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MEDICARE, MEDICAID, AND MATERNAL AND CHILD HEALTH BLOCK GRANT BUDGET ISSUES

HEARING

BEFORE THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

FIRST SESSION

JULY 10, 1987

Printed for the use of the Committee on Finance

(Part 2 of 2)

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MEDICARE, MEDICAID, AND MATERNAL AND CHILD HEALTH BLOCK GRANT BUDGET ISSUES

FRIDAY, JULY 10, 1987

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

The committee met, pursuant to notice, at 10 a.m. in room SD-215, Dirksen Senate Office Building, the Honorable Bill Bradley (chairman) presiding.

Present: Senators Bradley, Moynihan, Chafee, and Durenberger.

[The press release announcing the hearing and the prepared written statements of Senators Bradley and Chafee follow:]

[Press release H-55, June 26, 1987]

U.S. SENATE COMMITTEE ON FINANCE

FINANCE COMMITTEE TO HOLD HEARINGS ON MEDICARE, MEDICAID, AND MATERNAL AND CHILD HEALTH BLOCK GRANT BUDGET ISSUES

WASHINGTON, DC.—Senator Lloyd Bentsen (D., Texas), Chairman, announced Friday that the Committee on Finance will hold a series of three hearings to examine budget issues affecting the Medicare, Medicaid, and Maternal and Child Health Block Grant programs. The hearings are in preparation for Committee markups of proposals necessary to comply with the reconciliation instructions contained in the First Concurrent Resolution on the Budget.

The first hearing will focus on Part A of the Medicare program, the second will focus on Part B of Medicare, and the third will focus on Medicaid and the Maternal and Child Health Block Grant programs.

Bentsen said that the Finance Committee will examine changes in the Medicare program necessary to reduce spending in accordance with the budget resolution, and will also examine expansions of coverage under Medicaid and the Maternal and Child Health Block Grant. Possible initiatives include expanded coverage of pregnant women and children, reducing spousal impoverishment of nursing home residents, and improving quality assurance of long-term care.

The hearing schedule is as follows: July 8, 1987—Medicare Part A; July 9, 1987—Medicare Part B; July 10, 1987—Medicaid and Maternal and Child Health Block Grant.

All hearings will begin at 10:00 A.M. in Room SD-215 of the Dirksen Senate Office Building.

OPENING STATEMENT OF SENATOR BILL BRADLEY

This hearing will help us focus on a national shame—the problem of infant mortality. One of the ways we judge progress in a society is the health of its people—particularly through such indicators as infant mortality. Health care is one of our Nation's fastest growing industries, yet the United States has the highest infant mortality rate among industrialized nations.

In recent years we have seen a serious decline in the progress we were making in reducing the rate of infant mortality. And our infant mortality rate would be even higher if this country did not have such advanced medical technology for treating low-birthweight babies. We are fortunate to have this technology. But I would rather see these machines rust from disuse because we are providing adequate prenatal care to avoid the birth of underdeveloped babies. Neonatal intensive care units are extremely costly; just one day in a newborn intensive care unit averages between $1,000 to $1,200.

Over the past few months, I have visited several neonatal intensive care units in my home state of New Jersey, and I tell you, there are few sights more tragic and frightening than a tiny, fragile newborn, weighing no more than a few pounds, hooked up by wires and tubes to the imposing machinery which keeps the baby alive. While this is a scene that none of us likes to think about, it is a scene that happens far too frequently in this country. A black infant born within 10 miles of this hearing room, in our Nation's capital, is more likely to die in the first year of life than an infant born in Third World countries like Jamaica, Trinidad, and Tobago.

For the most part, these children are not dying of untreatable viruses such as AIDS or another fatal disease; they die for a very simple reason—they were born too small. These low-birthweight babies are 40 times more likely to die in the first month than babies who weigh more.

In New Jersey, 60 percent of all infant deaths were caused by low birthweight. And the primary reason that infants are born too small is that their mothers did not receive adequate prenatal care. One-third of the pregnant women in New Jersey in 1984 did not receive adequate prenatal care. Among pregnant teenagers in New Jersey, only half received any care at all in the first trimester.

The Institute of Medicine has determined that the most critical first step we can take to address infant mortality is to expand access to early prenatal care and services for infants in the first year of life. This approach is also extremely cost-effective. For every $1 spent on prenatal care, over $3 can be saved over the first year of an infant's life.

Last year, Congress enacted legislation giving states the option of providing Medicaid coverage to pregnant women up to the federal proverty level and their children up to age 5 (on a year-by-year phased-in basis). But that did not solve the problem. One-third of all uninsured pregnant women have family incomes between 100 percent and 200 percent of proverty. These meager incomes are too high to qualify for Medicaid, yet are inadequate to buy either necessary health care or private health insurance.

That is why I introduced legislation, along with a bipartisan group of 9 Finance Committee colleagues, which gives states the option of providing Medicaid coverage to pregnant women and to their infants up to age 1 when family income is 185 percent of poverty or less.

This legislation, the Medicaid Infant Mortality Amendments of 1987, would address the issue of access to care for poor children, as well as pregnant women and infants. The health problems of poor children are particularly serious. They are significantly more likely to start life sick, and poor children are more likely to live in conditions that cause a range of problems, including elevated blood lead levels; greater and more serious hearing and vision problems; more severe cases of chronic illness; and higher rates of chronic mental illness. Early detection can avoid many of these problems. It costs approximately $350 a year for a child to have full preventive health care services, while one day in the hospital for an untreated illness costs at least $600.

That is why I propose expanding Medicaid coverage for pregnant mothers, for infants, and for young children. My bill would do three important things for young children: it would require those states which do not already do so to extend Medicaid coverage to children ages 6, 7, and 8 on a year-by-year basis for those children whose family incomes do not exceed AFDC standards; it would give states the option of accelerating the currently existing year-by-year phase-in of children up to age 5 whose family incomes are between AFDC standards and the federal poverty level; and it would give states the option of covering these children on a year-by-year basis up to age 8.

We frequently talk about the chain of problems facing our poor. This tries to break the cycle through early intervention. Low-birthweight infants experience a range of health problems. If these health problems go unresolved, they contribute to school difficulties and failure. Children who do poorly in school are more likely to become dropouts and join the ranks of the unemployed. And, in turn, these unemployed, undereducated, and welfare-dependent individuals are more likely to become teen parents and fail to secure prental care. Thus, the cycle continues unabated.

While it may seem hard-hearted to talk about this problem from a dollars and cents perspective, the fact is that the cost of low-birthweight infants and sick children for parents, for the government, and for society is tremendous. The average stay in a hospital for one underweight baby may cost from $30,000 to $150,000. Most of these families have little or no insurance. They can't even afford the $4,000 to 45,000 in maternity care required for a healthy baby, so we could hardly expect them to come up with $30,000 or more. By the end of this decade, at its current rate of progress, the Nation will have spent at least $2.1 billion to help how-birthweight babies survive their first year of life. Considering the long-term savings it engenders. The projected $65 million cost for my proposed legislation is a real bargain.

The real waste from inaction is not measured in dollars. It is in the pain, suffering, and loss of human life. The sacrifice of children to death and debilitating handicaps in the very first year of their life is the greatest waste of all. These children deserve a fighting chance to achieve their full potential, to become the best that they can be.

STATEMENT BY SENATOR JOHN H. CHAFEE

Mr. Chairman, today's hearing has been scheduled to discuss the Medicaid program and the Maternal and Child Health Care Block Grant.

When the Senate budget resolution was considered in May, I offered an amendment which would have provided an additional one billion dollars to the Medicaid program in fiscal year 1988. During the debate, the distinguished Chairman of the Senate Budget Committee made some assurances to the Senate that he would consider moving to more generous funding levels in this program during the budget Conference. I know that these assurances prevented many of my colleagues from voting for my amendment. The Conference Report, which has been approved by Congress, does provide an additional $600 million for the Medicaid program.

Although I am pleased with this aspect of the budget resolution and I think we will make important progress with these additional funds, I am disappointed in our unwillingness to go further. I am disappointed in our unwillingness to focus our energies and spend the time and resources needed to truly identify and address the health care crisis we are facing. The Finance Committee has jurisdiction over three of the most critical health care programs in this Country: Medicare, Medicaid and the subsidy we provide to businesses for providing health care benefits to their employees.

Last year expenditures under Medicare amounted to $74 billion; Medicaid cost $25 billion; and the tax subsidy program resulted in about $32 billion in lost revenues. Yet with all of this spending we still have children who receive no health care services; pregnant women who receive no prenatal care; disabled individuals who are forced to live away from their families and communities; families financially devastated and torn apart because of illness; 37 million people with no health insurance at all; and senior citizens who have to impoverish themselves in order to receive long term care. Our system is a disaster.

We are here today to ask these witnesses to help us decide the best way to use the additional $600 million in the budget resolution to fill in a few of the many gaps in our health care system. I have read the testimony and I know the witnesses here today will give us a stark outline of those who are falling through the holes in our system.

During the Committee's consideration of budget reconciliation in the coming weeks, I plan to offer at least two amendments to fill the gaps we will hear about today.

The first amendment would:

1. Mandate coverage of all children below the state poverty levels;
2. Increase the authorization for the Maternal and Child Health Block Grant Program to provide assistance to infants with catastrophic illnesses; and finally
3. Allow those individuals or families who exhaust their private insurance coverage, or who have been denied insurance coverage by the private sector because of a pre-existing condition, to purchase Medicaid insurance at a full premium rate.

The second amendment would reform the Medicaid program as it applies to individuals with disabilities. This amendment would make it possible for each individual—regardless of the severity of his or her disability—to have the opportunity to pursue education, recreation and vocation to the best of their ability. My amendment would reform the Medicaid program so that it will assist these individuals attain their fullest potential rather than hinder them. We have had three hearings in the Finance Committee on this type of reform over the past three years and we know enough now to move forward. It is time to act.

My amendments are just two of many that will be proposed in the coming weeks. If we are wise and careful I believe we can accomplish quite a bit with the limited resources we have been given to work with this year. However, the sheer breadth of the proposals we will be considering in the coming weeks should be enough to make it clear that the time has come for us to take a good, hard look at our present health care system. We must devote more of our time in this Committee to these critical issues. If we do not, the growth of the population over 65 and growth of those, especially children, without access to any sort of health care, will reach crisis proportions.

My greatest fear is that when budget reconcilitation is passed we will pat ourselves on the backs and say we have solved our Country's most troubling health care problems. At the end of this process we merely will have scratched the surface.

The purpose of my statement today is not to make light of the important progress we have made in recent years and will make this year. Rather, my comments are meant to share some of the frustration I feel when I look at our health care system, and to urge my colleagues in the Senate to join me in saying that our actions this year will not be sufficient. We cannot rest on these small achievements in good conscience. Instead we should retain the momentum of our efforts thus far and forge ahead on our quest to ensure that all of our citizens have adequate and appropriate health care. There is much more to be done.

Senator **Bradley**. The hearing will come to order. I am pleased to be here today to chair this reconciliation hearing on Medicaid and maternal child health issues. There are a few problems as serious as the lack of access to adequate health care.

One of the ways we judge progress in a society is the health of the people. In our Nation, where health is one of the fastest growing industries, it is appalling that the number of uninsured Americans has drastically increased by over 40 percent since 1980.

Estimates of the number of uninsured people in this country are as high as 37 million, 11 million of whom are children.

The serious problem that I would like to address today is the inadequate care for pregnant women and their infants. The United States ranks behind most other industrialized nations in the infant mortality rate. The rate would be even higher if we didn't have the most advanced technology in the world for treating premature newborns.

When I learned that a child born in Trenton, NJ, has less chance of survival in its first year than an infant born in a relatively poor country like Cuba, and that an infant born in New Brunswick, NJ, has less chance for surviving its first year than a child born in Singapore, I knew that there was much more that we had to do to prevent these tragedies from occurring.

The greatest tragedy of all is that many of these infant deaths are unnecessary. The main reason that infants die is because they are born too small—low birth weight. Sixty percent of all infant deaths in New Jersey were because of low birth weight. And the primary reason that infants are born too small is because their mothers did not receive adequate prenatal care.

One-third of the pregnant women in my State in 1984 did not receive adequate prenatal care. That is according to the standard set by the American College of Obstetricians and Gynecologists. Among pregnant teenagers in my State, only half received any care at all in the first trimester.

Most of these women had no health insurance and were unable to afford the cost of prenatal care services. During the last Congress, we fought and enacted legislation that would expand Medicaid coverage so that States had the option of covering pregnant women up to the Federal poverty level, and their children up to age 5 on a year-by-year, phased-in basis.

However, the work is far from done, because still one-third of all uninsured pregnant women have family incomes between 100 and 200 percent of poverty. These meager incomes are too high to qualify for Medicaid, yet are inadequate to buy either necessary health care or private health insurance.

If a family's income is greater than $4.75 an hour, which is significantly less than the average teacher's aide makes, a pregnant woman is considered too well-off to qualify for Medicaid coverage, and that is even under last year's Medicaid expansion. That is why a number of us have introduced a bill which would give States the option of expanding Medicaid coverage to pregnant women and their infants up to age one whose family income is between 100 and 185 percent of the poverty level.

This bill will also give States the option of expanding coverage of children up to age eight for those children whose family income is less than the federal poverty level, and mandate that in those few States that do not already cover children up to the age of 8 below the State poverty level, Medicaid coverage must be provided for those children.

We frequently talk about the chain of problems facing the poor in this country. This bill deals with the entry point. Inadequate prenatal care contributes to the incidence of low birth weight infants. These low birth weight infants, if they survive, experience a range of health problems which, in turn, lead to school difficulties and failure. These children are more likely to join the ranks of the unemployed, and in turn, these unemployed, undereducated, and welfare dependent individuals are more likely to become teenage parents and less likely to secure proper prenatal care, and thus more likely to have low birth weight babies, and thus, the tragic cycle continues.

If ever there was a place to intervene, this is it. We can no longer afford in dollar costs or human costs not to extend prenatal care and health services to pregnant women, infants, and young children. We can have an impact on our citizens, giving them the chance to be the very best they can be from the beginning.

I look forward to today's hearing. I think that it will be very informative. And I would like to begin.

Senator Durenberger, do you have an opening statement?

Senator DURENBERGER. No, just that your statement was, as usual, excellent, comprehensive, and I think sets the pattern for today's hearing very well.

Senator BRADLEY. All right. Our first panel will be Mr. Aaron Johnson, who is the chairman of the State Medicaid Directors Association for the American Public Welfare Association; and he will share the table with Mr. Robert Gettings, executive director, National Association of State Mental Retardation Program Directors.

Gentlemen, welcome to the committee. We look forward to taking your testimony and having a chance to ask you a few questions. You understand the subjects that we are covering today, and you probably have seen as well that there are many bills that have been introduced that deal with our general area of concern—and that is Medicaid and Maternal and Child Health Block Grant issues.

Mr. Johnson.

STATEMENT OF AARON JOHNSON, CHAIRMAN, STATE MEDICAID DIRECTORS ASSOCIATION, TESTIFYING ON BEHALF OF THE AMERICAN PUBLIC WELFARE ASSOCIATION, ATLANTA, GA

Mr. JOHNSON. Good morning Mr. Chairman and members of the committee.

Senator BRADLEY. They are here in spirit, Mr. Johnson.

Mr. JOHNSON. All right.

Senator BRADLEY. And in alter egos.

Mr. JOHNSON. All right. I am the commissioner of the Georgia Department of Medical Assistance and also serve as chairman of the State Medicaid Directors Association, which is affiliated, of course, with the American Public Welfare Association.

I have come today to discuss several proposals before the committee regarding the Medicaid program, and present the State Medicaid directors' view of these proposals. In particular, I want to discuss proposals to expand Medicaid eligibility to certain pregnant women and children, reduce spousal impoverishment, and reform the current quality of care standards for nursing homes.

First, I would like to back up just a little to give you the context within which the American Public Welfare Association and the State Medicaid Directors Association comment today on these issues. As many of you are aware, Mr. Chairman, the Association made a series of sweeping recommendations for overhaul of our present welfare system in a report released late last year. Many of those recommendations have been incorporated in legislation now before the House. We hope those recommendations will be considered by the Senate Finance Committee as well.

One major area not addressed by that report was the issue of access to care for America's poor families. That broad issue is now under intense discussion by an APWA task force on access to health care, a task force on which State Medicaid directors have representation.

This task force is reviewing, and will make recommendations on the access to health care for families and children who are currently receiving Medicaid, and those who have recently left the cash assistance programs for work. I hope you will permit the task force to present its recommendations to this committee at the appropriate time.

Because of the progress already made with regard to welfare reform in Congress, the task force has already formulated recommendations on health care coverage for welfare families that leave the cash assistance rolls for employment. This includes an extension of standard Medicaid benefits, followed by a longer time period during which individuals might pay a premium to "buy-in" to the Medicaid program, or States might establish alternative health benefit programs.

It is within the context of this major policy development within the Association that I would like to provide you with the State Medicaid directors' views on several specific current proposals before the Finance Committee.

The State Medicaid directors support legislation to expand Medicaid eligibility to certain pregnant women and children. In particular, S. 422, sponsored by you, Mr. Chairman, and supported by many of the committee's members, would be another major step in providing care to those pregnant women in need.

We support S. 422 because of the obvious benefits to low-income women and children. We also support the legislation because it provides States with additional flexibility in operating the Medicaid program. As admirable as the initiatives for these vulnerable programs have been in the past 2 years, States have needed the option to decide how far they can extend coverage given their fiscal conditions.

Nevertheless, at least 20 States, many of them in the south, have already decided to provide coverage to women up to 100 percent of the poverty level, as was provided for by Congress last year.

The State Medicaid directors believe that the proposal on spousal impoverishment has a great deal of merit, but we do have some concerns.

First, we hope the committee realizes that dealing with this particular program is only treating the symptom of a much larger disease—the lack of long-term care insurance in this country.

Second, we are concerned that too many mandates by the Congress this year may lead to an erosion of the initiatives being made for pregnant women and children.

Finally, this morning, let me comment on the "Medicare and Medicaid Nursing Quality Care Amendments" in S. 1108, sponsored by Senator Mitchell and supported by members of the committee.

In April of this year, I had the privilege of testifying before Senator Mitchell's subcommittee. We support the elimination of the distinction between skilled nursing facilities and intermediate care facilities, though the change will be costly.

We believe in a requirement for conducting standardized resident assessments. We support the bill's provisions related to the resident's rights, including the provisions regarding anti-discrimination. We believe in a requirement for nurses aide training, but we would want the bill's proposal modified.

We support the provision on survey and certification, because it would streamline the process and focus monitoring activities on facilities and poor quality care.

Mr. Chairman, I recognize that the time is out here. Let me just say that I do appreciate this opportunity to come and testify, and I hope that our testimony will be given good consideration.

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

[The prepared statement of Mr. Aaron Johnson follows:]

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TESTIMONY OF
AARON J. JOHNSON
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OF THE
AMERICAN PUBLIC WELFARE ASSOCIATION
AND
COMMISSIONER, GEORGIA DEPARTMENT OF MEDICAL ASSISTANCE

FOR THE

COMMITTEE ON FINANCE
U.S. SENATE

MEDICAID AND THE MATERNAL AND CHILD HEALTH BLOCK GRANT

JULY 10, 1987

GOOD MORNING MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE. MY NAME IS AARON J. JOHNSON. I AM THE COMMISSIONER OF THE GEORGIA DEPARTMENT OF MEDICAL ASSISTANCE AND ALSO SERVE AS CHAIRMAN OF THE STATE MEDICAID DIRECTORS ASSOCIATION (SMDA) OF THE AMERICAN PUBLIC WELFARE ASSOCIATION.

I HAVE COME TODAY TO DISCUSS SEVERAL PROPOSALS BEFORE THE COMMITTEE REGARDING THE MEDICAID PROGRAM, AND PRESENT THE STATE MEDICAID DIRECTORS' VIEW OF THESE PROPOSALS. IN PARTICULAR I WANT TO DISCUSS PROPOSALS TO EXPAND MEDICAID ELIGIBILITY TO CERTAIN PREGNANT WOMEN AND CHILDREN, REDUCE SPOUSAL IMPOVERISHMENT, AND REFORM THE CURRENT QUALITY OF CARE STANDARDS FOR NURSING HOMES.

FIRST I WOULD LIKE TO BACK UP JUST A LITTLE TO GIVE YOU THE CONTEXT WITHIN WHICH THE AMERICAN PUBLIC WELFARE ASSOCIATION AND STATE MEDICAID DIRECTORS COMMENT TODAY ON THOSE ISSUES. AS MANY OF YOU ARE AWARE, MR. CHAIRMAN, THE ASSOCIATION MADE A SERIES OF SWEEPING RECOMMENDATIONS FOR OVERHAUL OF OUR PRESENT WELFARE SYSTEM IN A REPORT RELEASED LATE LAST YEAR. MANY OF THOSE RECOMMENDATIONS HAVE BEEN INCORPORATED IN LEGISLATION NOW BEFORE THE HOUSE, AND WE HOPE WILL BE CONSIDERED BY THE SENATE FINANCE COMMITTEE AS WELL. ONE MAJOR AREA NOT ADDRESSED BY THAT REPORT WAS THE ISSUE OF ACCESS TO HEALTH CARE FOR AMERICA'S POOR FAMILIES. THAT BROAD ISSUE IS NOW UNDER INTENSE DISCUSSION BY AN APWA TASK FORCE ON ACCESS TO HEALTH CARE, A TASK FORCE ON WHICH SMDA HAS REPRESENTATION. THIS TASK FORCE IS REVIEWING, AND WILL

MAKE RECOMMENDATIONS ON THE ACCESS TO HEALTH CARE FOR FAMILIES AND CHILDREN WHO ARE CURRENTLY RECEIVING MEDICAID, AND THOSE WHO HAVE RECENTLY LEFT THE CASH ASSISTANCE PROGRAMS FOR WORK. IN ADDITION TO REVIEWING THE VARIOUS ISSUES AFFECTING ACCESS, THE TASK FORCE IS COMMITTED TO DEVELOPING MECHANISMS TO SUPPORT ITS POLICY RECOMMENDATIONS. FINDING SUCH MECHANISMS WILL ENTAIL A REVIEW OF THE CURRENT MEDICAID PROGRAM IN ITS ENTIRETY, INCLUDING LONG-TERM CARE ISSUES. THE TASK FORCE WILL PURSUE THIS AGENDA THROUGH THE REMAINDER OF THIS YEAR. I HOPE YOU WILL PERMIT THE TASK FORCE TO PRESENT ITS RECOMMENDATIONS TO THIS COMMITTEE AT THE APPROPRIATE TIME.

BECAUSE OF THE PROGRESS ALREADY MADE WITH REGARD TO WELFARE REFORM IN CONGRESS, THE TASK FORCE HAS ALREADY FORMULATED RECOMMENDATIONS ON HEALTH CARE COVERAGE FOR WELFARE FAMILIES THAT LEAVE THE CASH ASSISTANCE ROLLS FOR EMPLOYMENT. THIS INCLUDES AN EXTENSION OF STANDARD MEDICAID BENEFITS, FOLLOWED BY A LONGER TIME PERIOD DURING WHICH INDIVIDUALS MIGHT PAY A PREMIUM TO "BUY-IN" TO MEDICAID, OR STATES MIGHT ESTABLISH ALTERNATIVE HEALTH BENEFIT PROGRAMS.

IT IS WITHIN THE CONTEXT, THEN, OF THIS MAJOR POLICY DEVELOPMENT EFFORT WITHIN THE ASSOCIATION THAT I WOULD LIKE TO PROVIDE YOU WITH THE STATE MEDICAID DIRECTORS' VIEWS ON SEVERAL SPECIFIC CURRENT PROPOSALS BEFORE THE FINANCE COMMITTEE.

THE STATE MEDICAID DIRECTORS SUPPORT LEGISLATION TO EXPAND MEDICAID ELIGIBILITY TO CERTAIN PREGNANT WOMEN AND CHILDREN. IN PARTICULAR, S.422, SPONSORED BY SENATOR BRADLEY AND SUPPORTED BY MANY OF THE COMMITTEE'S MEMBERS, WOULD BE ANOTHER MAJOR STEP. IT WOULD PROVIDE THE RESOURCES SO THAT STATES CAN ASSUME ADEQUATE PRENATAL CARE TO PREGNANT WOMEN WHO OTHERWISE WOULD NOT RECEIVE THAT CARE DUE TO LACK OF INCOME AND/OR INSURANCE. THE BILL WOULD ALLOW STATES TO PLACE THE INCOME TEST FOR MEDICAID ELIGIBILITY AT 185% OF POVERTY. AND IT WOULD ENABLE STATES TO PROVIDE MEDICAL CARE TO LOW-INCOME CHILDREN DURING THEIR CRITICAL FIRST YEAR OF LIFE. THESE ARE IMPORTANT, NEEDED, CHANGES IF WE ARE TO COMBAT THE CONTINUING EPIDEMIC IN INFANT MORTALITY AND POOR HEALTH GENERALLY AMONG LOW-INCOME CHILDREN.

