those without.

Nearly 6 million children in families with incomes below the poverty level are without Medicaid coverage. Less than 40
percent of children in poverty are covered by Medicaid. Of these uninsured poor children, 2 million live in families with incomes below 50 percent of the poverty level.

These gaps in coverage occur largely because States are not required to cover children living in two parent families under Medicaid and because state income standards for program eligibility are generally far below the poverty level. Currently, only 12 states have an AFDC income eligibility cutoff limits for Medicaid greater than 60 percent of the federal poverty level; 20 states have income eligibility levels between 40 and 60 percent of poverty; with the remainder of the states with income eligibility levels below 40 percent of the federal poverty level. Alabama, for example, has an income eligibility level of 15 percent of the federal poverty for a family of three. Maryland has an income eligibility level of 43 percent of the federal poverty level for a family of three, although it covers some medically needy families with incomes slightly above that level.

Cutbacks in federal financial support for Medicaid in 1981 and reduction in coverage of the poor under AFDC have resulted in a loss of Medicaid coverage for many poor children and pregnant women. The rapid rise in poverty among children in the early 1980s made this cutback in federal support particularly ill-timed. The gap between children in poverty and children covered by Medicaid widened markedly.

It is particularly gratifying, therefore, that the Congress has taken steps in recent years to expand Medicaid coverage for
poor children and pregnant women. Provisions in the Deficit Reduction Act of 1984 and the Consolidated Omnibus Budget Reconciliation Act of 1986 to mandate coverage of pregnant women, infants and children up to the age of 5 in families with incomes below state income standards were extremely important. This means that no longer will a pregnant woman or young child with incomes below state income eligibility levels will be denied coverage because both parents are in the home or because the family does not receive welfare. But these recent changes do not address the problems of coverage in states with income eligibility standards well below the federal poverty level. Therefore, I would like to commend the Chairman for his support of the provisions recently passed by the Senate Finance Committee as part of the Budget Reconciliation bill to permit states to expand coverage of Medicaid to all children under age 5, pregnant women, and elderly and disabled with incomes up to the federal poverty level. This would permit states to expand coverage under Medicaid, without requiring that they expand coverage for welfare income assistance. These are important steps to close the gaps in Medicaid coverage that are so important to assuring access to health care services for this especially vulnerable group of our nation's population.

Need for Research Funding

The reversal of the pendulum from cutbacks in Medicaid coverage to expanded coverage for those most at risk is extremely important. However, it is important not to be complacent about
these measures. The scarcity of resources and economic restraints are likely to be a persistent fact of public life. Any new expansion, whether at the federal or state level, will require rigorous justification and have to pass close scrutiny. Political support for recent Medicaid expansions was increased by the Institute of Medicine report on low birth weight infants and the report of the Southern Governors Task Force on infant mortality. Other research was instrumental in causing Medicaid and certain other programs assisting poor children to be exempt from Gramm-Rudman-Hollings budget cuts. Continued policy research efforts are essential to lay the groundwork for further action:

- **Analysis of the impact of governmental programs such as Medicaid, Title V maternal and child health programs, and primary care centers on child health.**

  Amazingly, even such basic facts as the impact of Medicaid on prenatal care and infant mortality have not been systematically collected and analyzed. Documentation of the impact of governmental intervention is essential, if expansions or renewed commitment are to be proposed. Research on prenatal care and follow-up programs for high risk infants is particularly important.

- **Analysis of gaps in access to child health services.**

  Data surveys to document the gaps in access to health services need to be maintained on a more
current basis. Too often, we are using 1977 data when major shifts in the health care marketplace and insurance coverage have occurred in the early 1980s. These surveys need to be constantly analyzed on an ongoing basis. Existing data sources need to be improved, including ongoing linkage of birth records and death records, expansion of the Health and Nutrition Examination Survey to young children, and better information on pediatric care.

- **Cost effective ways of caring for children.** In an era of constrained economic resources, new and better ways of achieving child health objectives at lower cost will always be in demand. Selective demonstrations and analysis of natural experiments that provide indications of high payoff approaches to child health are important.

- **Impact of inadequate childhood health care on functioning and morbidity.** Motivating policy action requires some compelling evidence that intervention can and does make a difference. Maternal and child health is one of the few areas where solid evidence of high payoff exists. Yet, this evidence pertains primarily to prenatal care, infant care, and immunizations. The importance of health services in reducing the prevalence rates of disability, improving childhood functioning, or reducing adolescent mortality is
less well studied and understood. New measures of health status for children need to be developed. Longitudinal studies of child health to link patterns of medical care and health outcomes need to be conducted. Initiating research to explore these issues is a high priority.

- **State level analysis of child health coverage.** As federal legislation is enacted permitting states to expand eligibility under Medicaid to all poor pregnant women and young children it will be increasingly important to have state-level analyses of gaps in health insurance coverage of the poor and estimates of the fiscal consequences of expanding Medicaid eligibility.

Funding for research, however, has been cut back even more severely than Medicaid and other public programs that improve the availability of health care services for poor children. In real terms, health services research supported by the National Center for Health Services Research/Health Care Technology Assessment (NCHSR/HCTA) and the Office of Research and Demonstrations of the Health Care Financing Administration (ORD/HCFA) has been cut drastically in real terms in the last five years. Combined funding of NCHSR/HCTA and ORD/HCFA has dropped from $39 million in 1980 (in constant 1972 dollars) to $21 million in 1985. During the same time period real national health expenditures increased from $130 billion (in constant 1972 dollars) to $172
billion in 1985. The frequency of data surveys and publication of reports by the National Center for Health Statistics have been cut.

In a period of rapid change in the health care system, including the competitive pressures faced by hospitals, the growth of health maintenance organizations, preferred provider organizations, prepaid managed care systems, and other alternative delivery systems, as well as cutbacks in insurance coverage under both public programs and private employer health insurance plans, timely research on the consequences for health and health care of vulnerable population groups should be a high priority. Increased awareness of the importance of research to provide information on our nation's progress toward achieving health goals in an era of change and scarcity is extremely important. Thank you for the opportunity of participating in this hearing.
Senator SARBANES. Thank you very much. Dr. Kolb, please proceed.

STATEMENT OF MARVIN O. KOLB, M.D., PRACTITIONER IN CLINICAL PEDIATRICS, FARGO CLINIC, AND CHIEF OF STAFF, ST. LUKES HOSPITAL, FARGO, ND

Dr. Kolb. Thank you, Mr. Chairman, and distinguished members of the committee.

I'm Mary Kolb. I'm a pediatrician in Fargo, ND, and chief of staff of the St. Lukes General Hospital in Fargo, which is the largest hospital in the State.

I'm pleased to be here today as an advocate for children. I think your committee's keen awareness of the need to look at the long-term consequences of reduced Federal commitment to the health and safety of children is particularly important. Children's needs cannot be compromised 1 year and picked up the next year without severe consequences.

Hence, I think this hearing is particularly timely.

American children do not have the same problems that children did 20 years ago because they're not the same children. Today's children are poorer relative to the rest of society. A fifth of them live below the poverty line and 21 percent of them live in single-family homes. Emergency rooms are becoming the chief source of care for these families who have lost Medicaid benefits and have no private insurance.

Attempts to assist children have been fragmented. They're sporadic and they take place in the absence of really some well-established sense of priorities.

Consequently, children really suffer disproportionately in times of fiscal cutbacks.

Basic problems persist and really, they discredit us all. If we use survival rates of the newborns as an indicator of how well a society cares for its most vulnerable members, regrettably, as you've heard this morning, our national mortality rate puts the United States 17th among nations with a population greater than 2 million.

With 3.6 million births in this country annually, as Dr. Sabin mentioned, 40,000 infants will die during their first year of life.

There are obviously short- and long-term strategies that leaders must initiate if progress is to be made. Many of these involve the obvious. Prenatal mothers must receive adequate care and nutrition. Further research must be provided and children must be immunized.

In short, all efforts to prevent avoidable deaths and disability among infants and children must be taken.

In the last few years, I've had the unique privilege of serving on the advisory council of the National Institute of Child Health and Human Development. My testimony today will focus on cutbacks in the area of research—one of the invisible cutbacks in the public eye—and how these cutbacks obviously will impact on the health and care of children. In the time allotted to me today, I'd like to highlight five areas—one, the low birthweight; two, teen pregnancies; three is injuries; four is vaccines; and five is mental retardation.
As a practitioner, I'm very well aware of the public health accomplishments such as the development of synthetic growth hormones, the development of new and safer vaccines, alternative methods of contraception. All of these have been made through the years of progress in biomedical research. But if we do not conduct clinical trials and studies, these basic findings will never be converted into practice and into healthier children.

With relationship to low birthweight—and you've heard much of this today, these are the babies less than 5 1/2 pounds—it's a major factor which influences our infant mortality today. As stated earlier, the incidence is higher in the United States than in many developed countries. Low birthweight babies are likely to suffer many problems—handicaps, congenital anomalies, respiratory problems, vision, hearing. Also, the low birthweight babies are born in a disproportionately high number to real high-risk groups—the teenagers, the unmarried, the black, the poor, the women over 35, and women without a high school education.

We've done many things because through today's advance neonatal care, the intensive management has minimized the disability suffered to low birthweight babies in the 3 1/2- to 5-pound range. Those babies whiz through nurseries and have 90 percent survival rates and are good outcome babies. But the very low birthweight, as you heard defined, less than 3 1/2 pounds, they require long terms of intensive care and the annual cost is over $4 billion a year to care for these babies.

These babies under 3 1/2 pounds suffer high disability and death rates. The handicap rate of the very low birthweight has been estimated at 50 percent by school age.

The respiratory distress syndrome, the old Hyaline membrane disease, is a very common life-threatening condition in these babies. And an example of what has happened in the laboratory, the test tubes in the lab and how it's moved to the incubator and the nursery is that researchers today have identified that these premature babies have an insufficiency of an agent called surfactant. And through research today, they've brought trials presently going on on surfactant. It's been obtained from calves. And hopefully, through genetic engineering, a human product will be developed.

This is a good example of how, again, by basic research, we are about to make a major advance in the treatment of a disease.

As a result of these cutbacks in 1986 and further in 1987, researchers are going to be unable to develop new knowledge to better understand prematurity and infant growth retardation, interuterine growth retardation, which are the two major factors which contribute to low birthweight.

Teen pregnancy. It's a tragedy. There are over a million births each year to teenage mothers, and even though contraception is widely available, teenagers don't use it or they use it ineffectively or they use it inconsistently.

We need to find out more about the behavior and the social factors and we also need to have effective contraception. It has to be safe. It has to be effective. It has to be inexpensive. It has to be easy to administer. And it has to be acceptable to all population groups.
I see these children in my practice. It's in North Dakota like it is in Maryland. These are children having children. These are children raising children. And it is a tragedy.

I'd like to speak about injuries. Injuries are a real concern to me. If I can give you a figure, that between the ages of 1 and 35, more people die from injuries than from all other diseases combined—between the ages of 1 and 35. Half of the deaths between 1 and 14 and between 75 and 80 percent of the deaths between 15 and 25 are from injuries.

I'm saddened to see children maimed and dying from things that, maybe through research and intervention, possibly could be prevented. There's 100,000 children a year that suffer permanent disabilities from injuries. There are over 19 million children a year under 16 that are treated for injuries annually.

Prevention here is of paramount importance. It must involve both pediatricians and behavioral scientists.

Mr. Chairman, this is going to be a tough nut to crack. The causes are obvious and poorly understood. But our country has the minds and the technology to make an impact on this No. 1 killer in our society. I feel that it must receive a greater priority. It's only going to be through leadership, through your leadership, that appropriate direction and funding can be made in this area.

Vaccines, as we've heard so much today, are of vital importance to the maintenance of child health and development. It's through efforts of research in this area that we have in this country an effective immunization program. But even this effective program, which is the basis of preventive child health services, is in jeopardy.

Vaccine prices have soared and, as we heard owing to the insurance and liability costs, to fully immunize a child today has increased eightfold in 4 years.

We need to solve this problem.

And finally, with mental retardation. It's a lifelong problem and a major health problem and a social issue with multiple causes that require study of a full range of developmental variables.

Mental retardation affects millions of Americans and leads to annual public expenditures of billions of dollars. Budget cuts have had severe effects in mental retardation research. Mental retardation centers, augmented by some university-affiliated centers, such as the Kennedy Institute here at Johns Hopkins, had planned several clinical trials for new interventions to treat and ameliorate mental retardation.

Budget cuts this year will prevent this. In addition, many of the exciting new leads in genetics, in molecular biology and neurobiology will not be funded.

Research benefiting infants and children, Mr. Chairman, stands at an important crossroads. If we're farsighted, we can take advantage of the recent developments. We can build upon them. I think if we continue to strive toward increasing our infant survivability, we need to ensure a treatment for children with cancer. We need to reduce the risk of cancer because one out of every three babies born in 1985 will develop cancer in its lifetime. So this is not just a child issue. This is a society issue. It's a health issue.
We need to improve treatments for diabetes, for arthritis, for cystic fibrosis, and other debilitating diseases. And we need to provide hope for the families of the 2 million children who have severe mental disorders that require care.

If we choose to hesitate, we will see children suffer.

Mr. Chairman, I hope I've given you a little insight into what we, as the Nation, are capable of accomplishing. As a citizen, I'm keenly aware of our Nation's economic problems. I also know that we must be prudent and practical about our budget priorities. Yet, I must question our priorities. We're spending billions of dollars on care when we should be spending millions of dollars on preventive activities.

Today, I've asked you to step up research efforts to eliminate low birthweight, to reduce teen pregnancy, to promote a safer environment, to reduce the toll of injuries on our society, to develop new and safer vaccines, to ameliorate mental retardation.

In essence, sir, I'm asking you to put me out of business as a practicing pediatrician. I realize that these comments and suggestions are ambitious, but I do not think that they're impossible goals for our society.

I thank you for the opportunity to be here today.

[The prepared statement of Dr. Kolb follows:]

[The prepared statement of Dr. Kolb follows:]
Mr. Chairman, my name is Marvin O. Kolb, M.D., a full time practitioner in clinical pediatrics at the Fargo Clinic and Chief of Staff at St. Lukes Hospital in Fargo, North Dakota. I am a Fellow of the American Academy of Pediatrics and a member of the National Advisory Council to the National Institute of Child Health and Human Development at the National Institutes of Health. I am pleased to be here today as an advocate for children and child health and safety from the perspective of a busy pediatrician.

The Committee's keen awareness of the need to look at the long-term consequences of a reduced Federal commitment to health and safety programs is particularly important with respect to children. Their needs cannot be compromised one year and picked up the next without severe consequences. Hence this hearing is particularly timely.

With more and more solid information available now on the vulnerabilities of children, especially babies, it is unimaginable that members of Congress would sharply diminish their support for federal initiatives which help address these serious maternal and child health problems. Indeed, after five years of belt-tightening, increased attention and bold innovation are all the more necessary.

American children today do not have the same problems as children had 15 or 20 years ago because they aren't the same kind of children. Today's children are poorer, relative to the rest of society, than children of the 1960s were. One-fifth of U.S. children live below the poverty line and 21 percent live in single-parent households. Emergency rooms are becoming the chief source of care for families who have lost Medicaid benefits and have no private health insurance. Hence, attempts to assist children are fragmented, sporadic and take place in the absence of an overall context or well-established sense of priorities. Consequently, children suffer disproportionately in times of fiscal cutbacks and program consolidation. It is important to appreciate the uncertain position of pediatric programs in 1986 because it is from here that we enter a new era of sweeping change in our health care system.

Basic problems persist, and they discredit us all. The survival rates of newborn infants serve as an indicator of how well a society cares for its most vulnerable members. Regrettably, our national infant mortality rate for 1984 was 10.6 deaths per 1000 live births, ranking the United States only 15th among nations having a population greater than 2 million. With approximately 3.6 million births in this country annually, nearly 40,000 infants will die during their first year of life.

It is therefore of profound concern to pediatricians that current national policy has been but marginally effective in reducing the proportion of LBW infants. The decrease in the incidence of LBW deliveries from 7.7 (per 1000) in 1960 to 6.8 in 1983 represents only a 14-Percent decline. (Post neonatal mortality, deaths from 28 days to one year of age, accounts for the remaining 30 percent of infant deaths -- and fully 20 percent of these deaths occurs among former LBW infants. The remainder are related to environmental conditions and infectious diseases. Sudden Infant Death Syndrome accounts for 33 percent; infections, 10 percent; accidents, 7 percent.)
There are short-term and long-term strategies that leaders must institute if progress is to be made. And many of them involve the obvious, e.g., prenatal mothers must receive adequate care and nutrition; further research must be promoted; children must be immunized. In short, all efforts to prevent avoidable deaths or disabilities among infants and young children must be taken.

My testimony today will focus on cutbacks in the area of research -- one of the most "invisible" outbacks to the public eye -- and how they will impact on the health and well-being of our children. Since my professional experience has been focused at the NICHD, I will highlight important research efforts there and how budget reductions will effect them.

Recent public health accomplishments such as the development of synthetic growth hormone, the development of new and safer vaccines for childhood illness, and alternative methods of contraception have been made possible through years of basic biomedical research. If we do not conduct clinical research studies, these basic findings will not be converted into healthier children.

I am concerned that a lack of funds for the National Institute of Child Health and Human Development and other Institutes of the NIH (this Nation's world-renowned resource for biomedical research located in this state) will arrest progress in combating infant mortality, this Nation's single most important child health problem, as well as a host of others of major importance.

Low birth weight (LBW) (less than 5.5 lbs.) is the major factor influencing infant mortality in the United States today. And as stated earlier, the incidence of LBW is higher in the United States than in many developed countries. LBW infants are more likely to suffer neurodevelopmental handicaps, congenital anomalies, respiratory problems, vision and hearing disorders and a multitude of other conditions. LBW infants are born in disproportionate numbers to high-risk groups such as teenagers, unmarried women, the poor, black women, women over 35, and women without a high school education.

Today's improved neonatal intensive care minimizes the morbidity suffered by LBW infants in the 3.5 to 5.5 lb. range, but Very Low Birth Weight (VLBW) infants weighing less than 3.5 lbs. require long periods of intensive care and experience the highest mortality and morbidity.

The impact of LBW on society is profound. Two-thirds of all infant deaths occur among LBW infants; most of these are VLBW. The poor U.S. international ranking in infant mortality is due almost entirely to our higher rate of LBW. LBW infants require care in neonatal intensive care units (NICU's) for as long as four months. The annual cost of NICU care alone approaches $4.0 billion/year.

The impact of LBW on society is profound. Two-thirds of all infant deaths occur among LBW infants; most of these are VLBW. The poor U.S. international ranking in infant mortality is due almost entirely to our higher rate of LBW. LBW infants require care in neonatal intensive care units (NICU's) for as long as four months. The annual cost of NICU care alone approaches $4.0 billion/year. Costs for physician services not billed through the hospital and caring for lifelong morbidity must be added to this figure. Infants in intensive care experience a high incidence of illness and complications as newborns and VLBW infants in particular have a markedly elevated incidence of lifelong handicaps including: mental retardation, cerebral palsy, seizures, learning problems, blindness, and deafness. The incidence of such handicaps in VLBW children is over 50% at school age.
Unfortunately, many of these handicaps resulting from LBW and/or prematurity, are non-reversible and the victim and the victim's family spend a lifetime coping with his or her life. Respiratory distress syndrome, characterized by lung immaturity and caused by an insufficiency of a substance, surfactant, which lines the airspaces and prevents lung collapse, is a common cause of illness of premature infants. Investigation is in process to determine if administration of this substance, which has been obtained from calves and may soon be available through genetic engineering techniques, may provide successful treatment of respiratory distress syndrome. This is indeed promising research for those of us dealing with these infants.

Beginning in 1984, the NICHD assigned the highest priority to the conduct and support of a special research initiative on the prevention of low birth weight in infants. The importance is underscored by the selection of low birth weight prevention as one of the "1990 Objectives for the Nation" and its selection by the Institute of Medicine in 1982 as the subject for a comprehensive study by an interdisciplinary committee to examine the many factors that contribute to low birth weight.

As a result of budget cuts in 1986 and further cuts contained in the 1987 President's Budget, the NICHD will be unable to implement many of its planned research efforts to develop new knowledge to better understand prematurity and intrauterine growth retardation, the two primary efforts needed to prevent and ameliorate the problem of LBW.

A problem closely related to that of LBW is childbearing by adolescents (one of the groups at high risk for having LBW infants). Adolescent childbearing is recognized as a leading health and social problem in the United States. Current research focuses on various determinants and consequences of adolescent pregnancy and childbearing.

Given the large number of teenage pregnancies each year (approximately one million), and the inherent risks associated with such pregnancies to the health and welfare of mother and baby, research has addressed the causes of these early pregnancies. Although contraception is widely available, many sexually active teenagers appear to delay its use, to use less effective methods, and to contracept less consistently than adults. To find out more about the behavioral and social factors resulting in less consistent and effective contraceptive use among teens, more emphasis was placed on research on these factors. Budget cuts will impede the funding of this research. We must have an array of methods that are safe, effective, inexpensive, easy to administer and acceptable to various population groups.

Recent surveys show a close relationship between the health of the baby and whether or not the mother wanted to become pregnant. Not surprisingly, women with unwanted pregnancies report that they first obtain prenatal care later in pregnancy than those who wanted to become pregnant. Furthermore, among the births resulting from unintended pregnancies in the U.S. during 1979-82, the prevalence of low birth weight was significantly greater than among planned births. Thus, efforts to help couples avoid unintended pregnancies will complement and enhance the Institute's efforts to reduce the incidence of low birth weight.
Another major area of importance is injury and accident prevention, which is of particular interest to me. Annually, 19 million children 15 years old or less receive medical care for an injury. A study estimated that in the toddler age group, one child in ten was treated in a hospital emergency room for injuries or poisonings. Epidemiologists have also estimated that injuries incapacitate two million children annually for two weeks or longer. Further, at least 100,000 children each year suffer permanent disability as a result of injuries.

Once infancy is past, injuries, not disease, become the leading cause of death and disability. In this field, prevention is of paramount importance. Preventive approaches involve both pediatrics and the behavioral sciences. For example, studies the NICHD has supported have developed and demonstrated the effectiveness of pediatric office-based interventions to have parents use car seats and seat belts for their children, and lower their home hot water heater settings to prevent scalding. To expand this research, the Institute last year issued a special solicitation for research grant applications on behavioral approaches to injury prevention which invited scientists to submit proposals seeking to clarify the behavioral and environmental variables responsible for specific kinds of childhood injuries; to identify and measure observable behaviors of parents and children that are precursors of injury occurrence or injury avoidance (i.e., behaviors closely linked to injury morbidity and mortality); and to identify environmental conditions modifiable by parents or children which lead to injury or injury reduction. The solicitation also addressed the need for development of experimental models that explain, by use of analogy, the origins and continuation of risk-taking and safety behaviors, with a view toward developing effective intervention strategies.

With the budget cuts, the Institute will only fund one research project from those received from this solicitation, and a vital research planning conference in this area will be very limited in size and scope. The devastating and sometimes fatal injuries we see as practitioners only serve to reinforce our firm belief that more needs to be done in this area.