WE SUPPORT S.422 BECAUSE OF THE OBVIOUS BENEFITS TO LOW-INCOME WOMEN AND CHILDREN. WE ALSO SUPPORT THE LEGISLATION BECAUSE IT PROVIDES STATES WITH ADDITIONAL FLEXIBILITY IN OPERATING THE MEDICAID PROGRAM. AS ADMIRABLE AS THE INITIATIVES FOR THESE VULNERABLE POPULATIONS HAVE BEEN IN THE PAST TWO YEARS, STATES HAVE NEEDED THE OPTION TO DECIDE HOW FAR THEY CAN EXTEND COVERAGE GIVEN THEIR FISCAL CONDITIONS. NEVERTHELESS AT LEAST 20 STATES, MANY OF THEM IN THE SOUTH, HAVE ALREADY DECIDED TO PROVIDE COVERAGE TO PREGNANT WOMEN UP TO 100 PERCENT OF THE POVERTY LEVEL AS WAS PROVIDED FOR BY CONGRESS LAST YEAR.

LET ME COMMENT GENERALLY ON PROPOSALS BEFORE THE COMMITTEE HAVING TO DO WITH SPOUSAL IMPOVERISHMENT. AS THE DAY-TO-DAY ADMINISTRATORS OF THE MEDICAID PROGRAM, WE ARE QUITE AWARE OF THE HARDSHIP IMPOSED ON INDIVIDUALS BY THE CURRENT LACK OF LONG-TERM CARE INSURANCE, PUBLIC OR PRIVATE. THIS IS WHAT NOW HAPPENS: A HUSBAND OR WIFE, USUALLY THE HUSBAND, IN POOR HEALTH IS INSTITUTIONALIZED. THE SPOUSE REMAINS IN THE COMMUNITY. IN ORDER FOR THE SPOUSE IN POOR HEALTH TO BE ELIGIBLE FOR MEDICAID, THE COUPLE IS FORCED TO SPEND AWAY THEIR LIFE SAVINGS, AND INCOME. MANY OF OUR CITIZENS ASSUME MEDICARE WILL COVER COSTS FOR LONG-TERM CARE AND, AS ALL OF YOU KNOW, IT DOES NOT. ONLY MEDICAID PROVIDES THAT COVERAGE, AND ONLY WHEN A COUPLE HAS BECOME IMPOVERISHED.

PROPOSALS NOW BEFORE THE COMMITTEE, INCLUDING SENATOR MITCHELL'S (S.598), WOULD REDUCE THE PRESSURE ON A COUPLE TO IMPOVERISH THEMSELVES. IT WOULD RAISE THE INCOME AND/OR RESOURCE LIMITS THE SPOUSE LIVING IN THE COMMUNITY MUST MEET IN ORDER FOR THE SPOUSE IN THE NURSING HOME TO BE ELIGIBLE FOR MEDICAID. THIS IS A POPULATION WE WOULD AGREE IS IN NEED OF FINANCIAL RELIEF IN ORDER TO AVOID POVERTY AS A CONDITION REQUIRED IN ORDER FOR THE INSTITUTIONALIZED SPOUSE TO RECEIVE CARE.

THE STATES DO, HOWEVER, HAVE A CONCERN WITH THE APPROACHES BEING PROPOSED TO ADDRESS THIS PROBLEM. IT APPEARS THAT THE PROPOSALS, HOWEVER WELL-MEANT, WOULD ONLY TREAT A SYMPTOM AND NOT THE LARGER

DISEASE. AND IT IS VERY EXPENSIVE TREATMENT. THE PROPOSALS DO NOT ADDRESS THE BASIC PROBLEM: THAT, THERE IS ALMOST NO LONG-TERM CARE INSURANCE COVERAGE AVAILABLE TO INDIVIDUALS EXCEPT MEDICAID.

I WOULD HOPE THAT AS THE COMMITTEE PURSUES THIS ALTERNATIVE IT RECOGNIZES THAT THE LARGER PROBLEM WILL NOT BE RESOLVED AND THAT THESE ARE ONLY STOPGAP MEASURES. I HOPE THAT THIS INITIATIVE WILL INCREASE THE MOMENTUM TO DEAL WITH THE LARGER QUESTION OF FINANCING LONG-TERM CARE. MY COLLEAGUE, CHARLES ATKINS OF MASSACHUSETTS, TESTIFIED BEFORE SENATOR MITCHELL'S SUBCOMMITTEE ON THIS ISSUE ON JUNE 12. AS YOU KNOW, EVEN UNDER THE PROPOSALS NOW BEFORE THE COMMITTEE, A GREAT DEAL OF FINANCIAL AND EMOTIONAL SUFFERING WILL CONTINUE TO OCCUR.

IN ADDITION, I WOULD BE REMISS IF I DID NOT MENTION THAT BY MANDATING THE CHANGES IN A COMMUNITY SPOUSE'S INCOME OR RESOURCE LEVEL, THE COMMITTEE WOULD BE MANDATING A SIGNIFICANT INCREASE IN COSTS. ALONG WITH THE PROPOSAL IN THE COMMITTEE'S CATASTROPHIC PLAN TO HAVE STATE MEDICAID AGENCIES COVER COST SHARING FOR THE MEDICARE ELIGIBLE POPULATION BELOW THE FEDERAL POVERTY LINE, A SIGNIFICANT AMOUNT OF NEW MANDATED SPENDING FOR THE ELDERLY AND DISABLED WOULD BE NEEDED NEXT YEAR.

WITH LIMITED STATE APPROPRIATIONS FOR MEDICAID, YOU CAN BE ASSURED THAT CHOICES WOULD HAVE TO BE MADE IN LIGHT OF THE PROPOSED CHANGES. WHILE CHOICES AMONG MANY PARTS OF THE MEDICAID

PROGRAM COULD BE LOOKED AT, IT IS ALMOST CERTAIN THAT IN MANY STATES THE FIRST DECISION WOULD BE TO WHETHER TO IMPLEMENT THE BROADENED MEDICAID COVERAGE FOR PREGNANT WOMEN AND CHILDREN THAT CONGRESS ENACTED LAST YEAR AND IS CONSIDERING THIS YEAR. IT IS POSSIBLE THAT THE NEW MANDATES, IF ENACTED, WOULD JEOPARDIZE SUCH EXTENSIONS. THIS, I BELIEVE WOULD BE PARTICULARLY UNFORTUNATE, SINCE AS MANY AS 20 STATES HAVE CHOSEN TO PURSUE LAST YEAR'S OPTION OF COVERING PREGNANT WOMEN AND INFANTS UP TO THE FEDERAL POVERTY LEVEL.

THE PROPOSALS ON SPOUSAL IMPROVERISHMENT AND BUYING-IN TO MEDICARE FUNDS HAVE MERIT. BUT BY PUTTING EXPENSIVE ITEMS SUCH AS THESE IN PLACE, IT COULD HAVE A NEGATIVE EFFECT ON OTHER INITIATIVES WITH EQUAL MERIT. AS PUBLIC OFFICIALS WE ALL KNOW THAT TOUGH CHOICES HAVE TO BE MADE, AND MADE REGULARLY. YOUR ACTIONS MAY HAVE THE RESULT OF POSING DIFFICULT CHOICES FOR SOME STATES.

FINALLY, THIS MORNING, LET ME COMMENT ON THE "MEDICARE AND MEDICAID NURSING QUALITY CARE AMENDMENTS," S. 1108, SPONSORED BY SENATOR MITCHELL AND SUPPORTED BY MANY MEMBERS OF THE COMMITTEE. IN APRIL OF THIS YEAR I HAD THE PRIVILEGE OF TESTIFYING BEFORE SENATOR MITCHELL'S SUBCOMMITTEE ON HEALTH REGARDING LAST YEAR'S INSTITUTE OF MEDICINE (IOM) STUDY, ON WHICH S. 1108 IS LARGELY BASED. AS I SAID AT THAT TIME THE STATE MEDICAID AGENCIES

SUPPORT THE VAST MAJORITY OF RECOMMENDATIONS MADE BY THE INSIGHTFUL IOM STUDY. LET ME BRIEFLY SUMMARIZE THE STATE MEDICAID DIRECTORS' VIEW OF SENATOR MITCHELL'S BILL.

- 0 WHILE THE STATE MEDICAID AGENCIES SUPPORT ELIMINATING THE DISTINCTION BETWEEN A SKILLED NURSING FACILITY (SNF) LEVEL OF CARE AND AN INTERMEDIATE CARE FACILITY (ICF) LEVEL OF CARE, WE NOTE THAT THERE ARE SOME PITFALLS. ONE PROBLEM IS INCREASED COSTS, WHICH THE BILL ADDRESSES IN PART BY CALLING FOR A PHASE-OUT OF THE DISTINCTION OVER A PERIOD OF YEARS.

- 0 THE STATE MEDICAID AGENCIES BELIEVE THE PROPOSED REQUIREMENT FOR CONDUCTING STANDARDIZED RESIDENT ASSESSMENTS AT REASONABLE INTERVALS IS A GOOD IDEA. WE ALSO SUPPORT THE IDEA OF DEVELOPING A SINGLE UNIFORM ASSESSMENT TO EVALUATE A RESIDENT'S ABILITY TO PERFORM DAILY LIVING FUNCTIONS. IT IS IMPORTANT, HOWEVER, THAT STATES BE ALLOWED EXCEPTIONS TO THE SINGLE UNIFORM INSTRUMENT IF THEY RECEIVE THE SECRETARY'S APPROVAL. WHAT IS NEEDED ACROSS THE COUNTRY ARE UNIFORM ITEMS AND DEFINITIONS, NOT A SINGLE FORM.

- 0 WE SUPPORT EACH OF THE PROVISIONS IN THE BILL RELATED TO RESIDENT'S RIGHTS INCLUDING PROVISIONS ON ANTI-DISCRIMINATION.

- WHILE THE STATE MEDICAID AGENCIES SUPPORT A REQUIREMENT FOR NURSES AIDE TRAINING WE WOULD PREFER THE PROPOSAL PUT FORTH IN THE HOUSE BILL, H.R. 2270, THAT CALLS ON STATES TO ESTABLISH A PLAN THAT MUST THEN BE APPROVED BY THE SECRETARY AS MEETING CERTAIN MINIMUM STANDARDS.

- WE SUPPORT THE PROPOSALS REGARDING SURVEY AND CERTIFICATION, THAT WOULD HELP STREAMLINE THE CURRENT PROCESS AND TARGET MONITORING ACTIVITIES TOWARDS FACILITIES PROVIDING POOR QUALITY CARE. WE ALSO SUPPORT REWARDING FACILITIES THAT PROVIDE HIGH QUALITY CARE.

- THE STATE MEDICAID AGENCIES ARE CONCERNED WITH THE BILL'S REQUIREMENT THAT WE TAKE SPECIFIC PARTS OF THE NURSING HOME'S REQUIREMENTS INTO ACCOUNT WHEN ESTABLISHING NURSING HOME RATES. THERE IS NO OTHER SUCH SPECIFICATION REGARDING THE REIMBURSEMENT OF INSTITUTIONS UNDER MEDICAID.

- WE SUPPORT THE DEVELOPMENT OF INTERMEDIATE SANCTIONS THAT CAN BE USED AGAINST NURSING FACILITIES AS LONG AS STATES ARE GIVEN FLEXIBILITY IN HOW THEY ARE USED.

- WITH REGARD TO CREATING A COMMISSION ON LONG-TERM CARE, WE WOULD RECOMMEND HIGHLY THAT STATE MEDICAID AGENCY REPRESENTATION BE PRESENT ON SUCH A COMMISSION TO ADVISE ON ISSUES OF REIMBURSEMENT, STAFFING AND DISCRIMINATION ISSUES

IRRELATED TO NURSING HOME CARE PROVIDED UNDER THE MEDICAID PROGRAM.

THANK YOU FOR ALLOWING ME TO TESTIFY BEFORE YOU THIS MORNING. I WOULD BE HAPPY TO ANSWER ANY QUESTIONS YOU MAY HAVE.

STATEMENT OF ROBERT M. GETTINGS, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF STATE MENTAL RETARDATION PROGRAM DIRECTORS, INC., ALEXANDRIA, VA

Mr. GETTINGS. Thank you, Mr. Chairman. I am Bob Gettings, Executive Director of the National Association of State Mental Retardation Program Directors.

Let me begin this morning by addressing the need for a basic restructuring of Medicaid law as it impacts on the provision of long-term care services to persons with severe life-long disabilities.

Congress has, in recent years, taken several steps to minimize the institutional bias of Medicaid policy—most notably by establishing the home and community care waiver program. Six years of experience with the waiver program, however, has led us to conclude that as helpful as the program is, a Secretarial waiver authority is, at best, a temporary expedient.

Within the next few days, Senator John Chafee, a member of this committee, will introduce a revised version of the "Community and Family Living Amendments." This measure, we understand, will be designed to grant the States considerably more latitude to support cost-effective home and community care services for persons with developmental disabilities.

All of the major consumer, provider, and professional organizations interested in the welfare of persons with developmental disabilities, including NASMRPD, have expressed support for the basic concepts of Senator Chafee's revised bill.

While we certainly recognize, Mr. Chairman, that this Committee is forced to operate under extraordinary fiscal and time constraints, we urge you to carefully consider the inclusion of Senator Chafee's bill, or at least key provisions thereof, in your reconciliation package.

Second, when the Committee marks up the "Medicare and Medicaid Nursing Quality Care Amendments," introduced by Senator Mitchell, for inclusion in its reconciliation package, we strongly recommend that you add provisions of the House version of the bill, H.R. 2270, that will ensure appropriate services for developmentally disabled nursing home residents, and prevent future admissions of such individuals to nursing facilities.

According to a recent GAO report, there are approximately 140,000 mentally retarded nursing home residents nationwide. Recent studies indicate that upward to 90 percent of these individuals in some States require alternative placements. I might add that the proposed legislation is fully consonant with HCFA policies governing the appropriateness of serving persons with mental retardation in SNF and ICF facilities.

The related step we would urge the Committee to take is to permit the States to use the average per capita cost of ICF/MR services in calculating the cost-effectiveness of waiver services for current nursing home residents with developmental disabilities. At the present time, States face a serious barrier to enrolling such individuals in waiver programs, because the cost of nursing home care is often less than the cost of appropriate community-based alternatives.

Finally, NASMRPD strongly recommends that the Committee include in its reconciliation language provisions to (1) restore the Secretary's authority to allow States to disregard normal deeming policies under home and community care waiver programs; (2) afford the States greater statutory protections in Federal/State negotiations surrounding the renewal of waiver programs; (3) modify the provisions granting States the authority to cover optional targeted case management services, by allowing States to limit the number and types of agencies furnishing such services in a given catchment area; (4) clarify the State's authority to claim reimbursement for prevocational, educational, and supportive employment services to former institutional residents under a home and community care waiver; (5) permit the States to extend Medicaid coverage to childhood Social Security beneficiaries who are living at home, but are at risk of institutionalization, under the same statutory terms that Congress adopted on behalf of other severely disabled and chronically ill children in 1982; and (6) require HCFA to accept ICF/MR phase-down plans submitted in accordance with legislation adopted by this Committee 2 years ago, if the affected facility is notified by HCFA of deficiencies on or after the effective date of that legislation—April 7, 1986.

A brief justification of each of these proposed technical amendments is contained in my written testimony. However, I want to stress that, to the best of our knowledge, none of the suggested changes—and I emphasize none of the suggested changes—would entail significant increases in Medicaid outlays.

Mr. Chairman, thank you for this opportunity to present the Association's views regarding the forthcoming legislation.

[The prepared statement of Mr. Robert M. Gettings follows:]

STATEMENT OF TESTIMONY

Medicaid Provisions of the 1987 Reconciliation Act

Respectfully Submitted
to the
SENATE FINANCE COMMITTEE

The Honorable Lloyd Bentsen, Chairman

by
Robert M. Gettings
Executive Director

National Association of State Mental Retardation
Program Directors, Inc.

July 10, 1987

I. INTRODUCTION

My name is Robert Gettings. I am the Executive Director of the National Association of State Mental Retardation Program Directors, Inc. The membership of NASMRPD consists of the principal officials in the fifty states and territories who are directly responsible for the provision of services to a total of over half a million children and adults with developmental disabilities.

My testimony today will focus on the Medicaid provisions of the 1987 reconciliation bill. I will discuss the need for both basic, substantive reforms in existing Medicaid law as it impacts on persons with severe, life-long disabilities, as well as more immediate steps that must be taken to clarify and correct defect in the existing statute.

II. LONG TERM CARE REFORM

In recent years, Congress has taken several steps to partially redress the so-called "institutional bias" of Medicaid policy -- most notably by authorizing the home and community-based waiver program (Section 2176, P.L. 97-35). Six years of experience with the HCB waiver program has led us to conclude that a Secretarial waiver authority is, at best, a temporary expedient, rather than a substitute for more basic, statutory reforms aimed at rectifying the present imbalance in Medicaid long term care policy.

Within the next few days, Senator John Chafee (R-RI) will be introducing a revised version of the "Community and Family Living Amendments", which he originally introduced in 1983. This measure would grant the states considerably more latitude to support cost-effective home and community-based services for persons with developmental disabilities, while, at that same time, requiring the states to move in a planful, fiscally responsible manner to implement such alternatives to institutional care. All of the major consumer, provider aid professional organizations interested in the welfare of developmentally disabled citizens -- including NASMRPD -- have expressed their support for Senator Chafee's bill.

We recognize that this Committee is forced to operate under extraordinary fiscal and time constraints in preparing its portion of the 1987 reconciliation bill. Nonetheless, we urge you to carefully consider Senator Chafee's new version of the "Community and Family Living Amendments," with an eye toward encorporating in reconciliation legislation all, or at least key provisions, of this carefully crafted legislation. The basic, fundamental reallignment of Medicaid law called for in this forthcoming legislation, we believe, is the only effective way of solving the underlying problems currently plaguing Medicaid long term case policy as it affects citizens with developmental disabilities.

III. NURSING HOME QUALITY LEGISLATION

It is our understanding that the Committee tentatively plans to include in its reconciliation package an amended version of the "Medicare and Medicaid Nursing Quality Care Amendments" (S. 1108), originally introduced by Senator George Mitchell (D-ME) on April 29. As you consider possible modifications in the original Mitchell bill, NASMRPD strongly recommends the inclusion of provisions to ensure appropriate services for developmentally disabled nursing home residents and to prevent inappropriate admissions to such facilities in the future.

The House version of the legislation (H.R. 2270), introduced by Representatives John Dingell and Henry A. Waxman on May 5, includes: (a) a requirement that each state, no later than January 1, 1989, establish a pre-admission screening program applicable to persons with mental retardation and mental illness who are being considered for admission to Medicaid-certified nursing homes; and (b) a requirement that a state complete a review of the service need of each mentally retarded and mentally ill resident of a nursing home by April 1, 1990 and certify that only those persons who require the level of services provided by a nursing home are living in such facilities. Steps also would have to be taken to transfer any mentally retarded or mentally ill person who was found to be inappropriately placed in a nursing home.

According to a recent GAO report, HCFA officials estimate that there are approximately 140,000 persons with mental retardation residing in Medicaid-certified nursing homes, nationwide. Furthermore, special assessments of the service needs of such nursing home residents, conducted in Indiana and Illinois, suggest that upward to 90 percent of these individuals are not receiving the types of habilitative services they require. Under the circumstance, <u>NASMRPD urges the Committee to include in its marked-up version of the nursing home quality bill provisions similar to H.R. 2270</u>.

Most mentally retarded nursing home residents meet the criteria for admission to an ICF/MR facility and require an ongoing, individualized regimen of habilitative services. Indeed, if they were residing in an ICF/MR facility, some of them would be considered prime candidates for Medicaid-financed home and community care waiver services.

However, states currently face a significant barrier to qualifying such individuals for waiver services, ironically because of the very fact that they reside in ICF or SNF-certified nursing homes. In most states, the payment levels of such facilities are so low that state officials are unable to justify the cost effectiveness of alternative community-based services, since the average per capita cost of waiver-funded community services would exceed the average per capita cost of nursing home care for the affected population. Nursing home rates are lower, of course, because these residents do not have access to the full array of habilitation services.

To correct this problem, <u>NASMRPD recommends that states be permitted to use the average per capita cost of ICF/MR services in calculating the cost-effectiveness of HCB waiver services for persons who: (a) are developmentally disabled; (b) currently reside in a Medicaid-certified nursing home; and (c) meet the state's ICF/MR level of care criteria</u>.

The proposed amendment would not increase the number of persons potentially eligible for waiver services under current law; nor would it result in any long term increase in the total cost of Medicaid services, since the states are obligated under existing HCFA guidelines to either transfer persons inappropriately placed in general nursing homes to ICF/MR facilities or enhance the existing facility's capability of furnishing such services.

IV. TECHNICAL AND CORRECTIVE AMENDMENTS

In addition to the changes outlined above, NASMRPD suggests that the Committee include in its portion of the reconciliation bill a number of technical and clarifying amendments to Medicaid law. None of the proposed changes would result in a significant increase in Medicaid outlays to the best of our knowledge. Indeed, most of them are simply intended to correct administrative interpretations of existing law that seem to us to be contrary to the original aims of Congress.

A. Deeming Under Home and Community-Based Waivers. Section 9411(c) of last year's reconciliation bill (P.L. 99-509) inadvertently modified the language of Section 1915(c)(3) of the Act in such a manner that the Secretary no longer has authority to waive parental/spousal deeming requirements on behalf of otherwise eligible participants in approved waiver programs. The subject change has created serious problems for many of the 33 states with developmental disability waiver programs, since it limits participation of children with severe disabilities to those whose families meet the Medicaid income/resource test of eligibility.

Language should be included in the reconciliation bill to restore the Secretary's authority to allow states to disregard normal deeming policies under HCB waiver programs. Furthermore, this provision should be made retroactive to the original effective date of OBRA.

8. Waiver Renewal Policies. The problems inherent in supporting home and community care services through Secretarially-approved waivers has become increasingly apparent as more states have submitted renewal requests over the past year. Experience indicates that the most disruptive aspects of the waiver renewal process is HCFA's tendency to: (a) require states to re-justify their existing number of waiver participants as well as any proposed growth in future years of the program; and (b) recognize current and projected institutional capacity as the only acceptable evidence to justify future growth in demand for waiver services. Given the mathematical formula HCFA uses to calculate the number of approvable waiver slots, a state faces a serious dilemma: achievement of the statutory goals of the waiver program (i.e., diverting persons from institutional to community-based settings and, thereby, reducing its institutional bed capacity) undermines a state's ability to expand or even maintain the current number of participants in its waiver program. Indeed, under current HCFA policies, if a state were to eliminate all ICF/MR beds, it would be unable to qualify for a MR/DD waiver,

despite the fact that the state would continue to be responsible for serving former and prospective institutional residents in home and community service programs.

To correct this obvious inequity in current policy, NASMRPD recommends that the Committee consider legislation to either:

- permit a state to offer home and community-based services as an optional coverage under its regular Medicaid plan, but only on behalf of target populations (MR/DD; elderly/disabled; chronically mentally ill; etc.) which previously had been covered by a HCB waiver for a minimum of six years; or
- require HCFA to: (a) recognize a state's existing utilization level in negotiating a waiver renewal request; and (b) take into account factors other than current institutional capacity (e.g., waiting list data) in determining whether a state's proposed increase in the total number of waiver participants is justified.

Neither of these proposed steps constitutes a long range solution to the previously mentioned imbalance in Medicaid policy; but, they would add a needed element of stability to the existing waiver program pending the enactment of more far-reaching statutory reforms.