An area vital to the maintenance of child health is the development of new and improved vaccines. Exciting advances have been made by NICHD intramural scientists in the area of vaccine development. Whooping cough, typhoid fever, and meningitis due to Hemophilus influenzae are still responsible for illness, death, or permanent disability in many children. In the case of whooping cough, (pertussis), fear of side effects from the existing vaccine made from whole bacteria is inhibiting its use, resulting in an increase in the number of cases of this disease around the country. Intramural scientists of the NICHD recently have isolated and purified the single component of the pertussis organism that they believe is sufficient to produce an entirely safe and effective vaccine. They are about to start field trials of their new vaccine in Sweden, where without vaccine use pertussis has reached epidemic proportions.

These same intramural scientists have also been successful in developing new vaccines against typhoid fever and Hemophilus influenzae type B. The new typhoid vaccine, just entering field trials in India and Nepal, is inexpensive and is expected to have minimal side effects and to produce lifelong immunity.
Despite effective antibiotics, *H. influenzae* remains a serious cause of sickness and death in infants and is a leading cause of acquired mental retardation in this country. A recently licensed vaccine based on earlier work of these NICHD scientists is effective in older children but not in those under two years of age, the time of greatest risk. They have now produced a modified vaccine that has been successful in trials with infant monkeys, and the Institute would like to begin a field trial in human infants.

Budget cuts have affected the Institute's ability to continue vaccine trials already underway and to mount additional studies needed to complete clinical testing prior to general use.

It is the research efforts in this area that have resulted in the United States having such an effective childhood immunization program. But even this, the most basic of preventative child health services, is in jeopardy. Vaccine prices, owing substantially to insurance and liability costs, continue to soar. In fact, the price for vaccines to fully immunize a child has risen from $6 in 1982 to more than $50 today — an eight-fold increase in four years. Prices in 1987 may rise another 50 percent. Unfortunately, while costs of immunization have gone up steeply, the budget for federal childhood immunizations has not. The number of children to whom the government can provide vaccine has declined by two-thirds. If the President's budget for 1987 were adopted by the Congress, states would be able to supply vaccine for still 400,000 fewer children.

As startling as these numbers are, they tell only part of the story. States, faced with skyrocketing vaccine costs, are being forced to lay off immunization workers, leaving clinics and medical-records work unstaffed. They are beginning to implement copayments for the poor, some as high as $15 per shot. And the President's budget proposes no funds for the yet incomplete vaccine stockpile, even though only a year ago we were forced to ration childhood vaccines in this country.

All of these problems are compounded by Gramm-Rudman. The first round of relatively shallow cuts eliminated funds for more than 65,000 children's shots. Every percentage point cut from 1987's budget will mean another 10,000 children without federal vaccinations. If present deficit forecasts are accurate, hundreds of thousands of children may be eliminated from the program.

Finally, I would mention the problem of mental retardation. Mental retardation is a lifelong problem and a major health and social issue, with multiple causes that require study of the full range of developmental variables. Mental retardation affects millions of Americans and leads to annual public expenditures (federal, state, and local) of billions of dollars.

Mental retardation is caused by a complex of biological, psychological, and social determinants: genetic factors, metabolic disorders, prematurity, or other disturbances during pregnancy, are a few. Infection or injury at birth or in early childhood may also underlie mental retardation. In addition, lack of stimulation, inadequate educational opportunities, and generally deprived living conditions may be causal or contributory factors.
Much of the Nation's research on mental retardation is conducted in a network of Congressionally established Mental Retardation Research Centers supported by the NICHD. Studies in the biomedical sciences supported by the Institute have led to interventions that are highly effective in preventing mental retardation resulting from a few of the many biological causes, such as congenital hypothyroidism. NICHD-supported studies applying the behavioral sciences to the much larger category of socio-cultural-familial mental retardation have suggested that early behavioral interventions may be effective in reducing the likelihood of mental impairment in high-risk infants and children.

Budget cuts have had a severe effect on mental retardation research. The Institute had plans to use the Mental Retardation Research Centers, augmented by some University-Affiliated Facilities (such as the Kennedy Institute at Johns Hopkins), to conduct clinical trials of new interventions to treat and ameliorate mental retardation; budget cuts will prevent this. In addition, many of the exciting new leads in genetics, molecular biology and neurobiology will not be funded.

Research benefiting infants and children stands at an important crossroads. If we are farsighted, we can take advantage of recent developments and build upon them. We can continue to stride forward towards increasing our infants' survivability, ensuring treatment for children with cancer, reducing the risk of cancer (one out of every three babies who were born in 1985 will develop cancer during its lifetime), improving treatment for diabetes arthritis, cystic fibrosis, and other even more debilitating diseases, and providing hope for the families of the two million children who have severe mental disorders that require care. If we choose to hesitate, we will see children suffer.

Research for infants and children needs more than our moral support; it needs financial support. Endowment funds and private donations provide significant pediatric research support in only a handful of institutions and those foundations which provide specialized pediatric research are relatively small. Congress must be cognizant of the fact that most pediatric research funds come from the federal government, namely the National Institutes of Health. However, in 1983, the National Institute of Child Health and Human Development allocated only 11 percent of their research project grants and 17.1 percent of their funds to pediatric departments for research involving infants and children; most of the Institute's remaining funds went to maternal health and reproduction. Other Institutes contributing significantly to pediatric research include the National Institute of Allergy, Immunology, and Infectious Diseases (4.5 percent of its grants), the National Institute of Arthritis, Digestive and Metabolic Disease (3.1 percent of its grants), the National Heart and Lung Institute (3.2 percent of its grants), and the National Cancer Institute (1.4 percent of its grants).

The important role of the General Clinical Research Centers (GCRC) program of the Division of Research Resources within the portfolio of pediatric research must be noted and supported. Pediatric research places particular emphasis on clinical research providing the promise of direct benefit for infants and children. The GCRC program provides support for clinical research at 78 centers, 16 of which are devoted primarily, if not exclusively, to pediatric
clinical research. As of 1983 pediatric research accounted for 30 percent of the GCRC program budget, and 30 of the 100 graduates of the GCRC clinical associate physician program, a primary source for training physician investigators, have been pediatricians.

As a practicing pediatrician I have been concerned over one other threat to continued successful pediatric research -- the possible lack of the use of animals. Animal models are used only when necessary; other alternatives are employed where possible. However, if research programs were denied the use of animals, the only other living system available would be infants and children, and it is not logistically or ethically sound to be forced to make that choice.

Mr. Chairman, I hope I have given you a little insight into what we, as a nation, are capable of accomplishing. As a citizen I am keenly aware of our Nation's economic problems and I know we must be prudent and practical about our budget priorities. Yet I must question our priorities. Even during a time of shrinking budgets, it is shortsighted to decrease monies for research directed at preventing disability and death during the critical period surrounding infancy and the ensuing childhood years. Through your leadership, let us be far-sighted enough as a Nation to take advantage of these recent developments.

In conclusion, let me reemphasize that inferences must be drawn from our infant mortality rate which go beyond the immediate components of the measure, i.e., death to infants under one year of age, which speak to risks, needs and services for infants, children and young families. While this statement focuses on the role of research, many other federal programs influence infant mortality and morbidity and deserve attention and support. All play a role. One cannot be sacrificed for another. Changes in the measure of infant mortality and morbidity which can be sustained over time will not occur without diligent and continued attention to these several major influences on the health of this population.

As a society, we simply cannot afford the wastage of human resources in childhood and adolescence. As a pediatrician, I feel it is incumbent upon me to present to you in this context the opportunities we share to shape healthy and productive adults.
Senator SARBANES. Thank you very much. I want to thank all of you for some very helpful testimony.

Let me ask first whether you perceive a significant loss of people entering the research field. Are we facing a problem of that sort?

Dr. TILDON. Very definitely. As I indicated in my prepared statement, the training, the ability to train has been the first place where cuts have been taking place at the National Institutes of Health. But even more so, an attitudinal posture has developed within the scientific community, and that is, what is the point of going through such an arduous training period if, indeed, there are not going to be funds available at the end?

The message is becoming very, very clear, that very good ideas don't get funded. I sit on study sections where I almost cry when we talk about the cutoff peer review. They have a numbering system and in that numbering system, the higher the score, the more inappropriate.

It used to be that grants getting 250 would be funded. Now grants getting 165 don't get funded. That means that we have to almost do a lottery to choose what grants will get funded and what will not.

Senator SARBANES. Dr. Davis, do you have any comments?

Dr. DAVIS. I would just add to that, that I think the situation will get more serious in the future, that today, we give some indirect funding to biomedical research by the way we pay hospitals under the Medicare DOG prospective payment system. And we've built in an additional allowance for what's called indirect teaching costs. But that's being squeezed in and the administration has, in fact, recommended that it be halved.

So as that source of funding which is not only for patient care, but also goes to support biomedical research, gets squeezed, we could find our teaching hospitals in this nation in dire straits. And I think that that would also have an effect on interesting people about coming into the field.

Senator SARBANES. Dr. Kolb.

Dr. KOLB. I concur with that 100 percent. I think the issue of being able to fund not only exciting research by new people, but I think being able to allow the ability of a bright mind to have the opportunity to think and be creative in an environment that allows us research and exciting results from that research is something that is in great jeopardy.

I think you have a gentleman sitting next to you today that I think if he had been subjected to some of the things that have gone on in today's world of research, maybe we would not have the exciting events that have come from his work.

I think there are a lot of bright minds, as I sit on the council and see us fund a few years ago at 35, 40 percent, and now down in the teens that we fund, that there's a lot of exciting research out there that could do a lot to correct many of the ills of our society and many of the ills in the world today that are not being funded.

So it is a major concern.

Senator SARBANES. Do you think the current system under which the research is done is a pretty good system, or do you think changes ought to be made in the system?
I'm not addressing the money being put into the system, but the system itself.

What's your view on that question?

Dr. TILDON. I think, if I could answer that, the marriage between the Government and the universities via the National Institutes of Health has probably been one of the brightest ideas of our time in this country.

That took a lot of work to even get that done, to get that into place. Dr. Sabin indicated that for his work, that didn't exist. But it was efforts like his, I think, that helped to foster that.

So I'm saying, yes. First of all, it has a very good peer review system. There are many different aspects of checks and balances on the kinds of questions that are being asked, and scientists have all applauded it. Obviously, it's a rigorous one. But I think as it's in place and the level of autonomy that it has I think is very good.

Now, there is a balance to that because the kinds of things that people identify in the social arena as specific disease conditions need to be looked at by the Congress. And I know the debate Congressman Waxman and others have around this issue has been an important one.

But, by and large, I would not change the system because I do think it addresses the problems as they surface.

I mentioned AIDS, but I think that's a question of money, not a question of the nature of the system that had prevented the solving of the problem.

Senator SARBANES. Dr. Davis.

Dr. DAVIS. I think that the peer review system within the National Institutes of Health has helped safeguard the quality standards in the research. I think that's very good.

But I think what we've tended to do is to get a narrow focusing of research by splitting off different places in which different types of research are done. And what you find are important research areas that fall between the cracks. They're not the priority of any one institute and you don't get adequate funding for them.

The second problem that I see, thinking about it from just the research community, is that, increasingly, I see the need to wed the analytic skills of the clinical researchers, the physicians and the medical schools, with the analytic skills of economists, social scientists, that you'll find, for example, in public health schools. And it's very difficult to get the teams of researchers together. So if you have an economist who knows a lot about Medicaid and the way it's financed and the access issues, and if you have a clinician who knows what the implications of reduced access to care for health outcomes, if you put those teams together, you get very effective research.

And that's one of the things that falls between the cracks, that the biomedical research tends to get funded out of NIH and the more economic social science research out of the National Center for Health Services Research. And I think we're not doing what we could do to facilitate the types of team research, drawing on these different disciplines, that really would be helpful.

Senator SARBANES. Dr. Kolb.

Dr. KOLB. Living with the system in the last few years, I hope I'm coming to understand it. I think it's effective. It's very peer
review related. I think it’s an excellent system. I hate to see, I guess, the organization tampered with.

The problem exists, of course, and the fact that there are areas which may not be addressed, some of the Institutes, of course, are disease oriented. Some, like NICHD, are children’s health oriented. And if there are issues that are falling through the cracks, as Dr. Davis said, I would feel that those are coming there mainly because we have not allowed enough funding to exist for these organizations to address the issues that have come before them.

The research is there. The areas to be looked at are there.

Senator SARBANES. What are your views on research done by the private sector, first of all by the business community? How much of that is there and what are the prospects there? And then the other question is, by the nonprofit private sector.

Or has the cost and the scope of it all—well, why don’t you answer the question. Then I may follow up.

Dr. DAVIS. I think in terms of the business community, that they do do a fair amount of their own research but it’s primarily on a medical equipment, for example, type of research, as opposed to broad-based biomedical research.

So don’t think you would see those companies funding research so much on cancer or on AIDS or other kinds of conditions that would get the biomedical breakthroughs. They might be looking at a new drug that could be developed within the pharmaceutical industry that they could sell, or they might be looking at a new piece of equipment that they could sell.

So I think it’s a very different type of research, not on the basic research on the causes of disease and cures.

In terms of the nonprofit private sector, there are some major private foundations that do put money into research. But, again, they view their resources as so minute—even the largest foundation, like the Robert Wood Johnson Foundation, spends maybe $60 million a year. They look at NIH spending $6 or $7 billion a year and think that they can only tamper with certain things at the margin. So they might look at effective ways of delivering services to frail elderly in their homes. Or they might look at supports and demonstrations, get some innovative approaches to, say, prepaid managed care in the Medicaid program.

But they’re very small scale relative to the size of NIH. So I think they don’t begin to substitute or to compensate when the Federal Government cuts back that support.

Dr. KOLB. Two comments, if I may, Mr. Chairman, on that.

I think the basic research has to stay within some form of our governmental structure or it’s never going to get done.

The other thing, as you mentioned, about private industry, and just speaking with the Robert Wood Johnson people just last week, they say they are being continually bombarded now from requests of researchers doing basic research who have lost funding for some of their research assistants, lost funding for some of their projects,
resulting as you heard from the 12-percent cut, just to try and continue the projects that are existing.

And they say, that's not our focus. We have other areas that we need to look at. Surely, we will look at a certain specific area. But they say their requests have doubled and tripled in just the last year or two from basic research people saying, I can't complete my project on this essential research because my funding has been reduced significantly.

So I think it's multifocal.

By the same token, I think once basic research is completed, we're now seeing NIH, NICHD, anyway, beginning to work with industry to facilitate the production in the clinical areas of effective vaccines and genetic engineering.

So I think that marriage can exist once the basic research is done.

Dr. TILDON I just want to say that I think of national health in the same scope as I think of national defense. I made that comment.

The nature of the programs that you want to get at are so large and comprehensive in scope, private industry always focuses on a specific and it can always provide very good complementary activity. If a vaccine is developed and there is a profit to be made, it can go to those next steps.

But, by and large, those ideas, those concepts that come out of basic research activity, are going to have to be government supported, because it is the Government's broader interest, as opposed to the parochial and immediate interest that one sees in the private sector.

That doesn't mean that they shouldn't complement. But even the foundations, again, the Hughes Foundation or the Robert Wood Johnson, they don't come anywhere near the kinds of funding that the National Institutes of Health and the Government can.

Senator SARBANES. What's your view—and this is probably my final question—your view of the research being done in other countries and our ability to draw upon it?

Dr. DAVIS. I think that's a very important point. The United States has looked, I think, too much internally and really hasn't looked at what we might learn by doing cross-national studies, for example, with other industrialized nations that are grappling with many of the same kinds of problems.

Even in the United Kingdom, they're finding tremendous health status differences by socioeconomic class that haven't been eliminated by a universal health insurance system, and they are very concerned about that.

In Scandinavia, Norway has undertaken a special effort to get their infant mortality rate down below Finland's, even though it's 6.5 in Norway and about 6.0 in Finland, where it's 11 in the United States.

So they are very concerned about that. Childhood injuries in Norway, for example, drownings are a major cause of death among young children, and also accidents, pedestrian accidents.

So I think that if we'd look at other countries and what they're doing to improve health, that we could adopt some of those strategies here.
The World Health Organization, European office, for example, is just launching an initiative called Healthy Cities. They will select 15 cities from throughout Europe and mount major prevention programs—Liverpool, dealing with problems of adolescence, for example.

And it seems to me that we stand a lot to gain by looking at that experience and doing more cross-national work. Again, this is the sort of thing that's not touched at all by the private foundations and rarely by the Federal Government, that tends to look more inward at the problems in the United States.

Dr. TILDON. Many of us, I guess, have spent opportunities abroad. I actually took a sabbatical in the Netherlands to learn some of the things that they were doing and brought back especially our work with sudden infant death syndrome.

The Netherlands, in terms of its commitment, is far ahead of us in terms of gross national product that it commits to science. And again, as I mentioned earlier, China, which is a developing country, has a major commitment now to the scientists, taking and making sure that they target the child health. But at the same time making sure that these scientists are protected, that they don't suffer the kinds of cutbacks that we're suffering from right here.

Dr. KO.'s. My comments would be only just briefly on the concern with NICHD and its use of national data and worldwide data.

I think presently there's a consensus panel going on with relationship to AIDS and to infant apnea and use of home monitoring. And I think there's a lot of experience throughout the world, especially, as you've heard, in Scandinavian countries, in England and Australia. And this is being drawn together through the mechanism, really, of, in essence, of our efforts here in this country through NICHD to support this, to try and bring together worldwide people to look at this issue of sudden infant death.

And so I think the capabilities exist there. Maybe it would be done more if funding were there to allow it, because if there's good research elsewhere in the world that can be done in other parts of the world, as this vaccine trial is going to be starting in Sweden very shortly with the new tetanus vaccine, I think this is done. And it's probably restricted only by the restrictions of funds.

Senator SARBANES. Well, thank you all very much. Do you want to add anything?

Dr. SABIN. May I just say a word about the question raised about research?

Senator SARBANES. Certainly.

Dr. SABIN. I've been involved with the National Institutes of Health for just about 40 years, officially, serving on study sections, councils, and various other activities.

About 20 years ago, I testified before a congressional committee, I think it was chaired by Senator Hubert Humphrey at the time, and the subject of it was how to accelerate progress in medical research.

There's a good deal of confusion about research, what is basic research that should be done here, there. And I think Senator Humphrey, later the Vice President, made a very good distinction which I found very helpful and clear thinking.
He categorized, particularly with regard to the responsibilities of the National Institutes of Health, he divided things not into so-called basic or applied research, which means nothing, really, but in categorical basic research and noncategorical basic research.

Noncategorical basic research looks for knowledge that applies and is needed for all sorts of activities in, first of all, understanding health and the various disciplines which gives us the tools with which to answer questions. And they're not related specifically to multiple sclerosis or cancer or heart disease; they're general problems like in neurobiology or biochemistry and so on.

Obviously, they need support. And perhaps the National Institutes of Health is not the only place to do it. The National Science Foundation, and so on. And the question is always how much? How much of each? And what is categorical basic research?

Categorical basic research looks for knowledge that is specifically needed, let us say, for some problem in child as anything else may be. Or if there's something that you need to get to arthritis or to multiple sclerosis and so on.

Now, originally, the National Institutes of Health were set up as categorical institutes, realizing a need of concentrating the search for new knowledge in very specific areas. That's why you have an Institute for Child Health and Human Development, Infectious Disease, Cancer, and so on.

And one of the problems is how good the NIH has functioned. The support for research, just in the 40 years that I've been associated, has skyrocketed tremendously. To make any sort of suggestion that medical research is not being supported in this country is, I think, not fair.

But there's always another question—is it enough? And also, the question that you have raised—is there something that could be done to improve what the National Institutes of Health are doing? And there's the attitude that's been expressed here, no, don't touch it. I mean, if you touch one single hair, you're going to kill it off.

Nothing is so perfect that it cannot be improved. And what I personally think, as I expressed it 20 years ago and published in “Science,” is that the concentration on categorical basic research for which almost all of the institutes have been set up, is not being pursued in the optimum way.

The idea of saying, come, give me an idea, give me an idea, always asking somebody else, it's not enough. It's important to get ideas from others, but in categorical basic research, you have to stick to a problem. You have to have cooperative efforts. You have to have group thinking, which is not existent. It doesn't happen in the councils and the study sections.

And so, for example, research on multiple sclerosis has gone on for years. But it has been asking, in my judgment, and the judgment of others, the wrong questions.

Now it can be improved. Nothing is so good that it cannot be improved.

Now let's get down to some practical things.

We have a member of the advisory council of the National Institute for Child Health and Human Development who testified about some of the needs that are not being covered. And I happen to know that what the National Institute for Child Health and
Human Development is asking for and would like to have is not double its present budget of fiscal 1985, which, incidentally, is $312 million, but just another $68 million.

And I think that to do many of the things that Dr. Kolb has testified about, it is needed. I also deplore the idea that some cutback is devastating. Nothing is devastating. I mean, no budget is so absolute that if you cut 10 percent of it it's devastating.

I think that people in research have responsibilities for adjusting budgets. I've looked at budgets for 40 years and I'll tell you, the idea that it just cannot be cut by 10 percent or so, that it would make it devastating, I would not agree with.

So what is one to conclude from the remarks that I just made?

Senator SARBANES. Let me just interrupt you there.

Dr. SABIN. Yes.

Senator SARBANES. Suppose you cut it 10 percent year to year to year. Is that devastating?

Dr. SABIN. That's not exactly what's happened.

Senator SARBANES. No, but if that were to happen.

Dr. SABIN. You have so many more people asking questions and it's not happening that way, 10 percent. Actually, it's been growing because you have to look not only at the budget of the individual investigator—$500,000 for one grant. I spent 20 years working on polio and I spent only $1 million.

Of course, monkeys cost $7 apiece then and things like that. I'm not trying to say that. But the assumption—

Dr. TILDON. $540 now.

Dr. SABIN. You know, you add up, as you called it, a billion here, a billion there, and pretty soon, you're talking about real money. And if you take all the thousands of investigators, $500,000 here and $500,000 there, and pretty soon you have some real money. And actually, there is a great deal of money being put in.

But I think that it has to be looked at not in generalizations that you can just use more money or that if we don't train more people—half of the people in training would bring in ideas that just weren't worth a damn because they didn't think by themselves. In their training, they were hands to somebody else.

The method of training—they did not use the period of training to bring out independent thinking. Many of them are just a couple of hands. And when they go out on their own and they get an assistant professorship and they apply for a grant, it's just awful.

Even some 20 years ago, when I was very active, 50 percent had to be just thrown out in the study sections because they didn't have the expertise.

So I wouldn't wring my hands too much. If Dr. Kolb and the others at the National Institute for Child Health and Human Development believe that the budget they submitted originally, and which was cut $68 million, that that $68 million is really essential, I would go along with the opinion of those who are competent to judge there.