C. Freedom of Choice in the Provision of Targeted Case Management Services. Last year, when Congress authorized the states to cover, under their state Medicaid plans, targeted case management services, a proviso was included which requires a state to offer recipients a choice among available service providers (Section 9508, COBRA). HCFA has not yet issued regulations implementing the provisions of Section 9508; however, a number of states that have submitted Medicaid plan amendments to cover such services for persons with developmental disabilities have been informed by HCFA that the designation of a single provider of case management services in a given catchment area would constitute a violation of the recipients' freedom of choice. This interpretation ignores years of experience in the fields of mental health and developmental disabilities and virtually precludes coverage of such services for Medicaid-eligible mentally ill and developmentally disabled persons in most states.

NASMRPD recommends that language be included in the reconciliation bill to make it clear that -- at least in the case of services to persons with developmental disabilities or chronic mental illness -- (a) a state may not lock a recipient into a particular case manager, but may limit the number and types of agencies that are eligible to provide case management services; and (b) the case manager must permit the individual recipient a choice among available medical assistance services.

D. Effective Date of the COBRA Definition of Habilitation Services. The 1985 reconciliation bill includes an amendment that permits states to claim Medicaid-reimbursement for prevocational, educational and supported employment services on behalf of persons who are developmentally disabled and who participate in an approved home and community care waiver program, provided such habilitation services are not otherwise available through state/local educational or vocational rehabilitation agencies (Section 9502(a), COBRA). Title XIX-payments for these new elements of habilitation services may be claimed only on behalf of waiver recipients who previously resided in a Medicaid-certified facilities.

Although regulations implementing this provision of COBRA have not yet been issued, HCFA officials have informed states that have requested authority to cover prevocational, educational and/or supported employment services under their waiver programs that the new definition of habilitation services applies only to those recipients deinstitutionalized after the effective date of the legislation (April 7, 1986). This interpretation denies states the authority to claim reimbursement for such services on behalf of approximately 80 to 90 percent of all formerly institutionalized clients who are currently participating in HCB waiver programs. Yet, there is nothing in the legislative history of Section 9502(a) which supports HCFA's reading of the law.

Under the circumstances, NASMRPD urges the Committee to include a technical amendment to Section 9502(j)(1) of COBRA which makes it clear that a state may claim reimbursement for pre-vocational, educational and supported employment services rendered to eligible waiver participants who were deinstitutionalized into the waiver program prior to the effective date of Section 9502(a); however, they may not claim reimbursement for any such services furnished prior to April 7, 1986.

We wish to stress that this change will not increase the federal cost of the waiver program, since the affected recipients will receive other forms of day habilitation services (usually of a non-vocational nature) that will cost as much or more.

E. Parental Deeming of Home-Based Services for Certain OASDI Childhood Beneficiaries with Severe Disabilities. In 1982, Congress enacted legislation (Section 134, TEFRA) that permits a state to disregard the income and resources of a family caring for a child with severe disabilities at home, provided:

- the child requires the level of care offered in a hospital, SNF or ICF (including an ICF/MR);
- the child can be cared for appropriately outside of an institutional setting;
- the estimated cost of non-institutional services does not exceed the comparable costs of serving the child in a Medicaid-certified institution; and
- the child would be eligible for SSI disability payments if he or she were residing in a Title XIX-certified institution.

Unfortunately, one group of children with disabilities remains ineligible for Medicaid benefits while living in the homes of their families -- i.e., youngsters who are entitled to receive childhood Social Security benefits. Even where such children meet all of the other eligibility criteria, they would not be eligible for SSI benefits if institutionalized, since the modest Social Security checks they receive each month, due to the death, disability or retirement of a fully insured parent, disqualifies them for SSI payments. On the other hand, they would be entitled to receive Medicaid benefits while living in a Title XIX-certified institution, to the extent that the cost of institutional care exceeded their available income/resources.

Any additional Medicaid costs associated with extending the TEFRA eligibility provision to similarly situated beneficiaries of childhood OASDI payments should be largely offset by reduced demand for more expensive out-of-home care services. In any case, the potential number of recipients is exceedingly small by Medicaid standards. NASMRPD supports legislation to accomplish this purpose.

F. ICF/MR Reduction/Correction Plans Under COBRA. Section 9516 of COBRA grants states the option of reducing the population of an ICF/MR over a 3 year period when HCFA has found it out of compliance with federal standards. In order to qualify for this provision, the facility must have deficiencies which do not pose an immediate threat to the health and safety of its residents.

To date HCFA has not issued final implementing regulations. The lack of regulations is compounded by the fact that HCFA interprets the language of Section 9516 to mean that the reduction plan option will only be available to facilities which receive their list of deficiencies on or after the effective date of final rules.

This interpretation of statutory intent, ignores the explicit language of Section 1919(b)(1) of the Act, which specifies that the applicable provisions "shall become effective on the date of ...enactment" (i.e., April 7, 1986).

<u>NASMRPD urges the Committee to add a technical amendment to the reconciliation bill that makes it clear that HCFA must accept reduction plans from facilities that meet the criteria of the Act and were officially notified of their deficiencies by HCFA on or after April 7, 1986</u>.

* * * * * *

I appreciate this opportunity to share with the Committee the Association's views regarding the Medicaid provisions of the 1987 reconciliation bill. Please feel free to call on us if we can offer further advice or assistance as your begin to mark up this important legislation.

Senator BRADLEY. Thank you very much, Mr. Gettings. Mr. Johnson, if I could, I would like to ask just a few questions.

We have given the States some options, and you said that a number of the States have picked up the options. What are your predictions about what States would do if they were given the option to go to 185 percent?

Mr. JOHNSON. As you know, Mr. Chairman, the economy in States varies all the way across the spectrum. In my State the economy is strong; we are in relatively good shape. We would pick it up fairly readily.

There are other States where the economies are not in such good shape—I'm thinking now maybe even a State like Texas, where the economy is down at this point. Texas probably would have a difficult time picking it up. But I think there are States, as a matter of fact, probably most of the States would pick it up and actually include that option.

Senator BRADLEY. Is there anything that we could do to encourage States to pick up the option?

Mr. JOHNSON. Short of increasing the ratio of the expenditures which the Federal Government pays for, I doubt that there is anything else. But that is a way to do it.

Senator BRADLEY. So that other than the Medicaid match, you don't see any——

Mr. JOHNSON. At this point, I don't think—I can't think of any at this moment.

Senator BRADLEY. Could you give the committee any kind of sense of the barriers that exist for poor pregnant women getting access to health care?

Mr. JOHNSON. Well, most of the barriers, of course, are financial. There are Medicaid programs which don't include all of the possible services which could be provided through the programs. Some States have left some of the options out, mainly for economic reasons; and other States have it in there. The barriers are largely those which are related to whether or not the State actually picks up certain coverages.

Other than the financial barriers normally, where some of the mothers may even be partially working, there are some possibilities that mothers would have a job and throw them—by having a job, they would leave the Medicaid rolls. If they leave the Medicaid rolls, there is little likelihood that they can buy the kind of insurance which they need to cover their families, so they would be falling between the cracks, so to speak.

Senator BRADLEY. Well, are all women who are eligibile for Medicaid actually picking it up and using it now, even up to 100 percent of poverty?

Mr. JOHNSON. No, sir. Not all States' Medicaid programs permit eligibles who are up to 100 percent of poverty to participate in the Medicaid program—that per 100 percent of national poverty. As you may know, eligibility for the welfare programs is a function of the State's definition of what that eligibility should be, and sometimes that falls a little short of what the Federal poverty level is, which means that there is a gap between what the States consider poverty and what the Federal poverty level is.

Senator BRADLEY. But those who are eligible, you believe, in a State—do most of them take advantage of it?

Mr. JOHNSON. Yes, sir. I would think that would be the case.

Senator BRADLEY. Do you agree that, if you are looking at the cycle of poverty, that dealing with prenatal care is one of the best ways to counter low birth-weight babies?

Mr. JOHNSON. No question about it.

Senator BRADLEY. Do you have any kind of personal testimony to that in your own experience in Georgia?

Mr. JOHNSON. The only testimony that I can give is what I hear from providers who are obstetricians and gynecologists, and they say to me that much of the problem can be corrected if they can get to the woman before delivery. As a matter of fact, many of them—many mothers—come to many of our hospitals almost on the day that they are to be delivered. And, of course, that is much too late to take care of the real health of the child, the infant.

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

Senator DURENBERGER. Mr. Chairman, as you were talking with Mr. Johnson I was reminded of my visit down to Ruskin, FL, with a woman who is a nun from Minnesota, a very small town in Minnesota—so small that the population doubles when pheasant hunting season opens up in the fall. But, she is trying to run a migrant clinic down there particularly for new mothers. She took me up to Hillsboro County and introduced me to the welfare and Medicaid officials.

After we got through with the experience, she said, "can you believe any kind of a welfare operation that refuses my offer?" Her offer is that if you will give her $10 a visit for 25 visits—or $25 for each of 10 visits for these young mothers, she'll guarantee you that she can have the mother in and out of the hospital with a baby, perfectly healthy or as close as possible, for $250. I'm overexaggerating a little bit, but she could come pretty close to that.

They turned her down. They are willing to pay $550 or $650 a day for either 2 or 3 days of a normal birth, or in the case of a low live birth weight baby, maybe a month at $550, $600 then. I suppose that was the case, because that is the way they had always done it and you could not get them to change.

Mr. Gettings, there is a person who ought to be here today, but he is up fighting tobacco on the floor of the Senate—my colleague from Rhode Island, John Chafee. And on his behalf, I first want to introduce his statement in the record, Mr. Chairman.

Senator BRADLEY. Without objection.

Senator DURENBERGER. And then a series of letters, I'm not sure of the content, but I'm sure, since they have been prepared by his trusty staff, that they are all appropriate to the issue.

[The letters follow:]

Christina DellaRipa
Age: 6 years old
Soundbeach, New York

047651 JUL 0 8 1987

Maria DellaRipa 6-25-87

Sound Beach, N.Y. 11789

Phone#

To the Editor,

I am a very concerned parent of a 6 yr. old Child with a rare disease called Rasmussen's encephalitis. Which causes severe uncontrolable seizures, incontinence of both bladder and Bowel, paralysis, coma and eventally death if surgery is not performed (hemispherectomy). and even if surgery is done!

In my area of Suffolk County, New York I have found no help in finding any epilepsy organization or respite programs.

Also it has been nearly impossible to find any material about this disease even when reading your very informative "National Spokesman".

My daughter has had this disease 1 1/2 years now. We are now getting ready to go to Canada to the Neurological Institute of Montreal where there they will begin tests such as: brain mapping, M.R.I. Scans, E.E.G.'s, Cat scans, and a P.E.T. Scan. Then a byupsy will be performed to determine if her disease is in fact Rasmussen's encephalitis.

If so the next step will be removal of half her brain.

This disease has afflicted the right temporal lobe of her brain, so far causing atrophy.

We are drowning in medical bills, to say the least!

and were not finished yet with bills!

So any donations would truly be appreciated! They can be directly deposited to the Mid-Hudson Savings Bank. Route 52, Lake Carmel, N.Y. 10512.

Maria DellaRipa's Custodian acct. for Christina DellaRipa.

This story just had to be told about a beautiful and bright young girl!

Sincerely,

Mrs. Maria DellaRipa

State of Wisconsin

Council on Developmental Disabilities
One West Wilson Street/P O Box 7851 • Madison, Wisconsin 53707-7851 • (608)266-7826

June 12, 1987

U. S. Senator John Chaffee
Senate Office Building
Washington, D.C. 20510

Dear Senator Chaffee:

The Wisconsin Council on Developmental Disabilities wishes to bring to your attention a problem with the Katie Beckett Program, Medical Assistance for Disabled Children Living at Home (42 USC 1936 (a)(c)3). The child's income and assets are considered when determining eligibility, but the income and assets of the parents are not considered.

To be eligible, the child must be 18 years of age or younger and determined to be disabled by standards in the Social Security Act. The child must require a level of care in the home that is typically provided in a hospital, skilled nursing facility, or intermediate care facility (which includes the Wisconsin Centers for the Developmentally Disabled). The child must receive or be able to receive appropriate care outside an institutional setting. The cost for home care must not be greater than the amount Medical Assistance would pay for the child's care in an institution. And, finally, the child must be eligible for an SSI payment if he/she were institutionalized (no income in excess of $45 per month).

Wisconsin made the Katie Beckett Program a regular part of the State Plan. Other states operate similar programs under waivers. Currently, about 400 Wisconsin children are living at home and receiving Medical Assistance under this program.

However, 35 children, who qualify in every other respect, are ineligible because they have a parent who is deceased, disabled, or retired and receive a Social Security payment in their own name. Therefore, they would not be eligible for SSI in an institution. But as long as medical expenses exceed the child's income, he/she would be eligible for Medical Assistance in an institution, or in foster care.

Thus the family is faced with the old choice: medical coverage only if the child is placed outside the home.

A case example may help illustrate the issue. Emily (not her real name) is a teenager and lives with her mother and a cousin. Emily became disabled at age 12 by a rare syndrome which left her severely retarded and physically disabled. She cannot speak or walk or get in and out of her wheelchair by herself. However, she does go with her mother to visit relatives, shop, and go to community events, and she is an important member of her family. Emily's mother, in addition to taking care of Emily, has a part-time job. Her father is dead, so Emily and her mother

Member - National Association of Developmental Disabilities Councils

each get Social Security. Because of her Social Security, Emily cannot get Medical Assistance under the Katie Beckett program. Her mother pays about $6000 per year for medical costs, including visits to specialists, wheelchair costs, leg braces, physical therapy, and seizure medication. If Emily were in an institution, she would be eligible for Medical Assistance, but she would not get the love and care of her family. The cost of care at Central Wisconsin Center for the Developmentally Disabled (the likely alternative to her home) would cost Medical Assistance about $44,000 per year.

All of the 35 children we know about are severely disabled. All are receiving Social Security because a parent is dead (17), disabled (14), or retired (4). Typical medical expenses are $3,000-$10,000 per year, but the range is up to $20,000. Typically, these famlies are worse off than the families who are on SSI, because, in most cases, one parent is dead or under a substantial disability. This results in lower income and higher care demands on the other parent.

There would appear to be no policy reason for denying Katie Beckett status to a child because he/she would get SSI in an institution, since the $45 is intended as a personal needs allowance.

A possible solution would be to change the test to whether the child would be eligible for Medical Assistance in an institution. The test that potential Medical Assistance costs in the institution must be higher than costs under Katie Beckett would remain. Under these tests, the law would cover children in the home who would be paid for by Medical Assistance (at greater cost) outside the home. This is clearly the policy behind Katie Beckett. Children with high personal wealth would not be brought into the program, since the Medical Assistance resource test would still apply. The child's income is also factored into this test, as the income would lower the cost to Medical Assistance if the child were in an institution, and the child still must show that costs to Medical Assistance in the home are lower. Thus, children with high personal income would also be excluded, unless they had extremely high institutional costs.

A second possible solution would be to exclude income from Social Security or other benefits based on the death, disability or retirement of a parent from consideration in deciding whether the child meets the $45 SSI income limit. This is less desirable for two reasons. First, the $45 income test has no relation to the program's policy and complicates the program unnecessarily. Second, children with other kinds of income would still be excluded from Katie Beckett, even though they could get Medical Assistance, at greater cost, in an institutional setting.

The Council hopes that a change can be made part of this year's Reconciliation Act.

Sincerely,

Donald D. Cannady

Donald D. Cannady
Chairperson

cc: Bob Bohlman, Wis. Federal/State Relations Office
Susan Ames-Zierman, NADDC

**WISCONSIN
COALITION FOR
ADVOCACY**

May 15, 1987

Senator John H. Chaffee
Attention: Christine Ferguson
FD567, Dirksen Senate Office Building
Washington, D.C. 20510

Dear Senator Chaffee:

I am writing about a very serious problem that affects a particular category of Wisconsin families: families with severely disabled children with high medical needs where one or both parents has died, is disabled, or is retired.

Historically, a child who lived at home could only qualify for Medical Assistance if his or her parents' income and assets were at poverty level. This was because part of the parents' income and assets were "deemed" to be income and resources of the child. However, if the child was placed outside the home, in a foster home or institution, the parents' income and assets were no longer considered, and he or she could get Medical Assistance and other benefits. Low and middle income parents were faced with a difficult choice: impoverish themselves trying to meet medical and care costs, or place the child outside the home where comprehensive health care coverage would be available.

Recognizing that this system was inhumane and wasteful, in that it encouraged separation of families and expensive institutional care, Congress in 1982 created a special program, called the "Katie Beckett" program after the little girl who inspired it. Section 1902 (e) (3) of the Social Security Act, codified at 42 USC 1396a(e)(3), allows a state to certify a child living at home as eligible for Medical Assistance, regardless of the parents' income and assets, if:

1. The child needs the kind of care a hospital, nursing home, or institution would provide;
2. The child can receive appropriate care at home;
3. It will not cost the Medical Assistance program more to serve the child at home rather than in an institution; and
4. The child would be eligible for a Supplemental Security Income payment if he or she were institutionalized.

THE DESIGNATED PROTECTION AND ADVOCACY AGENCY FOR PERSONS WITH DEVELOPMENTAL DISABILITIES IN WISCONSIN
16 NORTH CARROLL ST. SUITE 400, MADISON, WI 53703
(608) 251-9600 Voice and TTY

personal needs allowance, and is irrelevant to Katie Beckett children living at home. The best solution in my opinion would be to change the test to whether the child would be eligible for Medical Assistance in an institution. The test that potential Medical Assistance costs in the institution must be higher than costs under Katie Beckett would remain. Under these tests, the law would cover children in the home who would be paid for by Medical Assistance (at greater cost) outside the home. This is clearly the policy behind Katie Beckett. Children with high personal wealth would not be brought into the program, since the Medical Assistance resource test would still apply. The child's income is also factored into this test, as the income would lower the cost to Medical Assistance if the child were in an institution, and the child still must show that costs to Medical Assistance in the home are lower. Thus, children with high personal income would also be excluded, unless they had extremely high institutional costs.

A second possible solution would be to exclude income from Social Security or other benefits based on the death, disability or retirement of a parent from consideration in deciding whether the child meets the $45 SSI income limit. This is less desirable for two reasons. First, the $45 income test has no relation to the program's policy and complicates the program unnecessarily. Second, children with other kinds of income would still be excluded from Katie Beckett, even though they could get Medical Assistance, at greater cost, in an institutional setting.

We are hopeful that the needed changes can be made part of this year's Reconciliation Act. We are extremely appreciative of your interest in this problem, and of all your efforts on behalf of home and community-based services for people with disabilities. Please let me know if I can provide further information.

Sincerely,

Roy Froemming
Staff Attorney

Note: No federal funding was used in the preparation of this letter. Efforts to change the Katie Beckett legislation are funded by the Joseph Seiler Memorial Fund.

Enc: Statute
HCFA letter

Easter Seal Society of Wisconsin, Inc.
1409 Emil Street Madison, WI 53713 608-257-3411

June 2, 1987

Senator John H. Chaffee
Attention: Christine Ferguson
FD567, Dirksen Senate Office Building
Washington, D.C. 20510

Dear Senator Chaffee:

I'm writing to let you know of the Easter Seal Society of Wisconsin's deep concern for a special group of families in Wisconsin. These are families who have severely multiply disabled children who require special care, have high medical costs and where one of the parents have died, is disabled or is retired. These are families who want to keep their disabled children at home with the family, but can't-simply because of an obvious oversight-which I'll explain.

These disabled children would be eligible for the Katie Beckett program and be allowed to live at home, be cared for by their family and be eligible for Medical Assistance-were it not for the oversight I mentioned. The oversight lies in the fifth "test" for eligibility for the Katie Beckett program. As it stands now, severly disabled children in families having limited income and where a parent has died, is disabled or retired, must be taken from the home and placed in an institution in order to be eligible to receive the medical care the child needs. The irony of this is that it could be corrected so easily without affecting the integrity or intent of the eligiblity test.

Section 1902 (e) (3) of the Social Security Act, codified at 42USC 139a (e)(3), allows a state to certify a child living at home as being eligible for Medical Assistance, regardless of the parents income and assets if fifth criteria are met. However, severely disabled children who have a parent who has died is disabled or retired cannot meet the 5th test for eligibility because of wording! It could be corrected simply and easily by changing it to read:

> "The child would be eligible for Medical Assistance (rather than Supplemental Security Income Payment) if he or she were institutionalized."

Approximately 400 severely disabled children in Wisconsin are currently living at home and being cared for by their families with the help of the Katie Beckett program (with considerable savings to the state). Sadly-and tragically because it isn't necessary-there are at least 35 other children in families who qualify in every respect for the Katie Beckett program but who have had to be removed from their homes and families simply because they have a parent who has died, is disabled or who has retired! If there are 35 in Wisconsin, one has to wonder how many there are nationwide? Simple calculations based on population ratios would suggest the number would be around 7,000 to 8,000 such children and families!

Please, Senator Chaffee, won't you try to initiate whatever action or take whatever steps are necessary to correct this unfortunate, unnecessary but correctable problem-hopefully as part of this years Reconcilation Act? I'm enclosing a more explanitory description of the issue, and a pamphlet on the Katie Beckett program in hope that it will be of help to you and your staff. Thank you for your interest, your concern and for helping.

Sincerely,

Roy M Campbell

Roy M. Campbell
Executive Director

RMC:se

Enc.

June 9, 1987

Senator John H. Chaffee
Attention: Christine Ferguson
FD567, Dirksen Senate Office Building
Washnington, D.C. 20510

Dear Senator Chaffee,

I recently learned you are interested in changing Medical Assistance to help people such as myself. Please feel free to use our situation as an example in introducing the change we need in the Senate.

We have a severely-handi-capped, legally blind, retarded daughter. She has uncontrolled seizures, and at the age of 12, functions at the 3-month old level.

Over the years, we have applied and re-applied for assistance with the many different programs. Since all the qualifications are relatively the same, we received rejection upon rejection.

We are not a wealthy family, but work hard to earn the assets we have. It is disgusting to see people purposely quit trying so that they can merit the government and tax-payers money.

The last few years have cast an even larger shadow over our happy home. Rick broke his back and had to relinquish his job on the C&NW Railroad. We then lost our health insurance.

I have SLE(systemic lupus erythematosis) with glomerular nephritis kidney disease. I receive Social Security Disability payments and Medicare. I recently purchaSED WI HIRSP high-risk health insurance, but the premiums and deductibles are tremendous.

The Katie Beckett Program would be a God-send to us. Our daughter Alta, is not eligible because she receives a check of $75.00 a month through my disability payment; not because of her disabilities at all. Alta does not receive SSI.

Alta is a sweet child who lives for love. An institution would not provide this. Her care is expensive. Home care is dramatically less costly than an institution, and that is what we want for her.

I have attached letters I have previously written and answers I have received in hopes that they too, may be helpful in presenting a change in this law.

I want to thank you very much for taking the time and making this great effort to help families such as ours. I believe a change is definately in order and hope you will share my concerns with other Finance committee members.

Thank you,

Julie A Johnson

Julie A. Johnson

Rt 3, Box 3371
Spooner, WI 54801

5-16-87

Dear Senator Chaffee,

I am writing to you about the Katie Beckett program. My son fits all the criteria except his father is disabled and he gets a small social security check which disqualifies him.

We are older parents with a fourteen year old son who has a spastic-athetoid quadriparesis condition. He also has a seizure disorder. He also has recurrent upper respiratory infections for which he receives bi-monthly injections of gamma globulin. He requires total care including dressing and feeding, transferring into his wheel-chair etc. He is also non-verbal which requires a lot of time for us to figure out what he wants to say. Wade has normal intelligence and is a real joy to us in spite of his many problems.

He is in desparate need of a new wheelchair and communication system as he has outgrown his electric chair and his communication system is now obsolete.

I work full time and also have many health problems including a heart pacemaker and diabetes

Thankyou for your willingness to sponsor a change in the law

Please share our concerns with other Finance Committee members.

Sincerely,
Ruth Ostrum
1718 C Z Arkdale WI
54613

612 Macomber St
Chippewa Falls, Wi
54729

May 19, 1987

Dear Senator Chaffee:

I am writing to you about a very serious problem that directly affects my family.

I am a widow with three dependent children. My oldest daughter, Michelle, is a 17 y.o. retarded youngster with cerebral palsy. I have raised her in my loving, home environment since her birth despite being told that she should be institutionalized.

In October 1986, Michelle became very ill with pancreatitis and a pituitary gland tumor. I have not been able to get anyone to insure her due to her many previous surgeries and medical conditions, so I was faced with massive medical bills totaling over $18,000.