But I wouldn't go at it in a way that is, I think, unfair. And I do think that greater attention to the categorical research responsibilities of the Institutes is needed. I mentioned multiple sclerosis research going on for 20 years and people wandering off to do the easy things, or in arthritis and many other fields.
So, first of all, I don't want to be misunderstood. I think, like the rest of the people here, that the National Institutes of Health is the best thing that has been developed. There's nothing as good anywhere else in any other country. They're also doing research. And of course research is interdependent.

If there weren't a National Institutes of Health, you'd have to create it. It was a Congressman, Fogarty, John Fogarty, who, working with Jim Shannon, one of the outstanding directors of the National Institutes of Health, who built it into an institution of which this country can be very proud. But that doesn't mean that it cannot be improved and shouldn't be improved.

And whether or not one spends the money that could be used on medical, biomedical research, involves a total national policy of allocations.

I remember once testifying before Fogarty, who was exhausted, and that's why he died so young—at 5 o'clock, he's heard 20 people. And I came to try to get the committee for a special $5 million allocation. In those days, it was a lot of money. And he said to me, Dr. Sabin, if you were in my place, would you approve this special allocation of $5 million?

And I said, but I'm not in your place. If I were in your place, as a Congressman, I would know all of the other national needs and I'd have the terrible responsibility of setting priorities.

My job is to make the best possible case for this $5 million. And that's the same way. The medical research community must make the best possible case, and then you have the responsibility of matching it up with all the other things, all the other priorities.

Excuse me for reminiscing too much. [Laughter.]

Senator SARBANES. Well, I think with that dilemma handed to us [laughter] we'll bring this hearing to a conclusion. Thank you all very much. It was very helpful testimony.

Dr. Sabin, thank you very much.

Dr. Sabin. Thank you.

[Whereupon, at 1:05 p.m., the subcommittee adjourned, subject to the call of the Chair.]
This report provides a summary of the Public Health Service Act Infant Mortality Amendments of 1987 (S. 1441), background information and rationale for the legislation, the text of the bill as reported, views of the Senate Committee on Labor and Human Resources, a statement of approval by the Committee, the Congressional Budget Office cost estimate, a regulatory impact statement, a section-by-section analysis, and specifications of changes the proposed legislation will effect in existing legislation. S. 1441 expands the fiscal year 1988 authorization for Migrant Health Centers by $3 million, the Community Health Centers program by $35 million, the Area Health Education Centers program by $3 million, and establishes a new program to provide grants to public and private nonprofit schools of nursing to operate fellowship programs for the training of nurse midwives and pediatric, family, obstetric, and gynecologic nurse practitioners. The bill requires that priority be given to programs which will train personnel for areas along the U.S.-Mexico border, frontier areas, the Pacific Basin region, and for areas with disproportionately high infant mortality and low birthweight infant rates. (RH)
PUBLIC HEALTH SERVICE ACT INFANT MORTALITY AMENDMENTS OF 1987

August 3 (legislative day, June 23), 1987.—Ordered to be printed

Mr. KENNEDY, from the Committee on Labor and Human Resources, submitted the following

REPORT

[To accompany S. 1441]

The Committee on Labor and Human Resources, to which was referred the bill (S. 1441) to reduce the incidence of infant mortality, having considered the same, reports favorably thereon with an amendment and recommends that the bill as amended do pass.

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I. SUMMARY OF THE BILL

MIGRANT HEALTH CENTERS

The bill expands the fiscal year 1988 authorization for Migrant Health Centers by $3 million. This additional authorization is intended to increase the resources under this program to enable it to combat high rates of infant mortality through expanded and enriched maternal health and child health services.
COMMUNITY HEALTH CENTERS

S. 1441 expands the fiscal year 1988 authorizations for the Community Health Centers program by $35 million. This additional authorization is intended to increase the resources under this program to enable it to combat high rates of infant mortality through expanded and enriched maternal health and child health services. The bill also requires the Secretary to give consideration to the needs of rural areas designated as frontier areas. The bill requires that fiscal year 1988 appropriations which exceed $418 million for the Community Health Centers program shall be utilized for grants to support special prenatal services and special perinatal coordinated projects.

AREA HEALTH EDUCATION CENTERS

The bill increases the fiscal year 1988 authorization for the Area Health Education Centers program by $3 million and requires that, of fiscal year 1988 appropriations, $3 million shall be utilized for contracts to support programs that will train personnel to offer maternal and child health services in underserved areas. The bill requires the Secretary to give priority to programs which will train personnel for areas along the U.S.-Mexico border, frontier areas, the Pacific Basin region, and for areas with disproportionately high infant mortality and low birthweight infant rates.

NURSE PRACTITIONERS AND NURSE MIDWIVES

The bill establishes a new program, authorized at $4 million for fiscal year 1988, to provide grants to public and private nonprofit schools of nursing to operate fellowship programs for the training of nurse midwives and pediatric, family, obstetric and gynecologic nurse practitioners. Such programs must give priority to applicants who are employed by Community or Migrant Health Centers, or by Indian Health Service Facilities or Native Hawaiian health centers.

II. BACKGROUND AND NEED FOR LEGISLATION

The United States ranks 17th in the world in infant mortality rate, behind Singapore and Hong Kong. Nearly 40,000 of the 3.7 million children who were born in the United States in 1984 died before their first birthday, a rate of 10.8 infant deaths per 1,000 live births. The disparity between black and white infant mortality is particularly alarming; black infants are nearly twice as likely as white infants to die in the first year of life. At our current rate of progress, the United States has little chance of meeting the Surgeon General's goal of reducing the infant mortality rate to 9 per 1,000 live births by 1990.

Two-thirds of all infant mortality can be attributed to those infants born at low birthweight. In 1987, a quarter of a million low birthweight babies will be born. These infants are 40 times more likely than normal birthweight babies to die in the first month of life, and 20 times more likely in the first year. They are also far more likely to have birth defects and mental and physical handi-
caps, which often mean lifelong challenges, hardships, and expenses for themselves, their families and society.

Low birthweight is largely preventable—and at relatively low cost. Early prenatal care can reduce the number of infants born at low birthweight by two-thirds. The Institute of Medicine has estimated that for every dollar spent for prenatal care, $3.38 would be saved in the total cost of caring for low birthweight infants.

Although lowering risk factors through access to prenatal care is the most effective way to prevent low birthweight, millions of women receive little or no prenatal care. National health statistics compiled by the federal government indicate that, in 1983, nearly one quarter of all pregnant women in the United States did not begin prenatal care in the first trimester of pregnancy. Among teenagers and black women, nearly one-half do not receive prenatal care in the first trimester and poor women were twice as likely to receive no or late prenatal care.

The report of the Institute of Medicine (IOM), Preventing Low Birthweight, provides guidelines for the type of medical and health services which could improve the quality of prenatal care. The IOM recommends that several specific components of prenatal care be offered to all women. Among these are: (1) patient counseling on potential problems and interventions; (2) formal risk assessment, including psycho-social and medical assessments; (3) ultrasound imaging for diagnostic purposes; (4) management of behavioral risks such as nutrition counseling and therapy, smoking cessation and substance abuse treatments; (5) prenatal and parenting education; and (6) special medical and health services to deal with specific risks, conditions and problems. For infants, based on the American Academy of Pediatrics' guidelines, routine care consists of a minimum of six visits in the first year of life. These visits should include a physician examination, measurement, developmental testing, and immunizations. There will also be a need for care for common illnesses during this time of life. In addition, high risk infants may need more frequent examinations, home visits, vitamin supplementation, prescription drugs, specialized medical or developmental testing, or rehabilitative services. Parents may also require intensive parenting education.

Significant contributions have been made to increase the access to quality health care for low-income and uninsured families by Community and Migrant Health Centers. Begun in 1965 as eight research and demonstration projects, the program has expanded over the past twenty years into 800 primary health care centers providing comprehensive primary care to nearly six million poor and underserved Americans in 50 states, Puerto Rico, and the District of Columbia.

Of those served by Community and Migrant Health Centers, it is estimated that 60 percent are poor, 48 percent lack any form of health insurance, over one-third are children under the age of 14, and over one-third are women of child bearing age.

However, it has been estimated by the Health Resources and Services Administration that the Community and Migrant Health Centers reach less than one fourth of America's 25 million medically underserved residents.
The Community Health Centers (CHC) and Migrant Health (MH) programs were reauthorized in 1986 for fiscal years 1987 and 1988. However, at that time the authorization levels were “frozen” for fiscal years 1987 and 1988 at the same levels as the fiscal year 1986 Congressional appropriations for these programs—that is, at $400.0 million annually for the CHC program and $45.4 million for the MH program.

Section 5, relating to Area Health Education Centers (AHEC), is aimed at improving maternal and child health care in areas particularly hard-hit by maternal and child health problems. This section addresses the tremendous shortage of health care personnel in the area along the U.S.-Mexican border, and the problems of delivery of health care in sparsely populated, rural or “frontier” areas. AHEC programs will be expanded, targeting resources to these especially needy areas in addition to areas with disproportionately high infant mortality rates. The services actually rendered by the AHECs will serve to fill existing gaps in the delivery of maternal and child health care. More lasting benefits will derive by health care professionals who receive training at AHEC sites, and who remain in these needy areas to practice.

III. TEXT OF THE BILL AS REPORTED

A BILL To reduce the incidence of infant mortality.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the “Public Health Service Act Infant Mortality Amendments of 1987”.

FINDINGS

Sec. 2. The Congress finds that—

1. the United States has made far less progress than other industrialized nations in reducing the infant mortality rate;

2. the Surgeon General in 1980 established the 1990 Health Objectives for the Nation concerning the provision of prenatal care early in pregnancy and for reducing the incidence of low birthweight babies and infant mortality;

3. the incidence of low birthweight, which is one leading cause of infant mortality and handicapping conditions (such as retardation, cerebral palsy, epilepsy, and autism) has been reduced only marginally;

4. insufficient progress has been made in the reduction of the overall infant mortality rate;

5. despite a declining infant mortality rate, black infants remain twice as likely as white infants to die in the first year of life;

6. it now appears that the Nation will fail to meet the objectives of the Surgeon General described in paragraph (2);

7. it is well established that appropriate and timely prenatal care and primary care for infants can reduce infant mortality and improve infant health and are essential if the Nation is to meet objectives of the Surgeon General described in paragraph (2);
(8) it is well established that inadequate prenatal care and infant mortality and disability are highest for those individuals who are poor and are without health insurance;
(9) recent statistics indicate that 1 out of every 3 poor children and 1 out of every 3 women of child bearing age does not have health insurance;
(10) community and migrant health centers were established to provide primary health care to poor individuals and individuals without health insurance;
(11) of the individuals served by such centers, 60 percent are poor, 48 percent lack any form of health insurance, over one-third are children under the age of 14, and over one-fourth are women of child bearing age; and
(12) the services of community and migrant health centers should be expanded to provide increased prenatal care and infant care, including an expansion of the number of health professionals providing such services.

MIGRANT HEALTH CENTERS

Sec. 3. Section 329(h)(1) of the Public Health Service Act is amended by striking out "$45,400,000" the second place it appears and inserting in lieu thereof "$48,400,000".

COMMUNITY HEALTH CENTERS

Sec. 4. (a) Section 330(g)(1) of the Public Health Service Act is amended by striking out "$400,000,000" the second place it appears and inserting in lieu thereof "$435,000,000".
(b) Section 330(c) of such Act is amended by adding at the end thereof the following new paragraph:
"(4) In making grants under this subsection and subsection (d), the Secretary shall give special consideration to the unique needs of frontier areas."
(c) Section 330(g) of such Act is amended by adding at the end thereof the following new paragraph:
"(4) In any case in which the amounts appropriated under paragraph (1) for fiscal year 1988 exceed $418,000,000, the total amount of any such excess shall be available for grants under subsections (c) and (d) to community health centers to support special prenatal services to decrease infant mortality and special perinatal coordination projects to develop and coordinate referral arrangements between community health centers and other agencies, institutions, and organizations that are crucial to the successful management of pregnant women and infants. In making grants from amounts available under the preceding sentence, the Secretary shall give priority to community health centers in areas in which there is a high incidence of infant mortality or in which there is an increased incidence of infant mortality."