I applied through my County social service department but I was denied any help due to my social security income. After being rejected, I applied for my state's "Katie Beckett" coverage. But, due to the current laws, I was again denied "Katie Beckett" coverage because of Social Security.

This program is very important to me because my child will require on-going medical care for the rest of her life.

I feel strongly that my child deserves a home "loving, nurturing environment not based on my income or assets.

I feel a change in the law is needed — ① Removal of the requirement that the child would be eligible for SSI in an institution. ② Substitute the requirement that the child would be eligible for M.A in an institution. ③ Removal of parents income as guidelines for Katie Beckett program.

I want to personally thank you Senator Chaffee, for your willingness to sponsor a change in the law regarding this program.

Please, share my concerns with the other members of your committee. I will be anxiously awaiting your committee's decision.

Sincerely
Bev Sedlitz

1016 Cypress St.
Little Chute, Wi. 54140
May 19, 1987

Senator John Chaffee
Senate Office Building
Washington, D. C. 20510

Dear Senator Chaffee:

I am writing to you after being advised by the Wisconsin Coalition for Advocacy that you are going to introduce a bill that would change the Katie Beckett law so that it can help families who receive Social Security benefits.

My husband died in an accident at work in December, 1979. My son Timothy was three months old at the time and his sister was 3 1/2 years old. About 4 months later I quit my full-time job to care for my family and home full-time. Tim was not progressing normally. I hoped that the additional time and attention I could give him would make a difference.

Tim is now over 7 1/2 years old. Mentally, he is still under one year of age. He feeds himself, but needs total assistance. He is not toilet trained. He can walk, but often doesn't want to. He has no realization or fear of danger. He has had surgery to correct a severe vomiting problem and a muscle biopsy that revealed that he only has weak muscles; no disease is present. He is diagnosed as being severely profoundly mentally retarded.

About 2 years ago, I applied for Medical Assistance for Tim in the hopes that I might be able to continue keeping him at home. Although Tim is pretty healthy now, adult diapers cost almost $100 per month. My Blue Cross Blue Shield premiums had tripled since I quit work. (Approximately $90 per month for a single parent family in 1980 to over $320 per month in 1985 - I now pay $425 per month for a single parent family plan.) This was the cost without anyone being sick or needing medical care. My insurance has a $250 deductible for medical visits and drugs for each person. Each trip to the hospital cost me $1,000 of the first $5,000 of the bill. Dental and vision care are not covered at all.

If I dropped our health insurance to save money and live within my budget, I risked losing my house and everything I had worked for during my 14 years of employment and everything my late husband had worked for.

It was no longer safe to leave Tim for a few minutes. Without a spouse or child old enough to help, I needed to hire babysitters so that I could grocery shop, cut the lawn, or run errands. I didn't dare to get sick. The only person I had to help me in emergencies was one sister who lived 1/2 hour away. I was glad she wasn't on vacation when I sprained my ankle and couldn't walk for 4 days.

I was fortunate to have worked for several years and to have had a home, savings, and life insurance benefits when my husband died. I'm sure I was better off financially than many people in my situation. I try to live within my means and I did without vacations and any extras that weren't necessary. Nevertheless, my interest income declined as my savings went down and the interest rates dropped and my expenses went up. I used up a lot of my savings when I bought a house that had additional room and safeguards for Tim.

In spring of 1985, two of Tim's teachers advised me that he should get behavior management training. That summer I received estimates of the cost of receiving Community Options home assistance or group home care for him. Both alternatives were equally as expensive to me, but with group home care I no longer had to buy diapers or find and pay so many sitters. If the living situation became permanent, I could drop him from my health insurance and find a policy with a greatly reduced premium for my daughter and myself. (Recent minor health problems may make this impossible now.) Since he qualified for M.A. outside the home, I would no longer have any expenses for him for medical, dental, or hospital bills. I would also be free to return to school or work.

My decision to place Tim was the most difficult thing I have ever had to live through. He was placed in an Agape Group Home in Appleton in February, 1986. I was grateful that he could be placed so near to home. He is only about 15 minutes away from here. An earlier recommendation that he be placed in Central Wisconsin Center for the Developmentally Disabled would have meant two hour trips one way to see him.

Tim's current Social Security benefit of $371 goes directly to Social Services for his care and I am assessed child support in addition to that, based on our household income. (Thus Tim gets his full 1/3 of the Social Security benefits and a portion of Sally's and mine through the additional support assessment.) Our contribution still falls far short of the $2,500 per month ($30,000 per year) that the group home costs.

If and when Tim is toilet trained and a little more self-sufficient, he might be able to return home. In spite of all his problems, he is a very happy and loveable little guy. I managed him at home for over 5 years and it wouldn't be impossible to have him home in the future, if I could afford it. When 40% and more of the family income must go toward medical insurance premiums and medical and dental bills when he lives at home though, it is hard to justify these costs indefinitely. My savings will not last forever.

Even though I am still using savings to live month-to-month now while I am in school full time, the day will come when I return to work and I will no longer need to do that. After I get my Associate Degree in Accounting, I hope to find a job that pays a better wage than I made in the past.

I'm still not sure that I could make enough to pay high insurance, medical, and day care bills for Tim. Being able to have Medical Assistance for him if he lived at home might very well make the difference in a decision to return him home.

It is very upsetting and stressful to have to request M.A. for a handicapped child; it is totally demeaning and demoralizing to be turned down when you qualify in every way except for some unfair technicality.

Intact families with more support resources can get SSI and MA for their children. Single parents on welfare get free medical benefits for their entire family and additional SSI benefits for their handicapped children. Those of us who have worked and are entitled to Social Security benefits because of death, disability, or retirement are not treated that well, even though our needs are often greater.

I urge you to work to change this law.

Sincerely yours,

Lois E. Coenen
Mrs. Lois E. Coenen

June 9, 1987

Senator Chaffee,

We do not qualify for the Katie Beckett program because my husband retired in 1983 due to ill health. In 1986, our 14 year old, physically and mentally handicapped son received $2904.00 in social security benefits as a dependent. That year we paid $2305.65 for medication, doctors and blood tests. This didn't include the basic necessities or other expenses.

After my husband retired, we were able to continue his group insurance for 18 months. Then the premiums were $2500.00 every three months. Needless to say, we couldn't afford that. We do not need extra income, we need a medical card. I racked my brain, devising ways to benefit my son. The disadvantages to every idea outweighed the advantages.

Once I even suggested to Central Wisconsin Center that they take my son, we would in turn become foster parents and take him back. Then he would have everything he needed. This idea didn't work - we were "too old" to be foster parents!!

There are many organizations willing to help — if you qualify — We never qualified! Our annual income was always too high or we didn't have more dependents.

The Katie Beckett program must be changed. Even though we ourselves still may not qualify, I pray the change will benefit the many others who simply fell through the "crack in the floor" of a well intended program.

I sincerely thank you for your interest in wanting to change the Katie Beckett law and hope you can prevail upon other members of the Finance Committee how important medical assistance is to all of us. This could prevent more families from giving up their child in order to survive. A disabled child and the financial burden, destroys more than family unity. We know - we've been there.

Thank you for taking time to read this letter and for your concern in changing the Medical Assistance law.

Mrs Gerhard Schmidt
815 Lafayette Street
Watertown, Wisconsin 53094

NEG. RM - FURNISH NEG + DYLUX
THIS WAS NOT SHOT.
JKILROY - PREP

May 16/87

Dear Senator Chaffee

I am a widow with a son who turned Sixteen in March of 87

For Eight years we were not eligible because of the money that was left when my husband died and our income was too high from Social Security benifits; now after all my funds are ephausted and a $20,000. [illegible] mortgage on our home, my son got a medical assistance card, but I am fifty seven and with no income, I do not qualify because I am not blind, disabled or under 18, yet I can not psss a physical and 12% unemployment here in Manitowoc, W.i.,

My medication costs $67.00 month mortgage payment $250.00 a month plus utilities, how do you live on $548.00 monthly?

I have no choice, but to stop taking my medication, I just can not afford it, Guess you have to die first and then you qualify. It is strange they can send all this money to other countries to help, but can not take care of people in this country, I used to think what a great country we have, but no more. I use to give to all those fund drives because I wanted to help, now that I need help, forget it they don't even want To Tell [illegible]

I am very thankful my son got a Medical card, but what do I do? Any help would be greatly appreciated.

Thank you.

Florence Langlais

Phone (414) 682-1933 526 West Lawn Blvd
Manitowoc, Wis. 54220

Senator **Durenberger**. I will make the observation, Mr. Gettings, that we have been working on this Chafee approach together for about 4 years now.

Mr. **Gettings**. That's correct.

Senator **Durenberger**. John keeps pushing us and I kept holding hearings. And for some period of time, you and your Association weren't so sure that this was the right way to go about it. I wonder if you wouldn't, for our benefit, tell us why the new Chafee approach works, or you think it will work; and why the current system of waivers doesn't work.

Mr. **Gettings**. OK. Let me start with why I think it will work. First of all, Mr. Chairman, there is a significant difference between—and Senator Durenberger—between the previous versions of the bill and this version of the bill. Most notably there is a change in terms of how the bill deals with the question of institutional phase down. In this version of the bill, basically what will happen, and as I understand it, is that the States would have reimbursement under Medicaid frozen at the current fiscal year level. That will achieve significant savings over the forthcoming years, which can, in fact, be used in a more cost-effective way to support community-based alternatives. That is the direction those States are going. There is tremendous disincentives to doing that.

The other issue that ought to be talked about in that respect is that current policy emphasizes continued dependency in order to receive long-term-care services. The new version of the Chafee bill will put an emphasis on (1) family based approaches, which will be certainly more cost effective as we know from past experience; and (2) a reduction of dependency by making people able to live in community settings and be employable, I might add, even though they have severe handicaps.

Why doesn't the waiver program work? Well, I think it doesn't work because there is a fundamental flaw in the logic underlying the waiver program, which is to say that if you fulfill the goals of the waiver program, that is, eliminate at institutional capacity, you simultaneously undermine your ability to qualify for waivered services. Your State has just gone through a very rocky attempt to get a renewal of its waiver program; Maine has just gone through the same thing; New Jersey will soon be in the same position.

I think the basic underlying philosophy behind it, concept behind it doesn't work in the long run.

Senator **Durenberger**. Thank you very much. Thank you, Mr. Chairman.

Senator **Bradley**. Thank you very much, Senator Durenberger. Let me thank both of you for your testimony.

Mr. **Gettings**. Thank you, Mr. Chairman.

Senator **Bradley**. I would particularly appreciate your testimony, Mr. Johnson, because I think that the problem of low birth weight babies is just not known in this country. I think if anybody knew that infant mortality in the United States, in some places in the United States is lower than in some parts of the developing world——

Mr. **Johnson**. That's true.

Senator **Bradley** [continuing]. That they would be shocked.

Mr. **Johnson**. That's right.

Senator BRADLEY. The point here, and I think your testimony highlights it, is that for very little additional dollars that would be shared by both State and Federal, we could make a dramatic improvement in our infant mortality rates. In other words, fewer babies would die.

Mr. JOHNSON. Absolutely.

Senator BRADLEY. I had the experience of—I'd like to have your reaction to this, having said I wouldn't ask any more questions, I can't resist. It was reported to me that the problem isn't only the infant mortality that takes place immediately after birth, but in many cases in many places of the country, if a mother qualifies and you have a low birth weight baby, and you get the kind of care that gets you through the first couple of months, and the low birth weight baby then goes to a home setting where there is not adequate care there is an astonishingly high number of deaths in that first year that didn't figure into the statistic of infant mortality. Has that been your experience?

Mr. JOHNSON. That is exactly the case. Putting a baby which needs a lot of heavy care into a home which is, by definition, poverty level, where the mother is probably without any other support, no husband, possibly living in a welfare-provided residence of some sort—it is very, very unlikely that even a healthy baby move back into that kind of environment would survive and be healthy.

Senator BRADLEY. But if it was a low birth weight baby it would have an exceedingly great problem.

Mr. JOHNSON. If it was a low birth weight baby, it would be exceedingly great.

Senator BRADLEY. So that unless we are prepared to make the investment necessary to ameliorate the problem of those homes, by far the most cost effective way to deal with this problem is to prevent the low birth weight baby in the first place.

Mr. JOHNSON. Absolutely.

Mr. GETTINGS. Senator Bradley, if I may add, as representing agencies that deal with the consequences of severe life-long disabilities, early prenatal care on behalf of infants and young children is absolutely essential to reduce the incidence of mental retardation, cerebral palsy, and a variety of other disabilities, which after all cost the taxpaying public, in each case, sometimes as much as $1 million over the life of the individual.

So it is also a matter of the long-term consequences of disability that grow out of this.

Senator BRADLEY. So the point that you make is not to raise Medicaid coverage up to 185 percent of poverty would be penny wise and pound foolish.

Mr. GETTINGS. Exactly.

Senator BRADLEY. Right? Because if you don't make the investment up front prior to the birth, you are then going to be making the investment for the entire life of the child.

Mr. GETTINGS. That's right, Mr. Chairman. Absolutely.

Senator BRADLEY. That investment will also be one that will have a human tragedy attached to it.

Mr. GETTINGS. Certainly.

Mr. JOHNSON. I would say it costs more to cure the problem after it has started, after onset, than it would to prevent the problem on the first hand.

Senator BRADLEY. Well, let me thank both of you for your testimony.

Mr. JOHNSON. Thank you.

Mr. GETTINGS. Thank you, Mr. Chairman.

Senator BRADLEY. Our next panel consists of Ms. Sara Rosenbaum, director, Child Health Division of Children's Defense Fund; Mr. Jacob Clayman, president, National Council of Senior Citizens; and Mr. Richard Nugent, chairman of the Health Task Force, the Epilepsy Foundation of America.

Let me welcome all of you to the committee. Let me say that we are in the midst of a vote on the floor, so when the five buzzers ring, I will have to excuse myself and don't be surprised if Senator Moynihan comes back to chair. It will be Senator Moynihan; it will not be me. So you should be aware of it. I think we should begin and then—I think probably we should begin and then if I have to leave, I'll leave—which will probably be in the middle of the first witness. So, Ms. Rosenbaum.

STATEMENT OF SARA ROSENBAUM, DIRECTOR, CHILD HEALTH DIVISION, CHILDREN'S DEFENSE FUND, WASHINGTON, DC

Ms. ROSENBAUM. Thank you for providing us with this opportunity to testify. We are grateful for the concern and leadership on maternal and child health that so many members of this committee have displayed, in particular yourself and Senators Bentsen, Durenberger, and Chafee. I have submitted longer testimony for the record, and will quickly turn to our recommendations in my remaining time.

It is simply essential that all children, whether they are healthy or sick or young or adolescent, have health insurance, given the high cost of routine care and the large number of children who are living at or near the Federal poverty level.

We therefore want to indicate our broad support for legislation introduced by Senators Kennedy and Chafee to remedy, in a major way, the problem of lack of health insurance among children and families. We recognize, however, that Congress is still a distance away from enacting universal coverage policies. We therefore recommend enactment this term of a number of Medicaid and Title V Maternal and Child Health reforms targetted to key groups of vulnerable children.

First, of course, we recommend enactment immediately of your bill, S. 422, which is absolutely essential to improve access to both maternity and infant care and pediatric services. Its' enactment was fully assumed in the Budget Resolution and we hope for speedy action.

Second, we ask that your committee act to end the discrimination engaged in by a number of States against disabled children. There are five States in the country that still fail to cover children who are eligibile for SSI benefits and many more that fail to provide Medicaid to children who could be cared for at home.

I would like to read to you a letter that we received yesterday from a mother of a disabled child in New Hampshire, one of the five States that discriminates against disabled children. The child is severely ill with neurofibromatosis. He is 20 months old. She writes:

> We have endured so much and have fought to remain a family, that the thought of having to put him in a hospital is not one we could bear. * * * Madison belongs at home and we have not been able to find any other source for keeping him there. The annual cost of keeping Madison at home is approximately $125,000. This is more than we are capable of. * * * I hope that Madison's history helps justify the need for different funding sources for situations such as ours. We have been told and believe that we are part of the small group of pioneers who are beginning to challenge the health care system as it has been for a very long time. Every person has the right to be with their family in their home, versus being in an institution because they are not perfect.

Madison needs Medicaid for this child to stay at home. New Hampshire will not supply Medicaid to the child for the reasons having to do with issues we raise in the testimony. We ask that all States provide Medicaid to children who could be cared for at home and that all States provide Medicaid to disabled children.

Finally, we also want to applaud Senator Durenberger, Senator Chafee, and Senator Bentsen for their concerns about disabled children. We recommend specifically a new program to provide Medicaid to children with family incomes under 200 percent of the federal poverty level who have illnesses, disabilities, and conditions that limit or impair normal childhood activities. There are about 400,000 such uninsured children. They are a high priority group, particularly in light of the new special education laws designed to promote early intervention and special education services.

Studies conducted by the Robert Wood Johnson Foundation show that many of these children are not benefitting from special education and early intervention, because they do not have the medical care they need to be able to take advantage of educational activities.

We also ask for the establishment of a special Title V program to assist families with children with high-cost illnesses, and newborns and infants who incur catastrophic costs. Finally, we ask that you include in the reconciliation bill a $200 million increase in the Title XX Social Services Block Grant, the major source of funding for a wide range of essential social services for children.

In closing, I would like to note that we are in support of Chairman Bentsen's recommendation for a select commission on children.

Senator BRADLEY. Thank you very much, Ms. Rosenbaum, for your testimony, and also, Ms. Rosenbaum, for your tireless advocacy of issues that affect children.

Ms. ROSENBAUM. Thank you.

Senator BRADLEY. I would like to express my personal appreciation for your help in the infant mortality bill, S. 422.

We now have three minutes left in the vote, so I will have to absent myself. The committee will stand in temporary recess and we will be reconvened as soon as the vote is over and Senator Moynihan returns. I look forward to reading the testimony of Mr. Nugent and Mr. Clayman.

Mr. NUGENT. Senator Bradley, before you leave, the disability community would like to thank you for your efforts on behalf of infants and children.

Senator BRADLEY. Thank you very much. Thank you. Oh, continue. [Laughter.]

Senator DURENBERGER. All right. Mr. Clayman, thank you.

[The prepared statement of Ms. Sara Rosenbaum follows:]

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Testimony of the Children's Defense Fund Before the Senate Finance Committee Regarding Medicaid, The Maternal and Child Health Block Grant And Other Matters Pending in the Fiscal 1988 Budget Reconciliation Process

Presented by
Sara Rosenbaum
Director, Health Division

July 10, 1987

Mr. Chairman and Distinguished Members of this Committee:

The Children's Defense Fund (CDF) is pleased to have this opportunity to testify today regarding Medicaid, the Maternal and Child Health Block Grant and other pending issures in the Fiscal 1988 Budget Reconciliation process. CDF is a national public charity which engages in research and advocacy on behalf of the nation's low income and minority children. For fifteen years, CDF's health division has engaged in extensive efforts to improve poor children's access to medically necessary care, including both primary and preventive services, as well as medical care requiring the most sophisticated and costly interventions currently available. I have submitted a longer statement for the record and will present a summary of my testimony at this time.

I. The Health Status of Children

Both ends of the medical care spectrum -- preventive and intensive -- are vital to the health and well-being of children. All children need primary care, including comprehensive maternity care prior to birth, ongoing health exams and followup treatment, care for self-limiting illnesses and impairments (such as influenza or strep), and vision, hearing and dental care. Additionally about one in five children will be affected during childhood by at least one mild chronic impairment, such as asthma, a correctable vision or hearing problem, or a moderate emotional disturbance, which will require ongoing medical attention.

Beyond these basic health needs, a small percentage of children require more extensive and expensive medical care; and a modest proportion of this latter group will face truly extraordinary health care costs over their lifetimes. About four percent of all children (a figure which by 1979 was more than double the percentage reported in 1967)[1] suffer from one or more chronic impairments resulting in a significant loss of functioning. Included in this group are children suffering from degenerative illnesses, multiple handicaps, and major orthopedic impairments. About two percent of all children suffer from one of eleven major childhood diseases, including cystic fibrosis, spina bifida, leukemia, juvenile diabetes, chronic kidney disease, muscular dystrophy, hemophilia, cleft palate, sickle cell anemia, asthma, and cancer.[2] Also included in this group are the several thousand children who are dependent on some form of life support system.

Finally, nearly 7 percent of all infants are born at low birthweight (weighing less than 5.5 pounds) each year.[3] Virtually all will require some additional medical services. About 18 percent of all low birthweight infants (approximately 43,000 infants) weigh less than 3.3 pounds at birth and will require major medical care during the first year of life. About 9600 infants will incur first year medical costs alone that exceed $50,000, and a portion will require ongoing care throughout their lives.[4] Low birthweight infants are at three times the risk of developing such permanent impairments as autism, cerebral palsy and retardation.[5]

II. The Health Needs of Children

Most children, even children with impairments, require relatively modest levels of health care. Only about five percent of all children incur annual medical costs in excess of $5,000, and only about 5 percent of these have annual costs exceeding $50,000.[6] However, both groups of children -- those with routine health care needs and those with high cost medical problems -- can be considered catastrophic cases, in either relative or absolute terms.

For low income uninsured families, even basic child health needs can result in catastrophic expenditures if the term "catastrophic" is measured in relation to a family's overall income. Between 1982 and 1985, the number of completely uninsured children climbed by 16 percent.[6a] In 1985, three quarters of the 11 million uninsured children,[7] and two-thirds of the more than 9 million uninsured pregnant women,[8] had family incomes below 200 percent of the federal poverty level. Poor and near-poor uninsured families, when confronted with even normal child health expenditures of several hundred dollars per year, face insurmountable health care barriers. As a result, uninsured low income children receive 40 percent less physician care and half as much hospital care as their insured counterparts.[9]

The uninsured are disproportionately likely to be children. In 1985, children under 18 comprised 25 percent of the under-65 population, but one-third of the uninsured under-65 population.[10]

Moreover, they are disproportionately likely to be poor. Over 60 percent of all uninsured persons in 1985 had family incomes below 200 percent of the federal poverty level, and one-third had family incomes below 100 percent of the federal poverty level.[11]

Even a parent's access to employer insurance by no means assures relief for a child. In 1985, 20 percent of all uninsured children lived with a parent who had private coverage under an employer plan.[12]

The two main causes of children's lack of health insurance are the major gaps in the employer-based health insurance system and the failure of Medicaid, the nation's major public health insurance program for children, to compensate for the failings of private plans.

The Private Health Insurance System Is Leaving More American Children Uninsured

Our nation relies primarily on private health insurance to meet much of the health care costs of the working-age population and its dependents. Most of this private insurance is provided as an employment-related benefit. Employer-sponsored health care plans are the single most important source of private health care coverage for Americans younger than sixty-five. In 1984, over 80 percent of all privately insured American children were covered by employer plans.[13]

Yet during the 1980's, dependent coverage under employer-provided health insurance plans has undergone serious erosion.

In 1982, employer plans covered over 47 million non-workers, including 36 million children. By 1985, even though there were actually more workers covered by employer plans than in 1982 (88 million versus 84 million), the number of covered children dropped to less than 35 million.[14] The recent decline in employer-provided coverage has been most apparent among children for several reasons. First, in pursuing cost containment strategies, employers have frequently reduced or eliminated their premium contributions for family coverage.[15] As a result, lower income employees, faced with dramatic cost increases, have been forced to drop family coverage.

Second, the employer insurance system also completely excludes millions families at the lower end of the wage of scale -- the fastest growing part of the job sector. Thirty percent of all employers who pay the minimum wage to more than half their work force offer no health insurance.[16] As these young adult workers have families, the children are affected by their parents' lack of coverage.

Third, as the number of single parent households grows, the percentage of insured children declines. Because single parent households have only one wage earner, the probability that a child will have indirect access to an employer plan drops. In 1984, children in single parent households were about 3 times more likely than those in two parent households to be completely uninsured.[17] Thus, the employer-sponsored health insurance system excludes those children whose parents' employers either do not offer any family coverage or else offer it only at an unaffordable cost. As a result of these trends, a child living in a poor working family is only about half as likely as a non-poor child to have private insurance.[18]

Medicaid, the Major Public Insurance Program for Families with Children, Is Covering Fewer Children

Medicaid, enacted in 1965, is the nation's largest public health financing program for families with children. Unlike Medicare, which provides almost universal coverage of the elderly without regard to income, Medicaid is not a program of universal or broad coverage. Because Medicaid is fundamentally an extension of America's patchwork of welfare programs, it makes coverage available primarily to families that receive welfare. With a few exceptions (including pregnant women and children younger than five with family incomes and resources below state-set Aid to Families with Dependent Children eligibility levels), individuals and families that do not receive either AFDC or Supplemental Security Income (SSI) are categorically excluded. For example, a family consisting of a full-time working father, mother, and two children normally is excluded from Medicaid, even if the father is working at a minimum wage job with no health insurance and the family's income is well below the federal poverty line. Moreover, even though states have had the option since 1965 to cover all children living below state poverty levels regardless of family structure states still fail to do so.[19]

In addition to its use of restrictive eligibility categories, Medicaid excludes millions of poor families because of its financial eligibility standards, which for most families are tied to those used under the AFDC program. In more than half the states, a woman with two children who earns the minimum wage (about two-thirds of the federal poverty level for a family of three in 1986) would find that she and her children are ineligible for coverage.[20] By 1986, the combined impact of Medicaid's restrictive categorical and financial eligibility standards had reduced the proportion of the poor and near-poor covered by the program to only 46 percent--down from 65 percent a decade earlier.[20a]

As a result of improvements enacted by Congress in 1984 and 1986, many previously uninsured low-income pregnant women and children will be aided.

- o The Deficit Reduction Act of 1984 (DFRA) mandated that states provide Medicaid coverage to all children younger than five with family incomes and resources below AFDC eligibility levels.
- o The Deficit Reduction Act and the Consolidated Omnibus Budget Reconciliation Act of 1986 (COBRA) together mandate coverage of all pregnant women with income and resources below state AFDC eligibility levels.
- o The Sixth Omnibus Budget Reconciliation Act (SOBRA) passed in late 1986 permits states at their option to extend automatic Medicaid coverage to pregnant women and children under age five with incomes less than the federal poverty level but in excess of state AFDC eligibility levels. Table I indicates that by July, 1987, 19 states had adopted SOBRA coverage.

  If fully implemented in every state, the SOBRA amendments will reduce by 36 to 40 percent the number of uninsured pregnant women and young children nationwide.[21]

However, even if fully implemented, these new laws will not compensate for Medicaid's growing failures. SOBRA's age limitations mean that Medicaid still will not reach children over age five with family incomes below the federal poverty level. Because of DFRA's age limits, in 19 states, poor children over age five are still excluded, no matter how severe their poverty, simply because they live with two parents and are beyond the age mandate of the 1984. Moreover, these new laws provide no relief for the millions of uninsured, nonpregnant, poor parents, whether working or unemployed.

Improvements enacted by Congress and the states in recent years are unlikely even to offset the decade of stagnation and erosion which Medicaid has experienced. In Fiscal Year 1985, Medicaid served 10.9 million children under age twenty-one--more than 400,000 fewer than were served in Fiscal 1978.[22] This drop occurred despite the fact that Fiscal 1985 was the first year that the 1984 Deficit Reduction Act amendments were in effect, and it followed enactment by about a dozen states of additional Medicaid child coverage improvements. This decline occurred as the number of children in poverty rose by one-third and the number of uninsured children grew by 16 percent.

The Special Needs of Children with High Cost Health Problems

By expanding the number of children with health insurance, Congress would also provde extensive relief for children with high cost medical needs which arise as a result of serious illness or disability.

Medical problems disproportionately affect low income children who tend to be born at lower birthweight and suffer more frequent, and more severe illnesses and disabilities.[23] Thus, insuring more low income children would also assist many chronically ill and disabled children.

Among the 10% of children who have an illness or disability sufficiently serious to limit normal childhood activities, we estimate that there are about 400,000 poor and near-poor children with incomes below 200% of the federal poverty level who are completely uninsured. Moreover, even normative levels of insurance, public or private, are inadequate in the case of the most severely catastrophically ill or disabled infants and children. There are about 19,000 such children (9600 of whom are under one year of age) who annually incur more than fifty thousand dollars in health care costs.

The traditional notion of health insurance is that it provides protection against grave health costs. But over time the nation has developed public and private health insurance systems that are designed to meet normative, rather than high cost catastrophic, medical care needs. Both public and private health insurers have developed myriad ways to limit their exposure for high-cost illnesses and disabilities, in favor of providing subsidies for more routine health expenditures:

- Among employers responding to a major health insurance survey conducted in 1986, 73 percent indicated that their plans exclude coverage of preexisting conditions.[24] More plans now also contain riders that exclude coverage of certain conditions that may develop among enrollees, such as cancer.

- Only about 75 percent of plans offered by medium and large-sized firms between 1980 and 1985 contained protections against huge out-of-pocket costs borne by enrollees in the event of catastrophic illness.[25]

- Only 67 percent of mid-and-large-sized firms offered extended care benefits between 1980 and 1985, and only 56 percent offered home health benefits.[26]

- In 1977 only 8.3 percent of all children had unlimited private coverage for major medical benefits, and one-third had coverage for a quarter million dollars of care or less.[27]

- Fourteen state Medicaid programs place absolute limits on the number of inpatient hospital days they will cover each year, with some states limiting coverage to as few as 12-15 days per year.[28] About an equal number place similar limits on coverage of physicians' services. Others place strict limitations on such vital services as prescribed drugs and diagnostic services.

- Finally, Medicaid, like private health insurance frequently fails to cover extended home health and related services (including such non-traditional items as home adaptation). When such coverage is available, it may be provided on a case-by-case exception basis.

The question of whether private and public insurers should provide comprehensive but shallow, versus deep but limited, coverage is a complex one, particularly since so many American families need a financial subsidy to meet even basic health costs. While this issue is being resolved however, thousands of uninsured are inadequately insured children with chronic health problems face serious underservice, particularly if they are low income.

Recommndations

It is essential that all children -- infants or adolescents, healthy or sick -- have health insurance. Given the high cost of even routine health care, particularly in the case of poorer families, comprehensive health insurance is an absolute necessity. We support both legislation introduced by Senator Chafee, which would provide public coverage through Medicaid for families and children who are without coverage, as well as legislation introduced by Senator Kennedy, which would expand the nation's private health insurance system to reach millions of working families.

We recognize, however, that Congress is still some distance away from enacting policies that would ensure adequate health coverage for all children. We therefore recommend enactment this term of both Medicaid and Title V Maternal and Child Health Block Grant reforms targetted on key groups of children with high priority needs.

Medicaid

o Enact S.422, the Infant Mortality Amendments of 1987. This bill, introduced by Senator Bradley and Congressman Waxman and cosponsored by many members, would add Medicaid coverage of children ages five to eight living below state poverty levels, as well as further strengthen states' capacity to serve poor and near-poor pregnant women, infants and young children. This bill has bipartisan support, and its passage was assumed as part of the Fiscal 1988 Budget Resolution.

o End states' discrimination against disabled children. Currently at least 5 states (Connecticut, New Hampshire, Indiana, Minnesota and Missouri) categorically exclude from their Medicaid programs children who receive SSI benefits, unless they are also eligible under some other Medicaid coverage category. This exclusionary practice grows out of an obscure legislative provision dating back to the 1972 enactment of SSI. It is time that all states extended coverage to all disabled children who meet these states' financial eligibility standards. Some of the nation's most severely disabled children would be assisted.

- Mandate coverage of so-called "Katie Beckett" children. In 1982 Congress gave states the option of providing Medicaid to any child under 18 would be eligible for SSI if institutionalized, who could be cared for in a home or community setting, and whose home care would be no more costly than his or her institutional care. By definition, this was a no-cost eligibility option; yet only a dozen states have taken it. As a result, hundreds of children who might return home if they had Medicaid continue to languish in institutions because their eligibility would cease immediately upon deinstitutionalization. All states should be required to furnish home and community coverage to children, who satisfy the 1982 standards.

- Provide Medicaid to children with family incomes under 200 percent of the federal poverty level who have illnesses, disabilities and conditions that limit or impair normal childhood activities. In 1974 and 1986 Congress enacted landmark legislation guaranteeing special education and early intervention services to infants and children with disabilities that impair normal activity and inbibit proper growth and development. Many of these children suffer simply from a learning disability or require assistance only in meeting routine health care costs. Others, however, have serious medical impairments that limit their ability to grow and develop and perform normal childhood activities. Special education funds do not provide coverage for these children's medical needs. Studies of uninsured children in special education programs conducted by the Robert Wood Johnson Foundation and the Havard School of Public Health determined that children in special education who were low income and uninsured received significantly less medical care.

If the goals of the special education and early intervention laws are to be reached, low income children with activity limitations must also be provided with Medicaid as complement to their educational benefits. We strongly recommend passage of such coverage, phased in over the next several years, beginning with 0-3 years olds who are now eligible for early intervention services under Public Law 99-457. Coverage should be furnished free of charge to children with family incomes below the federal poverty level and in accordance with an income-adjusted premium for children with incomes between 100 and 200 percent of the federal poverty level.

- Enact Medicaid improvements for working poor families leaving AFDC. Amendments recently added to the House Welfare Reform bill by the Energy and Commerce Health Subcommittee, contains significant Medicaid improvements for the working poor. These improvements can stand on their own in the Reconciliation bill. The committee bill would extend to 24 months the four-month Medicaid transitional period now provided to most working recipients losing AFDC. It would also give states the option of furnishing benefits for an additional 18 months. During most of the 24 - month period benefits would be furnished in accordance with an income-adjusted premium. This bill constitutes not only a strengthening of the current Medicaid work incentive but also an important modification of the existing Medicaid system that will permit the program to reach many working poor persons not covered by private insurance.

The Title V Maternal and Child Health Block Grant

- Establish a special Title V program to assist families with children with high cost illnesses and newborns and infants who incur catastrophic costs. Of the 9600 infants with medicals costs in excess of $50,000 annually, nearly 20% will be completely uninsured, and many of the rest will have inadequate or no protection for the range of institutional and noninstitutional care they need. We urge establishment of a fund for these children, accompanied by a strong system of case management for all children with annual health costs exceeding $5000. Full year costs of this proposal in Fiscal 1988 would be approximately $500 million.

The Title XX Social Services Block Grant

- Include in Reconciliation a $200 million increase in the Title XX Social Services Block Grant, the major federal source of funds for a wide range of essential social services. Many of these services are preventive and designed to reduce the incidence of more costly alternatives. Title XX is the primary source of federal support for child care for low-income parents who are seeking to become self-sufficient by working or participating in training programs. It is also a critical source of funds for protective services and foster care for children suffering from abuse and neglect. Between 10 and 20 perent of Title XX funds aid older adults, enabling them to benefit from homemaker and home services, day care, counseling, protective and health services, home delivered meals, employment, housing improvement and recreational services. Finally, Title XX is a key source of non-institutional, community-based services for the disabled.

Despite the fact that Title XX provides this core funding for so many essential programs, it is now funded at $600 million less than it would have been if it had not been cut in 1981. In fact, when inflation is considered, funding for Title XX is half of what it was a decade ago, when Title XX was authorized at $2.5 billion.

Without a restoration of funds, states will not be able to meet the needs of their most vulnerable young, elderly, and disabled citizens.

- Today, 23 states provide fewer children with day care services than in FY 1981. When inflation is factored in, 29 states are spending less now than in FY 1981 for child day care services and, nationwide, such expenditures are down by 12 percent.
- Some states have totally eliminated adult day services for person with handicaps. Remaining states have huge waiting lists.
- In all states, child welfare agencies are being hard-pressed by dramatic increases in reports of child abuse and neglect. In 1985, there were approximately 1.9 million such reports, a 10 percent increase from 1984, and a 58 percent increase since 1981. As the value of Title XX funding erodes, sttes are being forced to make potentially tragic choices among competing demands for staff and resources. The need for increased protective service investigations to reunify children already in care with their families or to place foster children in adoptive homes have been slowed in some states. Others have limited services aimed at averting mroe serious family crises. Perhaps as a result, this year has witnessed an increase in child fatalities.

National Commission on Children

Mr. Chairman, because our goal is to educate the nation about the needs of children and encourage preventive investment in children, the Children's Defense Fund also supports your proposal to establish a National Commission on Children. The activities of such a commission could help better inform the nation on the status of America's children and consider ways to better ensure their optimal mental, emotional, and physical development. We believe that the well-being of children should be a part of our national policy debates, and we hope that a commission will succeed in highlighting the unmet needs of our children.

Thank you very much. We look forward to working with the Committee on the development of these vital initiatives.

STATEMENT OF JACOB CLAYMAN, PRESIDENT, NATIONAL COUNCIL OF SENIOR CITIZENS, WASHINGTON, DC

Mr. CLAYMAN. Yes. Hello, Mr. Chairman. The words of an old Senate hero, Senator Hubert Humphrey, still ring in my memory. He used to declare elegantly that the conscience and the morality of a nation could be determined by how it treated its young and its old. That is why I am pleased to appear this morning with those who represent the young, the children.

Senator DURENBERGER. Those in the dawn of life, those in the twilight.

Mr. CLAYMAN. And Senator, there is no dichotomy at all between the young and the old in this fight, in this struggle to care for all of them.

Now let me read a bit from my short statement. This Nation's highest health care goals should be to protect the poor and the less fortunate. Unfortunately, the poor and the less fortunate in this country are often found among children and the elderly. The United States has one of the highest infant mortality rates among industrialized countries—a fact we should work hard to reverse.

The National Council of Senior Citizens is deeply concerned about the health and well-being of the infants and children of this America. They are this Nation's future and we support efforts to improve their lives and to secure for them a healthy and happy future.

The Budget Resolution also includes some very important improvements in health care policy that affect the poorest and most frail older Americans—those in nursing homes. Specifically, I would like to discuss three changes in the Medicaid statute that would bring long-term overdue relief to millions of senior citizens.

This year, we should finally put an end to the awful requirement that a wife or husband must impoverish her or himself before the spouse in the nursing home shall be cared for by Medicaid. The National Council of Senior Citizens applauds efforts in this area.

The institutionalization of a spouse is often a very traumatic and dreaded step that only is taken when no other alternatives are available. Forcing a wife or husband to also impoverish her or himself so that the disabled spouse may receive long-term care is surely requiring too great a sacrifice from elderly couples who have been partners for life.

But this is exactly the choice many elderly couples are forced to make. NCSC as a part of a coalition of senior advocacy groups concerned with this issue urges Congress to solve these problems. I have listened to a lot of testimony before this committee and other committees of people who have been caught in the vise of feeling that they had found for themselves, finally, enough resources to help them through their older years, only to have one of them succumb to Alzheimer's or one of the other diseases that affect the elderly particularly. And then are forced by Government mandate, as it were, to spend down into poverty before they can look to their Government for assistance.

This an anomaly, this is unconscionable, this is not deserving for a nation like ours, a democratic Nation.

This is also the year that we should finally increase the paltry personal needs allowance received by Medicaid nursing home residents. Nearly 800,000 Medicare nursing home residents depend upon their personal needs allowance—$25 a month. From that, they are supposed to take care of all of their personal needs—their washing, their cleaning, their toothpaste, their razor blades—the whole gamut of personal needs that most of us take as a matter of routine, of no concern at all—we don't even think of it.

But these people have to think of every little tiny penny that they have to spend $25 a month.

Senator DURENBERGER. Mr. Clayman, you have two more points you want to make, and that means you haven't got a lot of time to make them.

Mr. CLAYMAN. Well, I'm carried away by this one at the moment.

Senator DURENBERGER. I know, we all feel it strongly, but we don't want to miss those other two points either.

Mr. CLAYMAN. And hopefully you will permit me later in the question period to make a reference to those other points. Because this is so damned atrocious, and I say that meaningfully, knowing what I'm saying. This has to be changed. Am I finished?

Senator DURENBERGER. Well, you are not finished. This part of your presentation is, but we will come back to you in the questions, and I want to give you the opportunity to come to those other two points.

Mr. CLAYMAN. I appreciate your kindness, sir.

Senator DURENBERGER. Thank you. Mr. Nugent.

[The prepared statement of Mr. Jacob Clayman follows:]

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MEDICAID RECONCILIATION ISSUES

Testimony Presented Before the

SENATE FINANCE COMMITTEE

By

Jacob Clayman, President
National Council of Senior Citizens

Washington, D.C.

July 10, 1987

Mr. Chairman:

Thank you very much for giving me the opportunity to represent the 4.5 million members of the National Council of Senior Citizens before your committee on Medicaid reconciliation issues.

We are more fortunate this year than some years in the past, in that the Senate Budget Resolution offers an opportunity to modestly improve needed services to our nation's poor. And in a program like Medicaid, even modest improvements are sorely needed.

This nation's highest health care goals should be to protect the poor and the less fortunate. Unfortunately, the poor and the less fortunate in this country are often found among children and the elderly. Our most serious national health care problems are found at the opposite spectrums of our population. The problems of infant mortality and caring for the children of the poor continue to plague us. The U.S. has one of the highest infant mortality rates among industrialized countries--a fact we should work hard to reverse.

The National Council of Senior Citizens is deeply concerned about the health and well-being of the infants and children of America. They are this nation's future and we support efforts to improve their lives and to secure for them a healthy and happy future.

The Budget Resolution also includes mention of some very important improvements in health care policy that affects the poorest and most frail older Americans--those in nursing homes. Specifically, I would like to discuss three changes in the Medicaid statute that would bring long-overdue relief to millions of senior citizens.

This year, we should finally put an end to the awful requirement that a wife or a husband must impoverish her or himself before the spouse in the nursing home will be cared for by Medicaid. The National Council of Senior Citizens applauds your efforts in this area and we hope you will consider some of the specific technical suggestions we have included at the end of this statement as ways to possibly strengthen your legislation.

The institutionalization of a spouse is often a very traumatic and dreaded step that is only taken when no other alternatives are available. Forcing a wife or husband to also impoverish her or himself so that the disabled spouse may receive long-term care is surely requiring too great a sacrifice of elderly couples who have been partners for life. But this is exactly the choice many elderly couples are forced to make because, unfortunately, the way in which Medicaid determines who is poor enough to qualify for assistance often results in two individuals becoming destitute before one is given any assistance.

In most states, older persons are eligible for Medicaid only if they meet the income standard of the Supplemental Security Income (SSI) Program. These benefits provide just 75 percent of the poverty line for individuals or $340 a month in 1987. Couples' benefits are just $510 a month. An individual is allowed to retain just $1,800 in assets; $2,700 for a couple. Some states use even more restrictive eligibility requirements for Medicaid.

At an average annual cost of $22,000, the expense of nursing home care quickly exhausts the resources of most persons. Only then does Medicaid assistance become available.

When an institutionalized person with a living spouse becomes Medicaid eligible, the law assumes that all marital income is available to cover the cost of nursing home care. After one month, the spouse at home, often the wife, may retain her own income and resources, if she has any left. Unfortunately, the wife is often dependent upon a portion of her husband's income, in which case Medicaid provides for a "spousal maintenance allowance." Federal law puts a ceiling on this allowance comparable to the SSI income standard or the state's "medically needy" standard. This usually results in about $350 to $400 a month being allocated to the spouse at home and, in some cases, the allowance is even less.

In short, there are two problems that cause spouses to face impoverishment. First, the practice of deeming one spouse's income and resources available to the other for the first month of institutionalization acts as a huge deductible from people who are already in desperate financial need. Second, the Federal law which sets spousal maintenance allowances below the poverty line is inadequate.

NCSC, as a part of a coalition of senior advocacy groups concerned with this issue, urges Congress to solve these problems and the terrible choices they force seniors to make as follows: First, end deeming of resources and income when one spouse is admitted to an institution; second, set a uniform Federal minimum spousal maintenance allowance of at least $925 a month; and, third, exclude liquid assets owned by the institutionalized spouse or by both spouses jointly up to $12 thousand in fair-market value for purposes of determining Medicaid eligibility.

Only through taking these humane and sensible steps can we ensure that institutionalization of an older American will not mean pauperization and loss of dignity, home and a life's worth of hard work for the spouse who is "lucky" enough to remain at home.

This necessary and humane change in the statute would cost our nation less than $350 million, according to the Congressional Budget Office. As you may know, the House legislation on spousal impoverishment has been attached to the catastrophic package. We hope that the spousal impoverishment legislation will be accepted and conferenced by both Houses on whichever vehicle is most feasible--catastrophic or reconciliation.

This is also the year that we should finally increase the paltry personal needs allowance received by Medicaid nursing home residents. Nearly 800,000 Medicare nursing home residents depend on their "Personal Needs Allowance" each month--only $25.00 a month, or 82 cents a day--to cover a wide range of living expenses not paid for by Medicaid.

Nursing home residents in two categories receive Personal Needs Allowances (PNAs). Supplemental Security Income (SSI) recipients, once in nursing homes, no longer depend on SSI for their basic support because Medicaid covers their nursing home care, including room and board. However, they receive an SSI allowance of $25 a month to purchase personal need items not furnished by the nursing homes. About 211,000 nursing home residents receive PNAs through the SSI program. About 600,000 other nursing home residents have personal incomes over the SSI level, but their income is low enough to qualify them for Medicaid. In these cases, the residents are allowed to keep $25 a month of their person income for a PNA. The rest of their income is contributed toward the cost of their nursing home care.

The PNA is used to purchase basic supplies like toothpaste and shampoo, eyeglasses, clothing, laundry, newspapers and phone calls. In 15 states, more than half of the $25 must be spent on laundry alone. In addition to personal needs, many nursing home residents have substantial medical needs that are not covered by state Medicaid programs. Although the Personal Needs Allowance is not intended to cover medical items, these residents may have to save their PNAs over many months to pay for these costs, preventing them from tending to personal needs. In addition, if a nursing home resident enters a hospital, he must pay a daily fee to the nursing facility to reserve his bed there. Even though a resident who cannot pay the bed reservation fee is likely to lose his place in the facility, 40 percent of state Medicaid plans provide no coverage for bed reservations.

The $25 PNA has not been increased--even to adjust for inflation--since Congress first authorized payment in 1972. As a result, the PNA is worth less than $10 today. This means that all recipients of Social Security or SSI benefits have received COLAs to their benefits since 1974, except the frailest and most vulnerable--Medicaid nursing home residents.

The National Council of Senior Citizens advocates that Congress increase the PNA by $10 per month, plus a COLA, in order to restore just some of the purchasing power that nursing home residents have lost over the years. In fact, had the PNA been indexed by a COLA, Medicaid nursing home residents would receive $60 per month today. This small change from a $25 to a $35 PNA would help restore to Medicaid nursing home residents independence, dignity and just a small part of the purchasing power that Congress intended them to have. It would be small change for the Medicaid program, Mr. Chairman, and a big difference to recipients.

This modest change, on which legislation has been introduced, originally by Senators Heinz and Moynihan, since 1984, would cost an estimated $67 million.

Third, this is the year in which the Congress should ensure high quality care to all nursing home residents. This issue, too, has been discussed and studied to the nth degree for many years, with the need for legislation being proven again and again. The definitive documents are out now, a multitude of proposals are on the table, the funding is available. All that's left is for Congress to act.

The Institute of Medicine was given $1.5 million from the Federal government to study the issue of nursing home patient care. It found that substandard nursing home care does exist and can be linked directly to the current regulatory system. The main purpose of current Federal nursing home regulations is to ensure that nursing home resident receive adequate care in a safe, clean facility and they they are not deprived of their civil rights. The regulations consist of three interrelated parts: standards, monitoring, and enforcement. IOM found there to be "major problems" with all three parts.

The National Council of Senior Citizens supports legislation to address the problems of poor quality nursing home care, especially through the use of intermediate sanctions and Federal receivership authority for chronically substandard facilities. We also support your effort to take a comprehensive look at Medicare and Medicaid nursing home reimbursement policies. Given the paucity of reimbursement in some states and the senseless categorization of patients that has occurred in other states, a reasoned, thoughtful overview of good reimbursement policy is definitely in order.

Thank you again, Mr. Chairman, for the opportunity to appear this morning. We commend your thoughtful approach to the many issues this Subcommittee is dealing with and we hope you will look to us for continued support in the future.

National Council of Senior Citizens' Suggestions on Spousal Impoverishment

1. Legislation should protect resources and savings, as well as monthly income. This is especially important since the community spouse often outlives the spouse in the nursing home.
2. Legislation should ensure monthly maintenance levels that are high enough to support the community spouse. NCSC supports Congressman Waxman's efforts to allow the community spouse $925/month in living expenses.
3. We also urge that a floor is put in place to ensure that the community spouse will not receive less than a certain amount, even if the couple's resources divided in two would be below that level. In this regard, we believe a $12,000 floor is necessary.
4. Legislation should also allow states to be more generous in this area, if they so choose. Federal legislation should establish the minimums, not the maximums.