AREA HEALTH EDUCATION CENTERS

Sec. 5. (a) Section 781(a)(1) of the Public Health Service Act is amended—
(1) by inserting "(A)" before "The"; and
(2) by adding at the end thereof the following new subparagaph:

“(B) Under subparagraph (A), the Secretary shall enter into contracts to establish and support area health education center programs which include training of personnel to offer maternal health services and child health services in underserved areas. In entering into contracts under the preceding sentence, the Secretary shall give priority to programs which will train personnel to provide such services in areas along the border between the United States and Mexico, in frontier areas, and in areas in which the rate of infant mortality and low birthweight are disproportionately higher than such rates for the State in which such an area is located.”

(b) Section 781(c)(1) of such Act is amended by inserting before the semicolon a comma and “except that a program described in subsection (a)(1)(B) shall only be required to provide for the active participation in such program of individuals who are associated with the administration of the school and each of the departments (or specialties if the school has no departments) of pediatrics, obstetrics and gynecology, and family medicine”.

(c) Section 781(c)(2) of such Act is amended by inserting “except in the case of a program described in subsection (a)(1)(B),” before “provide”.

(d) Section 781(d)(2)(C) of such Act is amended—

(1) by inserting “(i) except as provided in clause (ii),” before “provide”;

(2) by inserting “or” after the semicolon; and

(3) by adding at the end thereof the following new clause:

“(ii) in the case of a program described in subsection (a)(1)(B), provide for or conduct a medical residency program in obstetrics and gynecology in which no fewer than six individuals are enrolled in first year positions in such program;”

(e) Section 781(d)(2)(F) of such Act is amended by striking out “and nurse practitioners” and inserting in lieu thereof “, nurse practitioners, and nurse midwives”.

(f) Section 781(g) of such Act is amended—

(1) by striking out “$18,000,000” the last place it appears and inserting in lieu thereof “$21,000,000”; and

(2) by adding at the end thereof the following new sentence:

“Of the amounts appropriated under this subsection for fiscal year 1988, $3,000,000 shall be available for contracts under subsection (a)(1)(B).”

FELLOWSHIPS FOR NURSE PRACTITIONERS AND NURSE MIDWIVES

SEC. 6. Part A of title VIII of the Public Health Service Act is amended by adding at the end thereof the following new section:

“FELLOWSHIPS FOR NURSE PRACTITIONERS AND NURSE MIDWIVES

Sec. 823. (a) The Secretary shall make grants to public or nonprofit private schools of nursing for the establishment and operation of fellowship programs for the education of nurse midwives and pediatric, family, obstetric, and gynecologic nurse practitioners. Such programs shall meet the guidelines prescribed by the Secretary under subsection (b).
“(b) After consultation with appropriate educational organizations and professional nursing and medical organizations, the Secretary shall prescribe guidelines for fellowship programs for the education of nurse midwives and pediatric, family, obstetric, and gynecologic nurse practitioners. Such guidelines shall, as a minimum, require that such a program—
“(1) extend for at least one academic year; and
“(2) consist of—
“(A) supervised clinical practice; and
“(B) at least four months (in the aggregate) of classroom instruction,
directed at preparing nurses to deliver pediatric, family, obstetrical, and gynecological services, particularly prenatal care and other services designed to reduce infant mortality.
“(c) A fellowship funded under this section shall include, for each year for which the fellowship is awarded, 100 percent of the costs of tuition, books, fees, reasonable living expenses (including stipends), reasonable moving expenses, and necessary transportation.
“(d)(1) In order to receive a fellowship funded under this section, an individual must be a registered nurse.
“(2) In awarding fellowships funded under this section, a school of nursing shall give priority to any applicant who—
“(A) is employed by a facility providing health services to medically underserved populations, such as a community health center, a migrant health center, a facility operated by the Indian Health Service, or a Native Hawaiian health center; and
“(B) has been recommended for the fellowship by the facility described in subparagraph (A).
“(e) No grant may be made for the establishment and operation of a fellowship program under this section unless this application for the grant contains assurances satisfactory to the Secretary that the program meets or will meet the guidelines which are in effect under subsection (b).
“(f) For grants under this section, there are authorized to be appropriated $4,000,000 for fiscal year 1988.”

IV. COMMITTEE VIEWS

The Committee recognizes that it is well established that appropriate and timely prenatal care and primary care for infants can reduce infant mortality and improve the health of infants. The Committee is concerned about the continued high incidence of infant mortality in our country and is committed to aggressive actions to meet the Surgeon General’s 1990 objectives in the area of material and child health. Most notably, those objectives relating to prenatal care improvements, reductions in low birthrate, overall mortality reduction for minorities and postneonatal mortality reductions are of great concern. The Committee recognizes that action is necessary to reduce the thousands of unnecessary low birthweight births and hundreds of preventable infant deaths.

Community and Migrant Health Centers were established to provide primary health care in medically underserved areas and among low-income and minority populations, many of whom have
no health insurance. These centers represent ideal locations for targeting efforts to improve access to prenatal and infant health services for poor and uninsured women and infants.

The purpose of this legislation is to directly contribute to the reduction of perinatal mortality/morbidity rates, improve pregnancy outcomes and enable underserved areas to reach the Surgeon General's 1990 infant health goals by:

- Improving pregnant women’s and children’s access to needed health services;
- Enhancing the ability of C/MHCs to provide comprehensive perinatal ambulatory care services;
- Enriching the services of C/MHCs through addition of staff for outreach, health care, nutrition education, etc.
- Better coordination of services between C/MHC and other local public and private providers of medical, health and health-related services;
- Increasing the number of Nurse Practitioners and Certified Nurse Midwives at C/MHCs and underserved areas and at Indian Health Service and Native Hawaiian Center sites; and
- Expanding educational programs for medical and health personnel in order to improve their ability to deliver maternal health and child health services.

A. COMMUNITY AND MIGRANT HEALTH CENTERS

The Committee intends that all funds appropriated under this authorization shall be used for efforts which, directly or indirectly, will contribute to reduce maternal, infant and child mortality and morbidity.

1. Grants To Develop New Centers, Expand Existing Sites, and Enhance the Provision of Primary and Supplemental Services

Under the provisions of the bill, the first $18 million in appropriations for CHCs that exceed $400 million, and the appropriations for Migrant Health that exceed $45.4 million, should be for general expansion of the programs through a combination of:

- Development of new service delivery systems in identified communities where no C/MHC services now exist;
- Expansion of service delivery capacity in existing C/MHCs, to provide delivery of services through expanded or additional sites in identified communities where current services are insufficient to meet needs;
- Enhancement of current primary and supplemental services at existing C/MHCs to improve quality and scope of care provided to pregnant women and children; or
- Better coordination with other statewide services in order to enhance perinatal delivery systems.

The Committee believes that using these funds to establish new centers or expand existing centers (through the addition of new service sites or new personnel, or both) will improve the availability of comprehensive, high quality maternal and infant care. In many high risk areas of the country, pregnant women are unable to find accessible and affordable prenatal care. Following birth, basic care for an infant’s health needs may be even more difficult
to locate. The Committee has special concern about areas of the country and States where infant mortality remains unusually high and there are no community services available. Southern States, border States along the U.S.-Mexican border, and frontier areas are identified by the Committee as areas meriting special attention for establishment of new facilities to improve access to care.

These funds should also be made available to meet the costs of hiring additional medical, nursing, ancillary service, or case management personnel, or the costs associated with deploying staff at additional service sites, in order to better serve high risk pregnant women, infants, and children.

While the bill requires that priority for grants supported with certain funds (those amounts appropriated for CHCs in excess of $418 million) must be given to areas with high or increasing incidence of infant mortality, it is also the Committee's intent that development of new service delivery sites, whether through new starts (new grantees) or expansions (existing grantees) should be limited to identified areas which are medically underserved areas and have a high or increasing rate of maternal, infant, or child health mortality or morbidity, including low birthweight, whether for the general population or for population subgroups (racial or ethnic minorities, those with below-poverty incomes, or the like).

For purposes of this act, a high incidence of infant mortality is considered to be a rate which is greater than the infant mortality rates for the Nation, either as a whole or by race. In 1984, these rates were 10.8 infant deaths per 1,000 live births for all races, 9.4 per 1,000 for whites, and 18.4 per 1,000 for blacks. The Secretary, in making grants to projects serving other populations, such as Native Americans or Hispanics, should apply appropriate mortality rates as developed by the National Center for Health Statistics for infants from each special racial and ethnic minority. The Secretary should also give special consideration to areas in which the neonatal (birth to 28 days) or postneonatal (29 days to one year) infant mortality rates are higher than average, even though the overall infant mortality rate may be at or below the national average and to areas with high concentrations of minority populations other than blacks. The Secretary should also give special consideration to areas which may be below overall the national average, but which have seen a dramatic increase in the incidence of infant mortality in recent periods.

Some communities may have a high concentration of Hispanic, Native American, Alaskan Native or Asian mothers and infants who may have increased health risks demonstrated through specialized studies. In these cases, the Secretary should consider racially and culturally appropriate statistics and special studies in prioritizing grant allocations. The Secretary is also directed to compare infant mortality rates presented in any grant proposal to appropriate racial and ethnic group rates.

While the Committee expects these new funds to assist high risk pregnant women, infants, and children, the Committee does not intend exclusive services must be provided to these populations by new programs established through this funding. The Committee agrees that through general enrollment, new C/MHC sites will be
providing care to a significant number of pregnant women and children.

Further, it is the Committee's intent that the Secretary make grants designed to enhance the scope and depth of primary and supplemental services offered by centers pursuant to Sections 329 and 330 of the Act. This is especially important in the case of high risk pregnant women and infants because the development of new technology and risk assessment techniques has dramatically outstripped centers' service capacity and grant levels. The Committee also intends that centers have the latitude to use these enhancement funds toward meeting their maternity and infant patients' hospitalization needs when, in the opinion of the centers, hospitalization is essential to patient management and other resources are unavailable.

2. Grants To Provide Outreach and Patient Management and Assistance Services and To Engage in Perinatal Coordination

The Committee supports outreach, and patient management and assistance services in a broad effort to reduce infant mortality. Enhanced medical care through new sites and additional personnel are fundamental to reduce infant mortality. In the case of low-income and racially, geographically, ethnically, and culturally isolated families, moreover, it involves aggressive efforts to coordinate a smoothly functioning perinatal and infant care system in which the range of agencies, institutions and providers serving the population can work smoothly together with common goals.

Therefore, the Committee intends that amounts appropriated over $418 million be used to fund outreach and patient management services as well as special perinatal/infant coordination projects between health centers and other agencies, institutions, and organizations that are crucial to successful management of pregnant women and infants.

The Committee intends that funds in excess of $418 million be used for outreach, patient management services and care. These services are defined as activities designed to get women and children into care as early as possible, keep them in care, and make the care system responsive to their needs. Specific services (many of which are already recognized as primary and supplemental services) include:

- Casefinding, including the use of lay and professional outreach workers;
- Translation assistance as well as other activities that reduce barriers to care such as transportation and child care;
- Patient and provider education regarding what medical and health services, assistance and resources are available in a community and how to gain access to them;
- Parenting and perinatal patient education classes; and
- Coordination of services with other perinatal care providers.