STATEMENT OF RICHARD NUGENT, DIRECTOR, GOVERNMENT AFFAIRS, EPILEPSY FOUNDATION OF AMERICA, TESTIFYING ON BEHALF OF EPILEPSY FOUNDATION AND CONSORTIUM FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES, LANDOVER, MD

Mr. NUGENT. Good morning, Mr. Durenberger. My name is Richard Nugent, and I am here today representing not only the Epilepsy Foundation of America but the Consortium for Citizens with Developmental Disabilities and the Coalition for Health Insurance Availability. Together, these two coalitions represent approximately 80 national organizations concerned with people with disabilities and serious health conditions.

Our organizations appreciate this opportunity to testify and urge the committee to use as a framework in drafting legislation the following philosophy.

First, people with disabilities need to be assured access to health care whether through the private insurance system or through public programs.

Second, the health care services must be appropriate as well as affordable. The services needed by some people go far beyond minimal health insurance packages. Some individuals need assistance to offset out-of-pocket expenses of an ongoing catastrophic nature even though their health condition or disability may not be chronic.

Third, others do experience catastrophic expenses due to the severity of their illness or disability. A mechanism must be made available to assist people who have serious health conditions requiring a more comprehensive array of health care and related services. These services should be made available to the individual in the most appropriate and cost effective setting, which is often the individual's own home.

While estimates may vary according to the definition of disability, data source and statistical methodology, it is generally accepted that there are approximately 35 to 36 million Americans with a disability or serious health condition. It is important to note that the disability community is not a homogeneous population. Needs, limitations, abilities and resources span the spectrum across disabilities as well as within each disability or health condition.

A 1986 survey by Louis Harris & Associates estimated that 18 percent of working age persons with disabilities are not covered by either public or private health insurance, or approximately 2.2 million individuals.

Although specific data on insuredness has not been retrieved relative to people with disabilities, the fact that they are three times more likely to have incomes at or near the poverty level, makes it very probable that individuals with disabilities would compose a significant percentage of the low income uninsured. Of those who are working age, only 35 percent are employed with less than one in four holding a full-time job. The median income for working age disabled men in 1987 was less than 50 percent of the median for non-disabled men. People with disabilities who are employed are more likely than not to be in the service sector jobs which pay at or below the minimum wage, and rarely provide health benefits.

Adding to the ranks of the disabled uninsured are almost one-third of working age disabled individuals who at any time are neither employed nor eligible for public programs.

Among uninsured children, who for the lack of preventive health care who will become chronically ill and disabled. Likewise counted in this group are children who have disabilities or are seriously ill, most likely at an incidence rate exceeding the national averages which indicate that 3 percent of all children have severe disabilities, and 11 percent have activity limitations requiring augmented health care.

Medicaid has proven to be an effective tool for meeting the health related needs of lower income individuals with disabilities and/or serious health conditions. This year's reconciliation bill presents an opportunity to build upon the Medicaid expansion options enacted as part of last year's reconciliation. Twenty-one States, it should be noted, have expended their Medicaid programs using this option as of the beginning of this month.

The CCDD, as well as the Coalition for Health Insurance Availability urge support for S. 1139, the MedAmerica Act of 1987, sponsored by Mr. Chafee. Senator Chafee's proposal offers a comprehensive response to those individuals whose income and employment status do not afford them access to private health insurance; those whose pre-existing conditions effectively exclude them from private insurance coverage: and those individuals with severe disabilities or health conditions who have reached the lifetime cap on their policies.

S. 1139 would build upon the existing Medicaid program in three ways:

First, it severs the tie between Medicaid and cash benefit programs such as AFDC and SSI. States would have the option of providing Medicaid benefits to anyone whose income is below the Federal poverty level, regardless of whether they qualify for cash assistance programs.

Second, States would have the option to allow individuals whose incomes range between 100 and 200 percent of the poverty level to purchase health insurance through Medicaid.

Third, States would allow individuals with family incomes and resources in excess of 200 percent of the Federal poverty level to buy into the Medicaid program for a non-income adjusted premium if they have been excluded from private health insurance coverage because of medical impairment.

This last provision is of particular importance to our community.

While MedAmerica will significantly improve access to appropriate health care and related services to many people, we urge the committee to address the catastrophic expense program as it relates to children and adults with disabilities.

Several members of this committee have been working independently to draft, including the Chairman. And we should add that we support strongly the Chairman's proposed commission.

Senator Chafee is planning to introduce a children's catastrophic bill which would assist the families of children who incurred unreimbursed expenditures exceeding $50,000 during the first year of life—an estimated 9,600 infants.

Senator Weicker has already introduced legislation, S. 1183, and yourself, Mr. Durenberger, is currently in the works and we find with great interest the Medicaid Amendments for Chronically Ill and Disabled Children, which would extend an enriched benefit package to all children below the Federal poverty level.

Thank you very much.

[The prepared statement of Mr. Richard Nugent follows:]

Consortium for Citizens with Developmental Disabilities

Health Task Force
Cochairs:
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STATEMENT OF RICHARD NUGENT

ON BEHALF OF THE EPILEPSY FOUNDATION OF AMERICA
AND THE HEALTH TASK FORCE OF THE
CONSORTIUM FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES

TO THE
COMMITTEE ON FINANCE
UNITED STATES SENATE

ON
MEDICAID EXPANSION AS PART OF
THE FISCAL YEAR 1988 RECONCILIATION BILL

JULY 10, 1987

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Mr. Chairman and Members of the Committee:

Good morning. My name is Richard Nugent, and I am here today representing not only the Epilepsy Foundation of America but the Health Task Force of the Consortium for Citizens with Developmental Disabilities (CCDD). The CCDD is a coalition of over 50 national consumer, professional and provider organizations representing the millions of children and adults with developmental and other disabling conditions such as autism, cerebral palsy, communicative disorders, epilepsy, head injury, learning disorders, mental illness, mental retardation, spina bifida and vision impairments.

The Epilepsy Foundation of America also co-chairs the Coalition for Health Insurance Availability. This coalition includes national health organizations representing other health and disabling conditions such as diabetes, cystic fibrosis, illeitis and colitis, multiple sclerosis and tourette syndrome.

The CCDD appreciates this opportunity to discuss the health care needs of people with disabilities or serious health conditions. Millions of Americans with disabilities and/or serious health conditions either lack access to any public or private health care delivery system or have access to inadequate, inappropriate and frequently more costly services.

This Committee is frequently confronted with the most complex issues facing the Congress. One of the most serious problems awaiting a solution is how to ensure the provision of appropriate health care and related services to Americans with disabilities and/or serious health conditions.

CHANGING SOCIETAL VIEWS

The last twenty-five years have been exciting, and in fact, liberating ones for people with disabilities. Major advancements have been forthcoming in the habilitative, rehabilitative and medical technologies necessary to facilitate the independence and capabilities of people with disabilities. The general population has become at least more cognizant, if not more accepting, of the rights and needs of people with disabilities. Government at all levels has claimed a protective and proactive stance relative to the special needs of people with disabilities. As a result we have had an affirmation of the rights of people with disabilities to become educated, to work, to be able to access and use public services - transportation, recreation, housing - to be able to live in the community. But in an area which is at least as basic a right as these, and perhaps more so, people with disabilities, and in fact much of the overall population, are more disenfranchised today than they were a decade ago. Access to affordable quality health care has not just been substantially ignored; it has been actively diminished.

LEGISLATIVE PRIORITIES

The CCDD appreciates this opportunity to appear before the Finance Committee. We urge the Committee to act favorably on legislation that recognizes that:

- First, people with disabilities need to be assured access to health care whether through the private insurance system or through public programs;
- Second, the health care services must be appropriate as well as affordable. The services needed by some people go far beyond minimal health insurance packages. Some individuals need assistance to offset out-of-pocket expenses of an ongoing catastrophic nature even though their health condition or disability may not be chronic; and
- Third, others do experience catastrophic expenses due to the severity of their illness or disability. A mechanism must be available to assist people who have serious health conditions requiring a more comprehensive array of health care and related services. These services should be available to the individual in the most appropriate and cost effective setting which is often the individual's own home.

DIMENSION OF THE PROBLEM

While estimates vary according to the definition of disability, data source and statistical methodology, it is generally accepted that there are approximately 35 to 36 million Americans with a disability or serious health condition. It is important to note that the disability community is not a homogeneous population. Needs, limitations, abilities and resources span the spectrum across disabilities as well as within each disability or health condition.

This point needs to be made since many elements within our society, particularly the insurance industry, presume that all individuals with a given condition have similar needs or abilities.

There are two and one half million Americans with epilepsy, for instance, but most of these individuals find their health condition rarely interfering with their daily lives particularly if they have had access to the state-of-the-art diagnosis and treatment methodologies. Others, approximately 20 percent of people with epilepsy, are severely disabled by their health condition. Yet pre-existing condition clauses often serve to deny or limit health care to any person who is labeled as having "epilepsy" regardless of the person's medical condition.

Many people with disabling conditions, it should be remembered, are not necessarily "sick" or high utilizers of health resources even though this belief surfaces in the underwriting policies of health insurers.

THE EXISTING PUBLIC AND PRIVATE ALTERNATIVES

The Medicare program provides limited health care services to approximately three million persons with disabilities. It is limited because it was structured primarily for retired members of our society. Coverage for workers who become disabled and for their adult disabled dependents was a secondary development. Although Medicare has a uniform benefit structure, it particularly delimits from coverage many of those items which are of greatest importance in the ongoing health care support for people with disabilities: prescription medications; certain support/maintenance therapies, numerous items of disposal and durable equipment.

Medicaid, which has a significantly better benefit package subject to state variations and provider limitations, serves another three million people with disabilities.

This leaves close to 30 million Americans with disabilities uncovered by the two primary public insurance programs. Unfortunately, the private health insurance system fails to provide coverage to many of these individuals, including many disabled workers. A 1986 survey by Louis Harris and Associates estimated that 18 percent of working age persons with disabilities are not covered by either public or private health insurance.

The primary reason is the same reason why most of America's 37 million uninsured citizens have no coverage, and why as many as 20 million more are seriously underinsured - the private health insurance arena has evolved as an almost entirely employment-based option. However, that evolution has not meant that simply being employed assures access to satisfactory health care.

Although specific data on insuredness has not been retrieved relative to people with disabilities, the fact that they are three times more likely to have incomes at or near the poverty level, makes it very probable that individuals with disabilities would compose a significant percentage of the very low income uninsured. Of those who are working age (17-64), only 35.5 percent are employed with less than one in four holding a full-time job. The median income for working age disabled men in 1987 was less than 50 percent of the median for non-disabled men. People with disabilities who are employed are more likely than not to be in service sector jobs which pay at or below minimum wage, and rarely provide health benefits. Adding to the ranks of the disabled uninsured are almost one-third of working age disabled who at any time are neither employed nor eligible for public aid.

Among uninsured children are many, who for lack of preventive health care, will become chronically ill and disabled. Likewise counted in this group are children who have disabilities or are seriously ill, most likely at an incidence rate exceeding the national averages which indicate that 3 percent of all children have severe disabilities and 11 percent have activity limitations requiring augmented health care. It is also likely that many children have not yet been diagnosed as disabled because of the erratic, if any, health care services which their families' limited income can allow. Still other low income children, though clearly disabled, may be caught in the trap which deems their parents' income available to them in such a way as to effectively disallow participation in Medicaid. Statistics show that Medicaid covers only 25 percent of all children with disabilities and only 60 percent of disabled children living in poverty. In order to get Medicaid coverage then, for what is likely to be a need for chronic care, their parents must divest themselves of their assets and reduce their incomes with insufficient regard for the needs of other family members, placing at risk the future support for all, including the child with disabilities.

In 1982, the much publicized Katie Beckett case resulted in an additional amendment to the Medicaid program to allow states to cover certain in-home care for a medical-technology dependent child for whom hospital based care would be a more expensive alternative. This option has not been exercised since 1984, although Model Waivers, now in place in eighteen states, have essentially replaced the intended function of the option. Model Waivers, which are limited to serving no more than 50 individuals in a state, are unfortunately a more burdensome process.

Recognition of the importance of continued health care access for those individuals with serious disabilities who are able to work has led to the strengthening of certain provisions in the Social Security Act just last year.

This Committee and Congress passed legislation permanently authorizing Section 1619 which allows people to work despite severe disabilities in spite of the fact that their earnings exceed the "substantial gainful activity (SGA) level" of $300 per month. For people with disabilities who are able to access employment, the SGA income ceiling, at which health care benefits would cease, has functioned as a serious disincentive to obtaining or returning to employment, especially since that employment was so likely to be in service sector jobs where health care benefits remain scarce.

MEDAMERICA: A COMPREHENSIVE SOLUTION TO HEALTH CARE ACCESS

Medicaid has proven to be an effective tool for meeting the health related needs of lower income individuals with disabilities and/or serious health conditions. This year's Reconciliation bill presents an opportunity to build upon the medicaid expansion options enacted as part of the Omnibus Budget Reconciliation Act of 1986. Twenty-one states have expanded their Medicaid programs using this option this year as of the beginning of July.

The Consortium for Citizens with Developmental Disabilities as well as the Coalition for Health Insurance Availability urge support S. 1139, the MedAmerica Act of 1987. Senator Chafee's proposal offers a comprehensive response to:

- o those individuals whose income and employment status do not afford them access to private health insurance;
- o those whose pre-existing conditions effectively exclude them from private insurance coverage; and
- o those individuals with severe disabilities or health conditions who have reached the lifetime cap on their health policy.

S. 1139 would build upon the existing Medicaid program in three ways:

- o First, it would sever the tie between Medicaid and cash benefit programs such as Aid to Families with Dependent Children (AFDC) and Supplemental

Security Income (SSI). States would thus have the option of providing Medicaid benefits to anyone whose income is below the Federal poverty level regardless of whether or not they qualify for cash assistance programs.

o Second, States would have the option to allow individuals whose incomes range between 100 and 200 percent of the poverty level to purchase health insurance through Medicaid for an income adjusted premium not to exceed 3 percent of the individual's or family's adjusted gross income.

o Finally, States would have the option to allow persons with family incomes and resources in excess of 200 percent of the Federal poverty level to buy into the Medicaid program for a non-income adjusted premium if they have been excluded from private health insurance coverage because of a medical impairment or disability or if they have exhausted one or more benefits under their private insurance plans.

This last provision is of particular importance to the disability community because it would offer access to a comprehensive package of health care services to individuals who have been effectively abandoned by the private insurance market through pre-existing condition clauses and experienced ratings.

It would also assist families where an individual - often a child - has a chronic health condition or disability so severe that the health care services consumed have reached the policy's lifetime expenditure limit.

CATASTROPHIC PROTECTION FOR CHILDREN AND THEIR FAMILIES

While MedAmerica will significantly improve access to appropriate health care and related services to many people, we further urge the Committee to address the catastrophic expense problem as it relates to children and adults with disabilities who are already covered by existing health insurance packages.

The subject of catastrophic health care involves not only a concern about insurance coverage, but also about the absence of any insurance for in-home care.

Like other people, most people with disabilities want to meet their health needs living in the community in their own homes -- not in medical institutions like hospitals or nursing homes. The disability community has been on the forefront of establishing the efficacy and cost efficiency of home and community based social and rehabilitative services in its deinstitutionalization efforts. It is time for the health service arena to move more aggressively in this direction to address not only cost containment, but more importantly, to preserve the family unit and to bolster the ability of individuals to maintain themselves as independently as possible within their own community. One of the important goals of a meaningful catastrophic health care plan is to develop a reimbursement mechanism for community-based and in-home care which will reduce the need for institutional care.

Several members of this Committee have been working independently to draft a children's catastrophic expenditure bill. Health care becomes a catastrophic expense when out-of pocket health expenditures exceed a certain level of income. "Catastrophic" refers to the impact on an individual's income and not to the type of care or the setting in which it is provided. Catastrophic expenses can be defined either by the actual amount of out-of-pocket expenditures or expenses in relation to income.

The number of children who incur such catastrophic expenses is relatively small using either definitional approach. According to the National Medical Care Utilization and Expenditure Survey of the 70 million children in this country, only 0.6 percent or 421,000 had out-of-pocket medical expenditures greater than 10 percent of their families' income in 1980. Data prepared for the Western Association of Children's Hospitals showed that of the 553,000 children under the age of 15 hospitalized in California during 1984, only one-half of one percent incurred charges in excess of $50,000.

Senator Chafee, for instance, is planning to introduce a children's catastrophic bill which would assist the families of children who incurred unreimbursed expenditures exceeding $50,000 during the first year of life. An estimated 9,643 infants annually incur such costs. These newborn and infants account for approximately 50 percent of all children, age 0 to 19, with very high medical costs.

Senator Lowell Weicker has recently introduced legislation to address catastrophic expenditures in relation to family income. The Medicaid Catastrophic Coverage for Children Act of 1987, S. 1183, would provide a new Medicaid eligibility mechanism for children with catastrophic expenses. Eligibility would be tied to a percentage level of a family's adjusted gross income spent on allowable medical expenses. Once this threshold level is met, the child would be eligible for appropriate medicaid benefits. By use of an early and periodic screening, diagnosis and treatment benefit specifically designed for children with disabling and catastrophic health care needs, an interdisciplinary care coordination team will consider each child's specific needs and accordingly design and oversee implementation of the individual care plans.

Yet another proposal is being developed by Senator David Durenberger. The Medicaid Amendments for Chronically Ill and Disabled Children Act is planned to extend an "enriched benefit" package to all eligible children with a chronic illness or disability whose family income is below 200 percent of the federal poverty level. An individually written health care management plan would be developed and coordinated with any other services provided through the early intervention program (P.L. 99-457) enacted last year or the special education program (P.L./94-142).

Finally, Mr. Chairman, the Consortium supports your efforts to strengthen and expand the service delivery capabilities of Maternal and Child Health agencies.

These "front-line" programs have established a track record of service delivery which should be considered as a vehicle to further addressing the unmet health care needs of children with severe disabilities or serious illnesses.

Quality health care must be made available for all. Obstacles such as pre-existing condition clauses which prevent an individual who can afford to purchase health insurance from doing so must be restricted or public insurance must be made available at reasonable cost. Employers should be required to provide adequate health protection to all employees and dependents. Individuals who cannot afford health insurance should be assured access to Medicaid either at no cost or low cost.

The risks of each individual should be shared by all. We are all subject to becoming disabled. We are all susceptible to cancer, multiple sclerosis, lupus, heart disease or diabetes. We might have a child or grandchild who is diagnosed as being mentally retarded. On the way home, one of us might suffered a head injury in an automobile accident and develop epilepsy as 20,000 Americans do each year in vehicle collisions.

Society as a whole already bears the cost attributable to the lack of adequate health care coverage - through incidence of preventable disabilities, lost productivity, income support programs, uncompensated care and individual and family stress. The question, therefore, is not whether such costs shall be met, but how.

A critical problem exists. Five out of every six Americans take health care for granted since we carry a card which ensures us access to health care upon demand. But there are other people - 37 million others including many children and adults with disabilities - who are being denied access. The member organizations of the Consortium for Citizens with Developmental Disabilities and the Coalition for Health Insurance Availability look forward to working with the Committee in the weeks and months to follow to ensure that the health care needs of people with disabilities or chronic health conditions are meaningfully and effectively solved. The CCDD will be submitting for the record a further written statement outlining additional recommendations. Thank you.

Senator DURENBERGER. Thank you. I am going to turn the Chair over to the appropriate side of this aisle, but I am going to take this opportunity to begin the questions.

First, to Ms. Rosenbaum, I regret I was over on the floor when you made your presentation, but I have read your statement and I have worked with you now long enough on some of these issues to appreciate the value of your testimony. I wonder if I could ask a summary kind of a question of you.

In your testimony, you set out a lot of proposals that would, obviously, improve on a systematic basis the health care coverage for children and pregnant women, but you also recognize the problem we have of limited resources. Related to that are the difficulties that have been referred to here today of knowing who is responsible for making what decisions.

When I heard earlier reference to the fact that maybe some States could meet the challenge of expanded benefits, but States like Texas could not, I had to think that it is certainly true that Texas, like other heartland States, is having tough times. But politically, Texas is just unwilling to make the decision to tax itself to help Texans in this way. At least that is the way it is observed from the outside.

I feel that way because I come from a State that has a high income tax and must compete with a State like Texas, which has no income tax. So I question the degree. It is a complicated problem, and we are in a period of time in which it is difficult to know where to start and what to do first.

Given that, would you refocus for us from the Children's Defense, Fund's point of view, where we ought to start. What should we be focusing on first? I don't ask you that question to limit us or you in any way, but where should we be starting?

Ms. ROSENBAUM. First of all, I want to echo something that Aaron Johnson raised, and that is certainly gaining acceptance throughout the country, if not always an immediate enactment, certainly in movement that we have not seen in recent years.

That is, I think, a number of States are beginning to understand that they are making the outlays regardless of whether they change their Medicaid plans to furnish the outlays on a front-loading basis or an end-loading basis. So one of the realities that struck home in Texas as much as Minnesota, and Texas, in fact, relative to its available resources, putting aside the question of its taxing capacity, certainly responded and has continued to respond, is that they are making tremendous expenditures on behalf of very sick infants, and that even when they try to limit the expenditure levels by putting limits on the length of hospital stays they will pay for and other kinds of limits on sick person care, nonetheless the expenditures are much higher than they would have been had the babies been born healthy. And so, while I would prefer that we weren't now going into the third decade without uniform coverage under Medicaid for low income families, I would say that we are more hopeful and more appreciative of the efforts that States have made.

As we point out in the testimony, there are two high priority areas that we think need immediate attention—meaning this summer as opposed to over the next couple of years.

One is clearly, again, pregnant women and infants. The bill that you have cosponsored, which Senator Bradley introduced, which so many members have cosponsored, would further strengthen States' capacity to deliver pregnancy and infant services in accordance with the same standards that are used for the WIC Program.

It is our strong belief that if a family is poor enough to need a nutritional supplement, it most certainly cannot afford the $5,000 in maternity care costs that go along with even a routine pregnancy today. That is a high priority.

Another high priority is the issue that you are concerned with this year, that Senator Bentsen has been concerned with, that Senator Chafee has a long-standing concern with, and that is what to do about children who are ill. In fact, if you look at childhood utilization patterns by income levels, the worst utilization deficits for low income children occur among children who have a chronic illness or disability.

Low income children don't fare as badly when it comes to preventive services—immunizations, check-ups. There are well-baby, well-child clinics. There is some preventive care. The crunch comes when a child is sick, either severely sick as in the case of the example I gave while you were out of the room of a child who is extremely ill, or a child who has a mild to moderate impairment or disability, ranging from asthma to mild to moderate epilepsy or another kind of chronic illness—cancer—that simply impairs that child's ability to function normally.

It is those children who register terrible utilization deficits—as much as half the health care utilization. And of particularly pressing concern now is zero to 3 children, because that is the group that was targeted last year by the Early Intervention Amendments. The Early Intervention Amendments are a landmark contribution toward child development work for low income families, but if the family does not have access to medical care, a lot of the early intervention services will not accomplish what they should.

So we would recommend, in addition, of course, is the issue that Richard mentioned, that I mentioned, having to do with catastrophically ill children. We would recommend that if you have to make some slicing and dicing choices, that certainly S. 422 too small but important discriminatory issues affecting disabled children, which I mentioned while you were out of the room that should be almost no-cost items to deal with, some catastrophic illness assistance of the kind that Senator Chafee is going to introduce, and your efforts on behalf of chronically impaired zero to 3 children.

Senator **Durenberger**. Thank you very much. Pat?

Senator **Moynihan**. No thank you.

Senator **Durenberger**. Mr. Clayman, we appreciate, and this testimony indicates, how important your comments about the intergenerational concerns of poverty are—the children and the elderly are hurt the most by poverty. I am glad you spent time on spousal impoverishment and the fears it generates, as well as the actual problems that occur.

But you weren't able to make the other two points that you felt were important. I will give you that opportunity now.

Mr. **Clayman**. I assume that I made two and failed to get to the third, because I was carried away——

Senator **Durenberger**. All right. Then make the third, if you would.

Mr. **Clayman** [continuing]. By genuine emotions. I almost sounded like Ollie North. [Laughter.]

I shouldn't apologize to that either, frankly.

Let me make the final point that I didn't make. The final point is the National Council of Senior Citizens supports legislation to address the problems of poor quality nursing home care, through the use of intermediate sanctions and Federal receivership authority for chronically, substandard facilities.

We also support efforts to take a comprehensive look at Medicare and Medicaid nursing home reimbursement policies. Thoughtful overlook of good reimbursement policy is definitely in order.

I remember that—and I have had a rather long career in terms of time, at least—and almost from the beginning of my work in the State of Ohio, we were concerned about nursing homes; we were concerned about the quality of attention; we were concerned about the abuse, the personal abuse of those who inhabited, unfortunately, those nursing homes; and we were concerned about the abuse of civil rights of those people.

In all that thunder and lightening, over 45 years that I can remember, there has been improvement, but in some areas and some places, maybe in many places, too many places in any event, that complaint still exists—it is there—with States not doing their job, with the Federal Government not doing its job. That needs the urgent, the quick, the sustained concern of Congress and of this Senate.

I know that all of you who sit up there are aware of these problems, and that would have been my third point that I would have made before Senator Moynihan came in.

Senator **Durenberger**. Thank you. Pat, I don't have any other questions of this panel.

Thank you all very much. The final panel is Dr. Donald Schiff and Mr. Robert H. Sweeney. Dr. Schiff represents the American Academy of Pediatrics. Bob Sweeney is the president of the National Association of Children's Hospitals and Related Institutions.

Gentlemen, your statements will be made part of the record, and you may proceed to summarize them in 5 minutes or less, beginning with Dr. Schiff.

STATEMENT OF DONALD SCHIFF, M.D., PRESIDENT-ELECT, AMERICAN ACADEMY OF PEDIATRICS, LITTLETON, CO

Dr. **Schiff**. Good morning, Mr. Chairman. I am Dr. Donald Schiff, a pediatrician from Denver, CO, and here this morning on behalf of the American Academy of Pediatrics, an organization of 32,000 dedicated advocates for maternal and child health. I am Vice-President-elect of this Academy, and I am delighted to have this opportunity to share with you our considered views involving Medicaid and the maternal and child health block grant.

To date, Mr. Chairman, despite your best efforts and those of your colleagues on this panel, there remains more promise than progress in these vital programs. But increasingly there are signs that the times are changing. Here in Washington and across the country, Americans seem to be genuinely awakening to the improvident neglect of our children in recent years. So it is with renewed optimism today that the Academy looks forward to working closely with you to remove financial barriers to care for children—an effort that would dramatically improve our children's health.

However, recent developments are distressing and demand our attention. The decreasing access to care that poor children are currently experiencing appears to correlate with an alarming rise in preventable morbidity and mortality. This can be documented by an increased incidence of preventable childhood diseases, such as measles and pertussis, and a rise in infant mortality rates in some regions that you have already been told about.

Since Medicaid is our largest and most comprehensive tax-supported health insurance program for children, it is worrisome that it protects fewer and fewer low-income Americans. As you know, enrollment has declined in recent years from a high of 23 million in 1977 to 21 million in 1984.

Additionally, we are concerned with the wide variations in state eligibility and benefit rules, which cause marked inequities for Medicaid recipients. In fact, as you know, many States do not cover people with incomes that are well below the Federal poverty line. In fact, in nine States, three-quarters of the poor are ineligible. Furthermore, one-third of all uninsured pregnant women and more than 30 percent of uninsured children have family incomes between 100 and 200 percent of the Federal poverty level.

I think that with this in mind, the Academy believes there are some specific recommendations that warrant your consideration.

First, mandating that states raise their income eligibility standards to 185 percent of the Federal poverty level and allow eligibility of children and pregnant women at State option to at least 200 percent of the poverty level.

Second, extending eligibility to all children through age 21, including children who are in two-parent families.

Third, and very importantly, improving the State outreach efforts for eligible families.

I think you can note that there are superb measures already before you that head Medicaid in precisely the right direction. Senator Bradley's bill, S. 422, is a prime example, and the Academy strongly supports its passage.

These incremental but important proposals for Medicaid must now be considered within the context of children's catastrophic health care. As you are well aware, catastrophic expenses incurred by children are a significant problem. Preliminary data indicates that the number of children who incur catastrophic expenses compared with the adult population is relatively smaller in absolute terms and proportionately. Characteristically, children's catastrophic expenses are long-term or even life-long, pointing to the need for coordinated home and community-based care options to ensure that these children and their families receive all of the essential services in a coordinated, financially sound fashion.

We also support Senator John Chafee's MedAmerica Act of 1987, which provides a number of significant reforms for the uninsured and underinsured. Of particular import, this bill would sever the tie between AFDC and SSI. We also believe that Senator Weicker and Senator Dave Durenberger, who I guess has left us—oh, there you are—both of which would improve access to Medicaid and improve coverage for certain populations, are laudable. Both emphasize the need for care coordination, or case management, as it is more commonly termed.

While Medicaid has progressed, however marginally over the past 4 years, the maternal and child health block grant is at a standstill. As you know, the purpose of this block grant is to enable each state to assure mothers and children access to quality health services.

Specific recommendations with respect to the child health block grant are not well formulated—and cannot be—without oversight hearings to review the implementation of this important program. We think that these oversight hearings should focus broadly on maternal and child health programs and how they should interlock to work together more effectively to establish a system of child health care.

We also support funding through this Reconciliation bill for demonstration projects for home- and community-based care for children. Well, I have lost my time.

Let me say——

Senator DURENBERGER. There will be an opportunity for questions.

Dr. SCHIFF. Thank you. I just want to say that we appreciate the opportunity to appear before you this morning, and I hope in the question period we can touch on some other topics.

Senator DURENBERGER. Thank you, Dr. Schiff. Mr. Sweeney.

[The prepared written statement of Dr. Donald Schiff, M.D., and answers to questions from Senator Bradley follow:]

American Academy of Pediatrics

TESTIMONY

BEFORE THE

UNITED STATES SENATE
FINANCE COMMITTEE

ON

MEDICAID
AND
THE MATERNAL AND CHILD HEALTH BLOCK GRANT

PRESENTED BY

DONALD SCHIFF, M.D., F.A.A.P.

also representing

Ambulatory Pediatric Association
American Pediatric Society
Association of Medical School Pediatric Department Chairmen
Society for Adolescent Medicine
Society for Pediatric Research

July 10, 1987

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Mr. Chairman, I am Dr. Donald Schiff, a pediatrician from Denver, Colorado, here this morning on behalf of the American Academy of Pediatrics, an organization of 32,000 dedicated advocates for maternal and child health. As Vice President-elect of the Academy, I am delighted to have this opportunity to share with you our considered views on issues involving Medicaid and the maternal and child health block grant.

To date, Mr. Chairman, despite your best efforts and those of your colleagues on this panel, there remains more promise than progress in these vital programs. But increasingly there are signs that the times are changing. Here in Washington and across the country Americans seem to be genuinely awakening to the improvident neglect of our children in recent years. So it is with renewed optimism today that the Academy looks forward to working closely with you to remove financial barriers to ambulatory, hospital and home care for children -- an effort that would dramatically improve our children's health and could help ensure them long and productive lives as American citizens.

Certainly, recent developments are distressing and demand attention. The decreasing access to care that poor children are currently experiencing appears to correlate with an alarming rise in preventable morbidity and mortality. This can be documented by the increased incidence of preventable childhood diseases, such as measles and pertussis, and the weakening decline in infant mortality rates since 1982. To be sure, 20 states report that in certain regions there has been an actual increase in the infant mortality rate. In addition there is the growing rate of teenage pregnancies -- one million annually among 15-19 year olds.

Medicaid, for its part, is still the largest and most comprehensive tax-supported health insurance program for children. However, in the past decade of rapidly rising health care costs, this joint federal-state health plan for the poor protects fewer and fewer low-income Americans. Enrollment has declined in recent years from a high of 23 million recipients in 1977 to 21.2 million in 1984. By 1985 Medicaid reached only 46 percent of the poor and near-poor, down from 65 percent a decade before. This drop followed 12 years of rising enrollment since the program's creation in 1965.

Also of adverse consequence are wide variations in state eligibility and benefit rules, which cause marked inequities for Medicaid recipients. The General Accounting Office reports that spending in fiscal 1985 varied from a low of $821 per enrollee in West Virginia to a high in New York of $3384. Many states do not cover people with incomes well below the federal poverty line -- in nine states, three-quarters of the poor are ineligible. Another egregious variation, to cite just one more example, is that six states (Hawaii, Montana, New York, Pennsylvania, Rhode Island and Wisconsin) cover all five major optional groups of recipients; Indiana and Missouri cover none.

A few rays of sunshine were visible in 1986, as a number of states complied with congressionally inspired opportunities to enhance Medicaid. The Consolidated Budget and Reconciliation Act of 1985, enacted in April of last year, required states to extend pregnancy-related services to all pregnant women with family incomes below AFDC-eligibility levels. Arizona now pays for medical care needed by children under the age of six in any household receiving food stamps, or with a family income below the federal poverty level. The Sixth Omnibus Budget Reconciliation Act of 1986, signed into law last fall, provides states the option of extending Medicaid to pregnant women and children under age five (on a year-by-year, phased-in basis) whose family incomes exceed AFDC-eligibility levels but are less than the federal poverty level. Movement of states toward embracing this important expansion of eligibility has been encouraging. Fifteen states have passed this option, and it is expected that at least 15 more will follow suit. Fortunately, in all but two of these 30 states, the income level adopted was the maximum -- 100 percent of the poverty line.

The sad news is that 10 states have rejected the option while another 10 are considering it.

In fact, every year since 1983, Congress, despite the specter of punishing deficits, has successfully fashioned marginal, incremental progress in the Medicaid program specifically aimed at the promotion of maternal and child health. Data from a variety of sources confirm that Medicaid expenditures for children are inexpensive relative to other populations. (Yet children continue to constitute roughly 50.3 percent of Medicaid recipients, while receiving only 19.3 percent of program expenditures -- that is $649 per child as contrasted with $2734 per adult.)

Meanwhile, other extremely serious health care access problems persist:

- One-third of all uninsured pregnant women and more than 30 percent of uninsured children have family incomes between 100 and 200 percent of the federal poverty level. These meager incomes are too high to qualify for Medicaid but inadequate to buy either necessary health care or private health insurance.

- Eighteen states still fail to extend Medicaid coverage to children over age five with incomes below AFDC-eligibility levels if they live in two-parent, working families.

It is thus imperative that maternal and child health advocates continue to press for a Medicaid program that is both equable and equitable. The Academy believes there are specific recommendations that warrant full consideration:

1) Mandating that states raise their income-eligibility standards to 185 percent of the federal poverty level, and allow eligibility of children and pregnant women at state option to at least 200 percent of poverty level.

2) Extending eligibility to all children through age 21, including children who are in two-parent families.

3) Improving state outreach efforts for eligible families.

But what is more, there are superb measures already before you here that head Medicaid in precisely this -- the right -- direction. Senator Bill Bradley's (D-N.J.) legislation (S.422) would 1) permit states to cover pregnant women and infants with family incomes under 185 percent of federal poverty; 2) permit states to accelerate coverage of certain children addressed in the new 1986 law, i.e., children under age five with family incomes below 100 percent of federal poverty; and 3) extend Medicaid coverage by FY 1991 to all children under age eight with family incomes and resources below AFDC financial eligibility levels.

This proposal would potentially aid 79,000 pregnant women and 239,000 children under age five in 1988 at a cost of only $65 million. It is especially important because private and public insurance mechanisms remain inadequate, because we know many pregnant women and children fail to receive needed health care as a result of gaps in insurance coverage, and because investing in preventive and primary health care is effective and economical. The Academy strongly supports inclusion of the Bradley amendments in the budget reconciliation bill, and applauds the senator for his continued leadership.

As part of the same measure, the Academy urges you to adopt provisions that would allow states to extend Medicaid coverage for six months, with no premium requirements, to families who lose cash-assistance benefits because of earnings. At the conclusion of the mandatory six-month period, states would be required to offer health coverage for an additional 18 months to families who continue to work. During this mandatory period, states could, at their option, extend health care coverage with an income-related premium for an additional 18 months; state costs for this optional coverage would qualify for federal Medicaid matching funds. Thus, the total mandatory coverage period would be 24 months; the total potential coverage period, if a state elects, would be 42 months. These provisions would apply to individuals who leave cash assistance due to earnings on or after January 1, 1988.

Information from a research project recently completed by the Academy indicates that such a provision could remove the existing work disincentives for Medicaid recipients. For the past five years the Academy, with funding from the Health Care Financing Administration, conducted a case-management demonstration project in Suffolk County, New York. Preliminary data suggest that by extending Medicaid eligibility and coverage, recipients are likelier to seek employment, because their children's health care coverage is guaranteed.

These incremental but important changes in and proposals for Medicaid must now be considered also within the context of the debate surrounding children's catastrophic health care expenses. As you are well aware, the catastrophic expenses incurred by children are a significant problem. During the past six months, several themes relative to the needs of children and families who incur catastrophic costs have emerged. First, although more information is necessary, the available empirical data indicate that the number of children who incur catastrophic expenses, compared with the adult population, is relatively smaller in absolute terms and proportionally. Second, by nature, children's catastrophic expenses are long-term or even lifelong, thus pointing to the need for improved home- and community-based care options. Third, given the varied requirements of these children and their families, there is a pressing need for care coordination to help ensure that these children and their families receive all the necessary services in a coordinated, financially sound fashion. We are pleased, Mr. Chairman, that you plan to hold a series of hearings this fall on the catastrophic health care expenses incurred by children to better identify who these children are, ascertain the cost of their care and develop effective mechanisms to meet their needs. We look forward to working with you on the development of a comprehensive and coordinated system of quality health care for all children.

Meanwhile, there are several proposals that merit your attention immediately. Catastrophic expense is relative to both a family's income level and their access to health insurance. For the millions of uninsured in this country, a seemingly mild health problem is a catastrophic event. It is at these families and their children, the "relative " catastrophes, that several of the current proposals are aimed. Senator John Chafee's (R-R.I.) Med America Act of 1987 (S.1139) provides a number of significant reforms for the uninsured and underinsured. Of particular import, this bill would sever the tie between AFDC and SSI; allow individuals at or near the federal poverty level to "buy in" to Medicaid; and allow those in excess of 200 percent of the federal poverty level who have been denied health insurance because of pre-existing conditions, or who have exhausted their insurance benefits, to purchase Medicaid. Further, states that elect this option would be required to provide a standard benefit package that does not inordinately expand existing state commitments. The Academy supports this bill, which clearly reflects the farsightedness of its sponsor. But we also appreciate that Med America is an ambitious proposal, perhaps impracticably expensive in whole. We urge you to consider during the process of budget reconciliation the provisions in the legislation that would allow individuals who are denied insurance because of a pre-existing condition, or who have depleted all their insurance coverage, to purchase Medicaid. We believe this step, which is consistent with Medicaid developments in the past several years, would help many children and families who are currently uninsured.

Unfortunately, the impact of such an effort would vary somewhat, given the scope of Medicaid benefits in each state. As aforementioned, state variation in Medicaid programs is a serious problem. We believe both Senator Lowell Weicker's (R-Conn.) and Senator Dave Durenberger's (R-Minn.) proposals, both of which would improve access to Medicaid and improve coverage for certain populations, are laudable. Both emphasize the need for care coordination, or case management, as it is more commonly termed. We particularly urge you to consider as part of reconciliation Senator Durenberger's soon-to-be-introduced proposal that would extend Medicaid coverage to children with a chronic illness, condition or disability who anticipated costs greater than $500 or greater than 125 percent of a state's average Medicaid expenditure per child, whichever is lower. States choosing this option would be required to provide all eligible Medicaid services, including those that are part of the 1915 waiver program. Although less comprehensive than Med America, which would provide coverage to families, we believe this legislation is a feasible step that would address effectively the needs of many uninsured and underinsured children. Further, this legislation would ensure that they receive more appropriate coverage than currently provided. We appreciate that mandating an array of benefits for Medicaid recipients is not economically compelling at this time. However, we urge you to help ensure that children who are most in need receive the benefits to which Congress believes they are entitled. If enacted, Senator Durenberger's bill would provide coverage to an important segment of the uninsured and underinsured children in this country for whom there has been no remedy. This legislation is consistent with previous movement in Medicaid and would set the stage for the committee in the fall to address the truly "catastrophic" needs of children.

While Medicaid has progressed however marginally over the past four years, the maternal and child health block grant is at a standstill. Aside from a one-time infusion in fiscal 1983 from the Emergency Job Appropriations Act, funding has remained virtually flat.

The purpose of the MCH block grant is to enable each state to assure mothers and children access to quality health services, reduce infant mortality and incidences of preventable diseases and handicapping conditions among children, provide rehabilitation services for blind and disabled children under the age of 16 and provide various services for crippled children. Clearly, these are worthy goals. How well the program has been able to meet these goals, given limited funds, is unclear.

Specific recommendations with respect to the MCH block grant are not well formulated -- and cannot be -- absent oversight hearings to review the implementation of this important program. Since this program was enacted in 1981, Congress has yet to exercise its oversight authority to review the implementation of this program or look to needed modifications and fiscal stability. The Title V program, which underpins the MCH block grant, just celebrated its 50th anniversary. It is now time to look at the directions we must take over the next 50 years.

Indeed, the medical environment has changed dramatically since the enactment of this block grant, both in areas of medical technology and treatment and financing for an array of needed services. It is important that we examine the design and ability of this system to meet the complex medical needs of today's children and their families -- needs that involve a range of services from health, education, social services and other arenas. As with Medicaid, the MCH block must be assessed with respect to its responsibility to children and families for preventive, sick and catastrophic care coordination. The MCH agency at the state level is a logical recipient of monies to benefit children -- in fact, it may be the only place where such funds could be protected. However, we must first define exactly what needs to be done. What are these children's and their families' unmet needs? What kinds of inter-agency agreements are necessary to develop a truly coordinated system of care? What and where are the existing programs that could serve as role models for the nation? And, if more dollars are to given to the system, should they go to service delivery, care coordination, or both? Indeed, oversight of the MCH block grant should not be a myopic assessment -- it should focus broadly on how maternal and child health programs should interlock more effectively to establish a coordinated system of child health care.

As we strive to fashion a more comprehensive system to address the needs of children, let us not take a band-aid approach to large holes in the so-called safety net. Rather, let us reason together in a focused oversight hearing to build a firm foundation with the capacity to provide the necessary comprehensive, high-quality care for all our children. Dollars may indeed be the answer, but they must be fully utilized to reach as many children as possible in a system that is designed to do just that.

The Academy also supports funding through this reconciliation bill for demonstration projects for home- and community-based care for children who have severe and long-term chronic illness. It is estimated that 2.3 percent of American children have severe, long-term chronic illnesses. Although we have learned much from demonstration projects on home- and community-based care for technology-dependent children, there have been few projects focusing on the needs of the severely chronically ill. Such demonstrations would need to develop models to provide comprehensive, coordinated, community-based, family-centered care providing an array of services from the following domains: medical/surgical, mental health, preventive health, social services, nursing care, occupational and physical therapy, rehabilitative services and respite care.

Another issue moving to the top of the agenda is funding for the childhood vaccine compensation legislation, P.L. 99-660, which passed last session. This issue is particularly pertinent to mention today because of its fiscal impact on the MCH Block and Medicaid. Without a compensation system, vaccine prices will continue to rise and many of our children will be at risk for totally preventable diseases. The cost of fully immunizing a child in the public system has gone from $6.49 in 1982 to $54.84 today. In our quest to address the health needs of children, we cannot lose sight of the most basic of our preventive health programs. We would urge you to take advantage of this opportunity to resolve the funding issues that currently block the implementation of this program. Specific costs estimates will be presented to you at hearings next week.

Finally, Mr. Chairman, the Academy would like to commend and support your proposal for a National Commission on Children. As is obvious from the previous testimony, the need for such a body is clear and overdue. We look forward to working with you and the commission to develop a true, sound, comprehensive child health agenda for America's children.

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July 29, 1987

The Honorable Bill Bradley
Hart Senate Office Building
Room 731
Washington, D.C. 20510

Dear Senator Bradley:

I am pleased to respond to your question submitted to me after the July 10 hearings. Your interest in taking a leadership role on the funding of the National Childhood Vaccine Act is very much appreciated.

We at the Academy look forward to working with your staff toward an immediate and positive resolution of this issue.

Sincerely yours,

Donald W Schiff

Donald W. Schiff

DWS/pam

QUESTION FOR THE RECORD
Senator Bill Bradley
July 10, 1987

To Dr. Schiff:

Would you be willing to provide for the record your analysis of the costs of implementing the National Childhood Vaccine Injury Act, and any suggestions you might have for reducing the costs of the program?

Senator Bradley, as one of the principal parties involved in the development of this legislation, we feel obligated to bring to you a responsible financing plan that will meet the objectives of the National Childhood Vaccine Injury Act. Basically, these objectives are: 1) to insure a safe and adequate supply of childhood vaccines; 2) to promote more research for even better vaccines; 3) to provide for a fair and just compensation program for those who are injured. Let me say at the outset that no amount of compensation is ever enough for a family whose child has suffered permanent injury or death from a mandated childhood vaccine. However, a fiscally responsible public policy must be developed that fairly compensates those injured children, while at the same time keeps the immunization program affordable for the additional 3.8 million children born each year.

We believe that P.L. 99-660 offers a reasonable funding structure for the vaccine trust fund. However, given the operational and budgetary constraints of trust funds and concerns expressed by the administration, we have explored, in depth, other options. With our overriding concerns of afford-ability of the childhood vaccines and the solvency of the vaccine trust fund, one issue stands out that merits review by this committee for its cost implications and by the authorizing committee for its policy implications. That issue is the extent to which mild, short-term injuries will be covered.

Shortly after Congress passed the childhood vaccine compensation legislation on October 24, 1986, the staff of the Senate Labor and Human Resources Committee requested that James O. Mason, M.D., the director of the Centers for Disease Control, estimate how many eligible events annually would be caused by vaccines (according to the Vaccine Injury Table that ultimately was included in the new law). One such event is "shock-collapse or hypotonic-hyporesponsive collapse." Dr. Mason's letter estimates that 9000 such events are caused annually by vaccines containing pertussis bacteria, "probably none with permanent damage." The medical literature cited by Dr. Mason is a study by Cody, et al of the rate of reactions of children to the pertussis vaccine. The study advises that "hypotonic hyporesponsive episode is a descriptive term which (sic) applies to an unusual and characteristic reaction associated with DTP immunization . . . Characteristically, the infant or child [having such a reaction] was pale, hypotonic and unresponsive to . . . parents for a period ranging from 10 minutes to 36 hours. These reactions were associated with the primary immunization series only . . . All [children in the study] returned to normal when evaluated by either their physician or one of the investigators."*

The basis for the estimate of 9000 such reactions each year is that nine of some 15,752 children studied following the first DTP immunization developed hypotonic hyporesponsive episodes. Assuming that 90 percent of the 3.8 million children born each year receive five doses of the DTP vaccine, 9000 such episodes are predicted annually.

On the basis of this figure, the Academy is concerned that compensation for hypotonic-hyporesponsive collapse could result in the program becoming excessively costly, particularly if awards include pain-and-suffering benefits. While the Academy wishes that all children who suffer any adverse reaction to a mandated vaccine would be able to benefit from the legislation, it is our opinion that potential awards that could result from compensation on the basis of this relatively minor side effect may jeopardize the stability of the childhood immunization program itself. Thus we recommend careful scrutiny of this issue, with specific consideration given to the elimination of eligibility for compensation for pain and suffering for these reactions. However, if there are residual effects from this type of reaction (for example, if such effects last for more than six months), then we believe that compensation for pain and suffering is appropriate.

We believe that the recommendations here put forth meet the above objectives, with a resulting surcharge on each dose of vaccine that will not adversely impact on the viability of the childhood immunization program. We fully recognize that this additional cost, which will ultimately be borne by parents and public health programs, comes at a difficult economic period, but this is the "bullet we have to bite" to contain the cost of the program.

RECOMMENDATIONS

1. The system would be funded by a surcharge on each dose of vaccine levied against the manufacturer, with proceeds going into a national trust fund.

2. Eligible claimants would receive a lump-sum award that would equal the net present value of expected future expenses. The lump-sum award would be used to purchase an annuity that would provide the claimant with guaranteed payments over his or her lifetime.

3. Allow pain-and-suffering awards only for adverse reactions involving long-term injuries. By including pain and suffering for the mild reaction cases, the annual cost of the program would almost triple in cost, placing an unsatisfactory surcharge on each dose of vaccine.