The Committee recognizes that these services can best be provided through employment of additional staff, especially lay outreach workers, and through the development of a "team approach", involving such outreach workers and the centers' clinical staff. It is the provision of these types of services which has made the C/MCH
programs unique and particularly successful in effectively caring for high risk, medical underserved populations.

In addition, the Committee supports funding of up to $3 million of the additional funds for centers to improve the quality and responsiveness of regionally ed perinatal care services for their patients. Centers might accomplish these objectives through a variety of activities. These might include: developing or upgrading transportation systems which would be suitable for high risk mothers and infants; training staff to provide better risk assessment, more appropriate referral, or better follow-up care; developing improved communication systems between centers and more specialized medical centers; providing prenatal outreach to better ensure timely entry into appropriate care; and developing a system for accelerated eligibility into public programs such as the Supplemental Food Program for Women, Infants and Children (WIC), Medicaid, and other indigent health care financing programs. These grants would be used to develop coordination and referral arrangements between health centers and other agencies, institutions and organizations within their communities that are crucial to the successful management of pregnant women and infants.

Additionally, centers might use funding to develop coordinated delivery and hospital admission programs so that pregnant patients who need high risk delivery services can be moved quickly and smoothly into specialized delivery settings.

The Committee believes that while the basic grant program will permit health centers located in high mortality areas to upgrade, improve and strengthen their own services, there will be women and children whose needs simply exceed the level of care that centers are equipped to furnish. This special supplemental grant program will permit centers to establish programs, standards and referral systems with other segments of the community, for ensuring prompt high quality care when such specialized interventions are warranted.

Because of the continuing problems of perinatal mortality and morbidity, it is the Committee's intent that additional funding for these activities be made available as soon as possible. Therefore, the Committee urges the establishment of a streamlined application and approval process with minimal reporting requirements. In this way, grant funding can be expedited and services made available in a timely basis.

Furthermore, the Committee does not intend that these funds be subject to formal demonstration evaluation procedures. However, in order to evaluate the success of these programs in reducing the incidence of infant mortality, the Committee intends, at a minimum, that the following data be collected: (1) the number of women and infants served; (2) in the case of pregnant women, the trimester of initiation of prenatal care; and (3) the conditions disclosed among pregnant women and infants served. These statistics should be reported to the Secretary annually, in conjunction with other reports already required of CHC and MH grantees. The Secretary shall, in turn, compile the data from various projects and issue a public report.
The Committee is hopeful that these activities will continue and expand through future considerations of the Community and Migrant Health Center legislation.

3. Frontier Areas

During the past year, as the public policy debate of the problems of financing and delivering health care services in rural areas has unfolded, the Committee has become aware of the special problems inherent in attempting to develop and operate health care delivery systems in the most sparsely populated rural areas of America. Borrowing from a DHHS-funded Task Force, the Committee has used the term “frontier” to describe these areas, which are defined as those with a population density of no more than six persons per square mile, spread over a broad geographical area (generally an entire county or multiple counties, although a sub-county area or adjoining parts of two or more counties would also fit this definition).

According to the 1980 U.S. Census, there were at least 382 counties, with a population of nearly 2.9 million persons, which would meet the above definition. These areas are principally found in 20 Western states, and encompass 45 percent of the U.S. land area.

In addition to having sparse population, these areas tend to be geographically isolated, have a fragile economic base and offer limited health services. The geographic isolation and population sparsity of such areas mitigate against traditional approaches to development and efficient operation of ambulatory health care delivery systems. The small size of such systems results in inherent cost inefficiencies, decreased productivity of clinical providers, difficulty in arranging referrals, and difficulties in recruiting and retaining high quality clinical and management personnel.

Despite the fact that most of the residents of the areas are obviously medically underserved, very few CHCs (or even free-standing National Health Service Corps sites) are currently receiving federal support in such areas. In fiscal year 1986, only 17 of the 648 CHC grantees were located in frontier areas as were 38 of 3,127 NHSC assignees. Moreover, the federal expectations and requirements of these sites were the same as those for much larger rural, and even urban, CHC sites. Although the statute permits considerable latitude in designing appropriate CHC systems, the federal program managers appear to have allowed little or no flexibility in permitting grantees to tailor their delivery systems to local needs or to the unique characteristics of these areas.

To remedy this situation, the Committee intends the Secretary to:

- Facilitate and support development of grant applications from frontier areas through use of federal technical assistance resources and appropriate state governmental entities and state associations of CHCs, supported under Section 330(0)(1).
- Ensure that applications for grant support (whether for planning and development or for operations) are accorded fair and equitable treatment by federal reviewing authorities.
- Develop criteria, standards, expectations and requirements for frontier sites which are relevant to their unique operational nature and are different from those for larger operations.
Within statutory limitations, explicitly allow and encourage creative approaches to systems development and operations. Support and facilitate continued research, data development and efforts to promote a better understanding of the needs of frontier areas, including the work of the Frontier Health Task Force.

The Committee wishes to clarify that it in no way intends to require the Secretary to ignore or waive current statutory requirements in this regard, nor does it expect the Secretary to support systems of care which are inadequate with respect to quality of care or completeness of care. For example, all frontier area CHCs must serve medically underserved populations and must meet the statute's requirements for governance, administration, fiscal and clinical systems and accountability, and the like. At the same time, such CHCs should be expected to make extensive use of mid-level providers, and to provide some services by referral arrangement rather than directly.

B. AREA HEALTH EDUCATION CENTERS (AHEC) PROGRAM

An adequate supply of well trained health care professionals is crucial to the delivery of medical care, including essential prenatal and postnatal care. The Committee recognizes both this fundamental principle and the shortage of health care professionals in underserved areas along the border with Mexico, and in sparsely populated frontier areas.

Section 5 addresses this shortage and seeks to alleviate it by providing for an expansion of the Area Health Education Center (AHEC) program, and by targeting additional resources to Florida and other Southern States, the Pacific Basin region, the area along the Mexican border and frontier areas. The Committee intends for the additional funding to be used to establish new AHECs and expand existing centers to increase and improve the delivery of prenatal and postnatal care in these targeted areas, and in areas with disproportionately high rates of infant mortality.

The AHEC program can play a crucial role in improving health care in these identified shortage areas in at least two important ways. First, the sensitivity of health care professionals to the needs of shortage areas should improve as physicians in training receive valuable experience in AHECs located in or serving shortage areas. Second, providing for training of health care professionals in shortage areas may increase the likelihood that these professionals will choose to practice there, and provide greater access to the needed medical care. The Committee expects those AHECs that receive funding under this section to work closely with C/MHCS, Indian Health Service facilities, and other providers serving the area, and with the statewide organizations representing the centers and other providers, in designing and implementing these new initiatives.

C. FELLOWSHIPS FOR NURSE PRACTITIONERS AND NURSE MIDWIVES

The bill establishes a new program to support the granting of fellowships for the education of nurse midwives and pediatric, family,
obstetric and gynecologic nurse practitioners, authorized at $4 million for fiscal year 1988.

There is a chronic shortage of health care professionals willing to provide high quality services to low income, high risk mothers and infants in rural, inner city, and other underserved areas. Often this shortage can be reduced by increasing the number of nurse practitioners (NP) and nurse midwives (NM) to serve in these areas. An Office of Technology Assessment report recently documented that within areas of competence, NPs and NMs provide care whose quality is equivalent to that of care provided by physicians. The report also credited NPs and NMs with improving the geographic distribution of care because many of them have been willing to locate in underserved rural and inner city areas. The Committee recognizes the critical importance of such practitioners to the success of the expanded perinatal care effort. At the same time, the Committee is concerned with the recent steep decline in the number of students in NP/NM training programs.

Under this new program, grants are to be made to schools of nursing for the establishment of fellowship programs, to assist individuals to meet the cost of educational and living expenses incurred while they are students in the NP or NM training programs. The Secretary is required to prescribe guidelines for such fellowship programs, in consultation with appropriate educational and professional organizations. The Committee does not expect such guidelines to be excessive or burdensome, or to require significant alterations to existing accredited NP and NM educational programs. It is expected that those NPs and NMs assigned to the Native Hawaiian health centers, funded jointly by HRSA and the Kamehameha Schools/Bishop Estate will themselves be Native Hawaiians whenever possible.

Priority for such fellowships is to be given to registered nurses who:

- Are employed by CHC and MHC grantees, or by Indian Health Service facilities or Native Hawaiian health centers;
- Have been recommended for the fellowships by their employers; and
- Agree to return to their employer following completion of NP or NM training and to remain there for a period of time at least equal to the length of their training or education program.

The clear intent of the Committee is to assist the health centers and other facilities to upgrade the capabilities of their staffs, in conjunction with the other activities authorized in the bill. Although the bill would not authorize the extension of salaries of applicants during their training period, the Committee understands that stipends may need to be provided by employers.

V. COMMITTEE ACTION

S. 1441 was introduced in the Senate on June 26, 1987, and referred to the Committee on Labor and Human Resources. The Committee met in executive session on July 1, 1987, and agreed unanimously to report S. 1441 to the Senate.
VI. CONGRESSIONAL BUDGET OFFICE COST ESTIMATE

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,

Hon. EDWARD M. KENNEDY,
Chairman, Committee on Labor and Human Resources,
U.S. Senate, Washington, DC

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the attached cost estimate for S. 1441, the Public Health Service Act Infant Mortality Amendments of 1987, as ordered reported by the Senate Committee on Labor and Human Resources on July 1, 1987.

If you wish further details on this estimate we will be pleased to provide them.

With best wishes,
Sincerely,

EDWARD M. GRAMLICH,
Acting Director.

CONGRESSIONAL BUDGET OFFICE COST ESTIMATE, JULY 29, 1987

1. Bill number: S. 1441.
3. Bill status: As ordered reported by the Senate Committee on Labor and Human Resources on July 1, 1987.
4. Bill purpose: To reduce the incidence of infant mortality.
5. Estimated cost to the Federal Government:

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<td>Estimated authorization levels:</td>
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<tr>
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The costs of this bill would fall within budget function 550.

Basis of estimate: This bill would increase the fiscal year 1988 authorization levels for the migrant health centers, community health centers, and area health education centers programs. The table below shows the current 1988 authorization levels for these programs compared to the levels proposed in S. 1441.
Authorization levels, 1988 current 1988 proposed Increase

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<th>1988 proposed</th>
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<tr>
<td>Area Health Education Centers</td>
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</table>

All authorization levels are specified in the bill. Outlays are estimated using spendout rates calculated by CBO on the basis of similar health service spending data.

6. Estimated cost to State and local government: Schools receiving federal support for area health education centers must provide 25 percent of their funds from nonfederal sources. If the additional $3 million is appropriated in fiscal year 1988, schools would have to provide an additional $1 million in nonfederal funds. This money could come from state or local governments.

7. Estimate comparison: None.
8. Previous CBO estimate: None.
10. Estimate approved by C.G. Nuckols, for James L. Blum, Assistant Director for Budget Analysis.

VII. REGULATORY IMPACT STATEMENT

The Committee has determined that there will be minimal or no increase in the burden of paperwork or additional regulation imposed by this bill.

VIII. SECTION-BY-SECTION ANALYSIS

Section 1 cites the title of this bill as the "Public Health Service Act Infant Mortality Amendments of 1987", and states the purpose of this legislation, to reduce the incidence of infant mortality.

Section 2 contains findings related to: the serious problems of infant mortality and morbidity on the United States; the failure of the U.S. to achieve significant reductions in the incidence of infant mortality and morbidity and the likelihood that the U.S. Surgeon General's 1990 Health Objectives for the Nation will not be achieved; the importance of expanding access to high quality medical and health care—especially for high risk pregnant women, infants and children—in order to successfully impact on infant mortality and morbidity; and the vital role Community and Migrant Health Centers can play in this effort.

Section 3 amends Section 329(h)(1) of the PHS Act to increase the fiscal year 1988 authorization for the Migrant Health programs by $3 million, from $45.4 million to $48.4 million.

Section 4(a) amends Section 330(g)(1) of the PHS Act to increase the fiscal year 1988 authorization for the Community Health Centers program by $35 million, from $400 million to $435 million.

Section 4(b) amends Section 330(c) of the PHS Act to require the Secretary to give special consideration to the unique needs of frontier areas in making grants under the CHC program.

Section 4(c) amends Section (g) of the PHS Act to require that, for fiscal year 1988, amounts appropriated for the CHC program
which exceed $418 million shall be used to support the cost of delivering special prenatal services designed to reduce infant mortality, and for grants to support special prenatal coordination projects to improve the coordination and delivery of all medical, health and related services for pregnant women and infants, with a priority for areas with high or increasing infant mortality rates.

Section 5 amends Section 781 of the PHS Act to establish a new effort within the Area Health Education Centers (AHEC) program, authorizing grants for the establishment and support of AHEC programs for the training of health personnel to offer maternal and child health services in underserved areas. The bill would increase the fiscal year 1988 authorization level for the AHEC program by $3 million, from $18 million to $21 million, and require that, of amounts appropriated for the AHEC program in FY 1988, $3 million shall be spent for this new effort.

The bill would require the Secretary, in making grants for this new effort, to give priority to programs that will train personnel to provide maternal and child health services along the U.S.-Mexico border, in designated frontier areas, and in areas with disproportionately higher infant mortality and low birthweight rates, when compared with other areas of the state(s) in which the program would operate.

The bill would also permit, under this new effort, the use of grant funds to support medical residency programs in obstetrics and gynecology with at least six first-year residents, and for the training of nurse midwives, as well as nurse practitioners.

Section 6 amends Part A of Title VIII of the PHS Act to add a new Section 823 establishing a new program of Fellowships for Nurse Midwives. Under this new program, grants could be made to public or nonprofit private schools of nursing for the establishment and operation of fellowship programs to train qualified individuals as nurse midwives or a pediatric, family, obstetric or gynecologic nurse practitioners. Such programs must extend for at least one academic year, and must include supervised clinical practice and at least four months of classroom instruction. The fellowship programs must give priority to applicants who are employed by facilities that provide health services to medically underserved populations, such as CHC's and MMHC's, Indian Health Service facilities or Native Hawaiian health centers, and who have been recommended by their employers for fellowships assistance. The bill authorizes the appropriations of $4 million for fiscal year 1988 for such fellowships.

IX. CHANGES IN EXISTING LAW

In compliance with rule XXVI paragraph 12 of the Standing Rules of the Senate, the following provides a print of the statute or the part or section thereof to be amended or replaced (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italic existing law in which no change is proposed in shown in roman):

PUBLIC HEALTH SERVICE ACT
TITLE III—GENERAL POWERS AND DUTIES OF PUBLIC HEALTH SERVICE

* * * * * * * * * *

PART D—PRIMARY HEALTH CARE

Subpart I—Primary Health Centers

MIGRANT HEALTH

SEC. 329. * * *

(h)(1) For the purposes of subsections (c), (d), and (e), there are authorized to be appropriated $43,000,000 for the fiscal year ending September 30, 1982, $47,500,000 for the fiscal year ending September 30, 1983, $51,000,000 for the fiscal year ending September 30, 1984, $45,400,000 for fiscal year 1987 and $48,400,000 for fiscal year 1988. The Secretary may not obligate for grants and contracts under subsection (c)(1) in any fiscal year an amount which exceeds 2 per centum of the funds appropriated under this paragraph for that fiscal year, the Secretary may not obligate for grants under subsection (d)(1)(C) in any fiscal year an amount which exceeds 5 per centum of such funds, and the Secretary may not obligate for contracts under subsection (e) in any fiscal year an amount which exceeds 10 per centum of such funds.

* * * * * * * * * *

COMMUNITY HEALTH CENTERS

SEC. 330. * * *

(c)(1) The Secretary may make grants to public and nonprofit private entities for projects to plan and develop community health centers which will serve medically underserved populations. A project for which a grant may be made under this subsection may include the cost of the acquisition and modernization of existing buildings (including the costs of amortizing the principal of, and paying the interest on, loans) and shall include—

(A) an assessment of the need that the population proposed to be served by the community health center for which the project is undertaken has for primary health services, supplemental health services, and environmental health services;

(B) the design of a community health center program for such population based on such assessment;

(C) efforts to secure, within the proposed catchment area of such center, financial and professional assistance and support for the project; and

(D) initiation and encouragement of continuing community involvement in the development and operation of the project.

(2) Not more than two grants may be made under this subsection for the same project.

(3) The amount of any grant made under this subsection for any project shall be determined by the Secretary.
(4) In making grants under this subsection and subsection (d), the Secretary shall give special consideration to the unique needs of frontier areas.

(g)(1) There are authorized to be appropriated for payments pursuant to grants under this section $400,000,000 for fiscal year 1987 and $435,000,000 for fiscal year 1988.

(2) The Secretary may not in any fiscal year—
   (A) expend for grants to serve medically underserved populations designated under subsection (b)(6) an amount which exceeds 5 percent of the funds appropriated under this section for that fiscal year; and
   (B) expend for grants under subsection (d)(1)(C) an amount which exceeds 5 percent of the funds appropriated under this section for that fiscal year.

(3) The Secretary may not expend in any fiscal year, for grants under this section to public centers (as defined in the second sentence of subsection (e)(3)) the governing boards of which (as described in subsection (e)(3)(G)(ii)) do not establish general policies for such centers, an amount which exceeds 5 percent of the funds appropriated under this section for that fiscal year.

(4) In any case in which the amounts appropriated under paragraph (1) for fiscal year 1988 exceed $418,000,000, the total amount of any such excess shall be available for grants under subsections (c) and (d) to community health centers to support special prenatal services to decrease infant mortality and special perinatal coordination projects to develop and coordinate referral arrangements between community health centers and other agencies, institutions, and organizations that are crucial to the successful management of pregnant women and infants. In making grants from amounts available under the preceding sentence, the Secretary shall give priority to community health centers in areas in which there is a high incidence of infant mortality or in which there is an increased incidence of infant mortality.

TITLE VII—HEALTH RESEARCH AND TEACHING FACILITIES AND TRAINING OF PROFESSIONAL HEALTH PERSONNEL

AREA HEALTH EDUCATION CENTERS

Sec. 781. (a)(1)(A) The Secretary shall enter into contracts with schools of medicine and osteopathy for the planning, development, and operation of area health education center programs.

(B) Under subparagraph (A), the Secretary shall enter into contracts to establish and support area health education center programs which include training of personnel to offer maternal health services and child health services in underserved areas. In entering into contracts under the preceding sentence, the Secretary shall give priority to programs which will train personnel to provide such services in areas along the border between the United States and Mexico, in frontier areas, and in areas in which the rate of infant
mortality and low birthweight are disproportionately higher than such rates for the State in which such an area is located.

(c) Each medical or osteopathic school participating in an area health education center program shall—

(1) provide for the active participation in such program by individuals who are associated with the administration of the school and each of the departments (or specialties if the school has no such departments) of internal medicine, pediatrics, obstetrics and gynecology, surgery, psychiatry, and family medicine, except that a program described in subsection (a)(1)(B) shall only be required to provide for the active participation in such program of individuals who are associated with the administration of the school and each of the departments (or specialties if the school has no departments) of pediatrics, obstetrics and gynecology, and family medicine;

(2) except in the case of a program described in subsection (a)(1)(B), provide that no less than 10 percent of all undergraduate medical or osteopathic clinical education of the school will be conducted in an area health education center and at locations under the sponsorship of such center;

(d)(1) Each area health education center shall specifically designate a geographic area in which it will serve, or shall specifically designate a medically underserved population it will serve (such area or population with respect to such center in this section referred to as “the area served by the center”), which area or population is in a location remote from the main site of the teaching facilities of the school which participate in the program with such center.

(2) Each area health education center shall—

(A) provide for or conduct training in health education services, including education in nutrition evaluation and counseling, in the area served by the center;

(B) assess the health manpower needs of the area served by the center and assist in the planning and development of training programs to meet such needs;

(C)(i) except as provided in clause (ii) provide for or conduct a rotating osteopathic internship or a medical residency training program in family medicine, general internal medicine, or general pediatrics in which no fewer than six individuals are enrolled in first-year positions in such program; or

(ii) in the case of a program described in subsection (a)(1)(B), provide for or conduct a medical residency program in obstetrics and gynecology in which no fewer than six individuals are enrolled in first-year positions in such program;

(F) conduct interdisciplinary training and practice involving physicians and other health personnel including, where practi-
cable, physician assistants [and nurse practitioners], nurse practitioners, and nurse midwives;

(g) There are authorized to be appropriated to carry out the provisions of this section $20,000,000 for the fiscal year ending September 30, 1978, $30,000,000 for the fiscal year ending September 30, 1979, $40,000,000 for the fiscal year ending September 30, 1980, $21,000,000 for the fiscal year ending September 30, 1982, $22,500,000 for the fiscal year ending September 30, 1983, $24,000,000 for the fiscal year ending September 30, 1984, $18,000,000 for the fiscal year ending September 30, 1986, $18,000,000 for the fiscal year ending September 30, 1987, and $21,000,000 for the fiscal year ending September 30, 1988. The Secretary shall obligate not more than 10 percent of the amount appropriated under this subsection for any fiscal year for contracts under subsection (a)(2).

Of the amounts appropriated under this subsection for fiscal year 1988, $3,000,000 shall be available for contracts under section (a)(1)(B).

TITLE VIII—NURSE EDUCATION

PART A—Special Projects

SECS. 820–822.* * *

FELLOWSHIPS FOR NURSE PRACTITIONERS AND NURSE MIDWIVES

SEC. 823. (a) The Secretary shall make grants to public or nonprofit private schools of nursing for the establishment and operation of fellowship programs for the education of nurse midwives and pediatric, family, obstetric, and gynecologic nurse practitioners. Such programs shall meet the guidelines prescribed by the Secretary under subsection (b).

(b) After consultation with appropriate educational organizations and professional nursing and medical organizations, the Secretary shall prescribe guidelines for fellowship programs for the education of nurse midwives and pediatric, family, obstetric, and gynecologic nurse practitioners. Such guidelines shall, as a minimum, require that such a program—

(1) extend for at least one academic year; and
(2) consist of—

(A) supervised clinical practice; and
(B) at least four months (in the aggregate) of classroom instruction,
directed at preparing nurses to deliver pediatric, family, obstetrical, and gynecological services, particularly prenatal care and other services designed to reduce infant mortality.

(c) A fellowship funded under this section shall include, for each year for which the fellowship is awarded, 100 percent of the costs of tuition, books, fees, reasonable living expenses (including stipends), reasonable moving expenses, and necessary transportation.
(d)(1) In order to receive a fellowship funded under this section, an individual must be a registered nurse.

(2) In awarding fellowships funded under this section, a school of nursing shall give priority to any applicant who—

(A) is employed by a facility providing health services to medically underserved populations, such as a community health center, a migrant health center, a facility operated by the Indian Health Service, or a Native Hawaiian health center; and

(B) has been recommended for the fellowship by the facility described in subparagraph (A).

(e) No grant may be made for the establishment and operation of a fellowship program under this section unless this application for the grant contains assurances satisfactory to the Secretary that the program meets or will meet the guidelines which are in effect under subsection (b).

(f) For grants under this section, there are authorized to be appropriated $4,000,000 for fiscal year 1988.