4. Increase the entry limit on unreimbursed medical expenses from $1000 to $2500. We feel that this amount is a more reasonable point of entry into the compensation system and eliminates coverage of short-term reactions.

5. Stagger the surcharge and compensation program by six months so start-up costs can be covered without borrowing.

6. Pay past claims over the first 30 months of the program to reduce surcharge inequities or pay past claims out of general revenues.

7. Limit the number of past claims to 2000. We feel this is a more realistic number and such reduction would help ensure the solvency of the fund.

The Academy has been working with the firm of Putnam, Hayes & Bartlett for our actuarial data. The principal investigator, Mr. John Butler, is submitting a detailed accounting for the record and we refer you to that statement for specific analyses. Based on the best and most recent data, we submit that program costs would be $2 million in year one, peak in the second year at $118 million, $90 million in the third year, $36 million in the fourth year and costs in the later years would simply increase with inflation. Allowing for a 25 percent "cushion," we believe that the vaccine surcharge for DPT would run $2.23, $2.17 for MMR and $.15 for polio.

STATEMENT OF ROBERT H. SWEENEY, PRESIDENT, NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS AND RELATED INSTITUTIONS, ALEXANDRIA, VA

Mr. SWEENEY. Thank you, good morning. Mr. Chairman, we have submitted a full statement. I am appearing here today as a substitute for Mr. George Farr from the Children's Medical Center of Dallas, who was taken ill and not able to be with us. I emphasize as substitute as opposed to a replacement.

We have 94 member hospitals and they are very active in the programs—Medicaid and Maternal and Child Health Programs—and very knowledgeable of the way these programs function and the results of them.

But first, if I may just borrow the opportunity for a moment to speak to another issue—and that is the question of the Medicare PPS update. Children's hospitals are exempted from PPS, as you know, and are still working off a 1981 case mix for their payment levels under the exempt hospital payment system. We have made a more detailed recommendation to the committee in our statement, and I would appreciate your consideration of that.

Now, in the context of the reconciliation process, we would like to speak briefly to the Medicaid and the MCH programs.

First, we are pleased to recommend the enactment and full funding of S. 422, introduced by Senator Bradley, cosponsored by Senator Chafee and other members of the committee, to allow states to expand Medicaid coverage for low-income pregnant women and children up to 185 percent of the poverty level, and to accelerate the phase-in of certain groups of children.

Too often, Children's hospitals see the results of the lack of prenatal care in their neonatal intensive care units, where premature and distressed infants are cared for at costs far exceeding the $1,500 to $2,000 that might be required for the cost of basic and adequate management of a pregnancy.

S. 422 will be extremely cost-effective in its prevention of maternal and infant distress, and we urge its adoption.

Further, it would mandate Medicaid coverage for children ages 5 to 8, with family incomes below the state poverty level. We would urge that that portion certainly needs to be enacted.

We would recommend further that states be required to provide benefits to all children with family incomes below the State poverty level, with this requirement phased-in by age groups over a 5-year period.

The second legislative proposal we would like to speak to is S. 1139, the MedAmerica Act of 1987, introduced by Senator Chafee, and once again demonstrating his continuing concern for those in need. This proposal would separate eligibility for Medicaid benefits from eligibility for cash assistance, and allow States to provide buy-ins for Medicaid benefits.

The separation of Medicaid eligibility and cash assistance eligibility is fundamental to improvement of the health of poor children and children with special needs. States ~~have been~~ hesitant to undertake the required step of an increase in the cash assistance maximum income ceilings so as to extend Medicaid eligibility, because of the financial and the social consequences.

There can be no more important action taken by the committee to enhance the States' ability to meet the health needs of their citizens under the Federal poverty level than this uncoupling, and the Association urges early consideration and enactment.

The buy-in provisions of that bill would be similarly valuable to low-income families. We would make one suggestion, for the employed low-income worker, who under the terms of the bill could buy-in to Medicaid. Frequently these workers themselves are provided health insurance benefits in the work place. But 30 percent of the children without health insurance are in a family where the principal wage earner does have such insurance in the work place. So we would suggest that the relationship be uncoupled so that the worker could buy Medicaid benefits for his dependents. But let's keep the onerous on the employer to provide the health insurance benefits for the employed worker. Otherwise, you will be shifting from the private sector to the public sector, and using public dollars to cover that employed worker.

Few initiatives to come before the Congress will have more potential for desirable social and economic change than those concerning reform of the welfare program, which we understand Senator Moynihan will be introducing shortly.

NACHRI would urge the committee, in its consideration of welfare reform, to recognize the importance of continuing Medicaid benefits during a transition period from cash assistance to gainful private sector employment. This is going to be essential, we think, to the success of the total effort.

If I may speak briefly, Mr. Chairman, on the question of catastrophic illness and children. Considerable attention has been paid to catastrophic illness problems of the elderly, and they are, indeed, profound—but they are not alone in this need.

Young families who are just beginning to establish their financial base similarly can be faced with the spectre of overwhelming medical expenses.

In conjunction with other organizations, we have developed a catastrophic proposal. Targeted at acute need of such families, we were pleased to have had the opportunity to acquaint Senator Chafee and his staff with it, and we look forward to their introducing this legislation.

Thank you, Mr. Chairman. In the questioning period, I might be able to make a couple other remarks.

[The prepared statements of Mr. Robert H. Sweeney and Mr. George D. Farr follow:]

Mr. Chairman, I am Robert Sweeney, President of the National Association of Children's Hospitals and Related Institutions. I am substituting for Mr. George Farr, President of the Children's Medical Center of Dallas, who was to present our testimony. Mr. Farr unfortunately became ill, and was not able to come to Washington.

NACHRI has 94 children's hospitals as its members. All are very knowledgeable of the Medicaid and Maternal and Child Health Programs.

If I may borrow the opportunity, I'll speak briefly to another question before the Committee - the Medicare update and the situation of hospitals exempt from prospective payment. We would appreciate the Committee members' consideration of the more detailed description of this situation in our written statement.

Medicaid

The Committee has before it, or will be considering, a number of proposals to improve the Medicaid program.

Among these are S-422, introduced by Senator Bradley and co-sponsored by Senator Chafee and other members of the Committee, to allow states to expand Medicaid coverage for low-income pregnant women and children up to 185 percent of the poverty level and to accelerate the phase-in of children currently eligible for this option.

TOO OFTEN, CHILDREN'S HOSPITALS SEE THE RESULTS OF THE LACK OF PRENATAL CARE IN THEIR NEONATAL INTENSIVE CARE UNITS, WHERE PREMATURE AND DISTRESSED INFANTS ARE CARED FOR AT COSTS FAR EXCEEDING THE $1500 COST OF BASIC AND ADEQUATE MANAGEMENT OF THE PREGNANCY.

S.422 WILL BE EXTREMELY COST-EFFECTIVE IN ITS PREVENTION OF MATERNAL AND INFANT DISTRESS, AND NACHRI URGES ITS ADOPTION.

FURTHER, IT WOULD MANDATE MEDICAID COVERAGE FOR CHILDREN AGES 5 TO 8 WITH FAMILY INCOMES BELOW THE STATE POVERTY LEVEL, AND ALLOW STATES THE OPTION OF PROVIDING COVERAGE TO SUCH CHILDREN WITH FAMILY INCOMES BELOW THE FEDERAL POVERTY LEVEL.

ITS COVERAGE OF ADDITIONAL YOUNG CHILDREN WILL PROVIDE FOR THEIR READY ACCESS TO ESSENTIAL PREVENTATIVE HEALTH SERVICES, THE COST-EFFECTIVENESS OF WHICH HAS BEEN DEMONSTRATED IN THE PREVENTION OR AMELIORATION OF COSTLY ILLNESS AND DISABILITY AMONG CHILDREN.

NACHRI WOULD RECOMMEND FURTHER THAT STATES BE REQUIRED TO PROVIDE BENEFITS TO <u>ALL</u> CHILDREN WITH FAMILY INCOMES BELOW THE STATE POVERTY LEVEL, WITH THIS REQUIREMENT PHASED IN BY AGE GROUPS OVER A FIVE-YEAR PERIOD.

MED AMERICA

ANOTHER MEDICAID PROPOSAL IS S.1139, THE MED AMERICA ACT OF 1987, INTRODUCED BY SENATOR CHAFEE, ONCE AGAIN DEMONSTRATING HIS CONTINUING CONCERN FOR THOSE IN NEED. THIS PROPOSAL WOULD: A) SEPARATE ELIGIBILITY FOR MEDICAID BENEFITS FROM ELIGIBILITY FOR CASH ASSISTANCE; B) ALLOW STATES TO PROVIDE BUY-INS FOR MEDICAID BENEFITS.

THE SEPARATION OF MEDICAID ELIGIBILITY AND CASH ASSISTANCE ELIGIBILITY IS FUNDAMENTAL TO IMPROVEMENT OF THE HEALTH OF POOR CHILDREN AND CHILDREN WITH SPECIAL NEEDS. STATES HAVE BEEN HESITANT TO UNDERTAKE THE REQUIRED STEP OF AN INCREASE IN THE CASH ASSISTANCE MAXIMUM INCOME CEILINGS SO AS TO EXTEND MEDICAID ELIGIBILITY, BECAUSE OF THE FINANCIAL AND SOCIAL CONSEQUENCES.

THERE CAN BE NO MORE IMPORTANT ACTION TAKEN BY THE COMMITTEE TO ENHANCE THE STATES' ABILITY TO MEET THE HEALTH NEEDS OF THEIR CITIZENS UNDER THE FEDERAL POVERTY LEVEL THAN THIS UNCOUPLING, AND THE ASSOCIATION URGES ITS EARLY CONSIDERATION AND ENACTMENT.

SIMILARLY, ALLOWING STATES TO OFFER MEDICAID BUY-IN DESERVES SIMILAR CAREFUL ATTENTION. WE WOULD SUGGEST AMENDING THIS PROPOSAL SO THAT IN THE INSTANCE OF A LOW-INCOME FAMILY WHERE THE EMPLOYED WORKER RECEIVED HEALTH BENEFITS AS AN EMPLOYMENT BENEFIT BUT SUCH BENEFITS ARE NOT PROVIDED TO DEPENDENTS OR ARE NOT AFFORDABLE, MEDICAID BENEFITS MIGHT BE PURCHASED FOR THOSE DEPENDENTS. NEARLY 30 PERCENT OF THE 11.1 MILLION CHILDREN WITHOUT INSURANCE PROTECTION LIVE IN FAMILIES WHERE THE HEAD OF

THE HOUSEHOLD HAS EMPLOYER-PROVIDED HEALTH INSURANCE. THIS AMENDMENT WOULD FORESTALL A SHIFT OF THE WORKER'S COVERAGE FROM THE PRIVATE SECTOR TO THE PUBLIC SECTOR.

WELFARE REFORM

FEW INITIATIVES TO COME BEFORE THE CONGRESS WILL HAVE MORE POTENTIAL FOR DESIRABLE SOCIAL AND ECONOMIC CHANGE THAN THOSE CONCERNING REFORM OF THE WELFARE PROGRAM, WHICH WE UNDERSTAND SENATOR MOYNIHAN WILL BE INTRODUCING.

NACHRI WOULD URGE THE COMMITTEE, IN ITS CONSIDERATION OF WELFARE REFORM, TO RECOGNIZE THE IMPORTANCE OF CONTINUING MEDICAID BENEFITS DURING A TRANSITION PERIOD FROM CASH ASSISTANCE TO GAINFUL EMPLOYMENT, TO THE SUCCESS OF THE TOTAL EFFORT.

MATERNAL AND CHILD HEALTH BLOCK GRANT

THE MATERNAL AND CHILD HEALTH PROGRAM HAS A LONG AND SUCCESSFUL HISTORY OF STIMULATING ACTIVITIES, PROVIDING BOTH FUNDING AND INCENTIVES TO STATES TO IMPROVE HEALTH CARE SERVICES FOR MOTHERS AND CHILDREN. ITS SPECIAL PROGRAMS OF REGIONAL AND NATIONAL SIGNIFICANCE (SPRANS) HAVE DONE MUCH TO IMPROVE THE ORGANIZATION AND STANDARDS OF CARE, SUCH AS PROGRAMS CURRENTLY FUNDED IN ILLINOIS, LOUISIANA, AND PENNSYLVANIA TO DEVELOP HOME-CARE SERVICES FOR TECHNOLOGY DEPENDENT INFANTS.

NACHRI WOULD URGE THE COMMITTEE TO CONTINUE THE ESSENTIAL SERVICES PROVIDED BY THE MATERNAL AND CHILD HEALTH PROGRAM, AND

TO USE ITS GOOD OFFICES TO OBTAIN FUNDING EQUAL TO ITS $557 MILLION AUTHORIZATION.

FURTHER, WE WOULD URGE CONTINUED ATTENTION TO THE SPECIAL NEEDS OF TECHNOLOGY DEPENDENT INFANTS, INITIATED BY THE SPRANS GRANTS, AND WE WOULD RECOMMEND FUNDING OF DEMONSTRATION PROJECTS WHICH WILL DEVELOP AND IMPLEMENT SYSTEMS OF TRANSITIONAL AND HOME AND COMMUNITY-BASED CARE FOR SUCH MEDICALLY FRAGILE INFANTS AND THEIR FAMILIES.

CATASTROPHIC ILLNESS AND CHILDREN

IN RECENT MONTHS, CONSIDERABLE ATTENTION HAS BEEN PAID TO THE CATASTROPHIC EXPENSE NEEDS OF THE ELDERLY BY THIS COMMITTEE AND OTHERS. THE ELDERLY ARE NOT ALONE IN THIS NEED. YOUNG FAMILIES WHO ARE JUST BEGINNING TO ESTABLISH THEIR FINANCIAL BASE SIMILARLY CAN BE FACED WITH THE SPECTRE OF OVERWHELMING MEDICAL EXPENSES.

IN CONJUNCTION WITH OTHER ORGANIZATIONS INTERESTED IN THE HEALTH CARE NEEDS OF CHILDREN, NACHRI HAS DEVELOPED A PROPOSAL TO ASSIST FAMILIES FACING FINANCIAL DEVASTATION FROM THE CATASTROPHIC ILLNESS EXPENSE OF A CHILD. MODEST IN COMPARISON TO OTHER PROPOSALS ON CATASTROPHIC EXPENSE AND TARGETED AT THE MOST ACUTE NEED, WE ARE PLEASED TO HAVE HAD THE OPPORTUNITY TO ACQUAINT SENATOR CHAFEE AND HIS STAFF WITH IT, AND WE UNDERSTAND SENATOR CHAFEE WILL BE INTRODUCING LEGISLATION ON THIS IN THE NEAR FUTURE.

50 PERCENT OF CATASTROPHIC ILLNESS EXPENSE IN CHILDREN OCCURS DURING THE FIRST YEAR OF LIFE. THE CONSEQUENCES OF THIS TO YOUNG FAMILIES, FREQUENTLY IN THE EARLY STAGES OF DEVELOPING ECONOMIC STABILITY, CAN BE DEVASTATING. IT IS SUCH INFANTS AND FAMILIES THE PROPOSAL WOULD SERVE. THE CATASTROPHIC PROGRAM WOULD BE ESTABLISHED AS A NEW FUND WITHIN TITLE V OF THE SOCIAL SECURITY ACT. ITS FEATURES ARE THESE:

COVERAGE: CHILDREN IN THE FIRST YEAR OF LIFE SUFFERING FROM VARIOUS CONDITIONS SUCH AS PREMATURITY, CONGENITAL ANOMOLIES, NEUROLOGIC AND CARDIAC DISORDERS, BIRTH TRAUMA AND OTHER SERIOUS PROBLEMS;

COVERED POPULATION: PROTECTION AGAINST VERY HIGH MEDICAL COSTS FOR THE 3.8 MILLION AMERICAN FAMILIES WITH NEWBORNS AND INFANTS. AN ESTIMATED 9,643 WOULD INCUR SUCH COSTS EACH YEAR AND BE ELIGIBLE FOR PROGRAM BENEFITS;

ELIGIBILITY: THE CATASTROPHIC FUND WILL ACT AS THE PAYER OF LAST RESORT, AFTER EXHAUSTION OF ALL OTHER PAYMENT SOURCES WHEN MEDICAL BILLS EXCEED $50,000, AND OUT-OF-POCKET LIABILITY OF 10 PERCENT OF ADJUSTED GROSS INCOME OCCURS; COVERAGE IN THE SUCCEEDING YEAR FOR CONTINUED EXPENSES EXCEEDING THE 10 PERCENT OUT-OF-POCKET LIABILITY;

EMPHASIS: CARE PROVIDED IN LEAST RESTRICTIVE SETTING, WITH EMPHASIS ON HOME HEALTH CARE; ALL SERVICES PROVIDED UNDER A CARE MANAGEMENT PROGRAM, APPROVED BY FAMILIES AND ATTENDING PHYSICIANS;

BENEFITS: UNIFORM NATIONAL BENEFITS AND FEDERALLY ESTABLISHED PAYMENT LEVELS, USING CURRENT MEDICARE PROSPECTIVE PAYMENT PRINCIPLES WHERE APPLICABLE;

ADMINISTRATION: THE OFFICE OF MATERNAL AND CHILD HEALTH IN CONJUNCTION WITH STATE MCH PROGRAMS.

COUPLED WITH THE CATASTROPHIC FUND PROPOSAL, AND ESSENTIAL TO IT IS A PROGRAM OF GRANTS TO STATE MATERNAL AND CHILD HEALTH PROGRAMS TO DEVELOP CARE MANAGEMENT SERVICES, TO BE AVAILABLE TO ALL CHILDREN WITH HIGH-COST SPECIAL HEALTH CARE NEEDS, IN ADDITION TO SERVING THE SPECIAL NEEDS OF THOSE QUALIFYING FOR THE CATASTROPHIC FUND.

THIS PROPOSAL WOULD PROVIDE RELIEF TO ONLY THE MOST SERIOUSLY THREATENED FAMILIES. IT'S A START. MORE ADEQUATE AND CURRENT DATA ON CHILDREN WITH HIGH-COST MEDICAL EXPENSES IS NEEDED. THEREFORE, WE WOULD URGE THAT THE OFFICE OF MATERNAL AND CHILD HEALTH BE AUTHORIZED AND PROVIDED FUNDING TO INITIATE A PROJECT FOR THE PURPOSE OF STUDYING THE INCIDENCE, MEDICAL EXPENSES, SERVICE NEEDS, AND ADEQUACY OF THIRD-PARTY COVERAGE OF CHILDREN WITH HIGH-COST MEDICAL EXPENSES.

LOOKING TO CHILDREN'S FUTURE

THE ASSOCIATION IS PLEASED TO LEARN THAT THE COMMITTEE HAS PROPOSED FOR ITS AGENDA, AN IN-DEPTH STUDY OF THE NEEDS OF CHILDREN, WITH PARTICULAR EMPHASIS ON THOSE WITH SERIOUS AND HIGH-COST HEALTH CARE NEEDS. A PART OF THIS ACTIVITY WOULD BE THE CREATION OF A DISTINGUISHED NATIONAL COMMISSION TO ASSIST IN THIS CHALLENGING UNDERTAKING.

NACHRI WOULD RESPECTFULLY SUGGEST THAT AS PART OF THIS EFFORT, THE EFFECTIVENESS AND CONSISTENCY OF THE FEDERAL/STATE MEDICAID PROGRAM IN MEETING CHILDREN'S NEEDS, AND THE PAST ACCOMPLISHMENTS AND FUTURE DIRECTIONS OF THE MATERNAL AND CHILD HEALTH PROGRAM, BE ASSESSED.

THE CHILDREN'S HOSPITALS ARE SUBSTANTIAL PARTICIPANTS IN THE ORGANIZATION AND PROVISION OF CHILD HEALTH SERVICES. THEY WILL ASSIST IN ANY WAY POSSIBLE, AND THE NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS AND RELATED INSTITUTIONS WILL BE PLEASED TO FACILITATE THAT ASSISTANCE.

THE ASSOCIATION IS MOST APPRECIATIVE OF THE OPPORTUNITY TO PRESENT THESE RECOMMENDATIONS AS THE COMMITTEE CONTINUES ITS IMPORTANT WORK ON BEHALF OF CHILDREN.

nachri An Association Statement

STATEMENT
OF THE
NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS
AND RELATED INSTITUTIONS
BEFORE THE
COMMITTEE ON FINANCE
UNITED STATES SENATE

ON
MEDICAID AND THE MATERNAL
AND CHILD HEALTH BLOCK GRANT PROGRAMS

JULY 10, 1987

Presented by
George D. Farr
President and Chief Executive Officer
Children's Medical Center of Dallas
Dallas, Texas

The National Association of Children's Hospitals and Related Institutions is a voluntary association dedicated to promoting the health and well-being of children. NACHRI is the only national organization of Children's Hospitals in the country. It represents 94 non-profit Children's Hospitals. All are teaching hospitals, committed to research, deeply involved with the communities they serve, and generous with charitable care. Through these programs, they become very knowledgeable of the Medicaid and Maternal and Child Health programs and the patients they serve.

The Association is aware that in addition to its concerns with these two programs, the Committee has responsibility for the Medicare program and its payment systems. Although this is not the focus of today's hearing, we would borrow the opportunity to speak to a pressing issue.

Children's Hospitals are currently exempt from Medicare's Prospective Payment System, but are subject to a reimbursement limit on cost per discharge. The limit is increased annually by an update factor. For several years now, Children's Hospitals and other PPS-exempt units have received artificially low update factors, because the law required a single factor for PPS and PPS-exempt hospitals, and because the factor was reduced to offset "DRG creep" and other phenomena pertaining only to PPS hospitals. Last year the Congress changed the law to allow separate factors for PPS and PPS-exempt hospitals. We strongly urge this Committee to approve the full 4.4 percent update factor for PPS-exempt hospitals that was recommended by the Prospective Payment Assessment Commission as the minimum necessary to maintain the current level of quality and beneficiary access. Although 4.4 percent will not make up for the past penalties suffered by the PPS-exempt hospitals, nor compensate for changes in their case mix from the 1981-82 time period upon which payments are based, we believe it is a fair and reasonable amount and will have a very small impact on the Medicare budget.

Such hospitals increasingly will be disadvantaged by payments for Medicare patients, the longer they are held in the "limbo" of the exempt payment system. The Congress had directed the Health Care Financing Administration to report to it by December 31, 1985, on recommendations for their inclusion in prospective payment. It is our understanding the report has been delayed in the Office of Management and Budget, and we would respectfully urge the Committee to inquire as to its anticipated delivery to the Congress.

Medicaid

The Committee has before it, or will be considering, a number of proposals to improve the Medicaid program.

Some of these proposals would improve the benefits provided the basic population for which Medicaid was originally intended - poor and disadvantaged children and their families. Others would address the needs of other age segments. Among the former are S.422, introduced by Senator Bradley and co-sponsored by Senator Chafee and other members of the Committee. This legislation would allow states to expand Medicaid coverage for low-income pregnant women and children up to 185 percent of the poverty level and to accelerate the phase-in of children currently eligible for this option.

Further, it would mandate Medicaid coverage for children ages 5 to 8 with family incomes below the state poverty level, and allow states the option of providing coverage to such children with family incomes below the federal poverty level. It continues the direction of the 1986 Reconciliation Act allowing such inclusion of mothers and infants up to the federal poverty level, which thirty states have implemented or are in the process of implementing.

The Association commends the effort made in 1986 to provide resources for adequate prenatal, obstetrical, and infant care. Too often, Children's Hospitals see the results of the lack of such care in their neonatal intensive care units, where premature and distressed infants are cared for at costs far exceeding the $1500 cost of basic and adequate management of the pregnancy.

S.422 will continue the improvements made. It is extremely cost-effective in its prevention of maternal and infant distress, and NACHRI urges its adoption.

Its coverage of additional young children will provide for their ready access to essential preventative health services, the cost-effectiveness of which has been demonstrated in the prevention or amelioration of costly illness and disability among children.

NACHRI would recommend an important addition to S.422, to accelerate the progress being made. States should be required to provide benefits to all children with family incomes below the state poverty level, with this requirement phased in by age groups over a five-year period.

Med America

The Committee will have before it S.1139, the Med America Act of 1987, introduced by Senator Chafee, once again demonstrating his continuing concern for those in need. This proposal would: a) separate eligibility for Medicaid benefits from eligibility for cash assistance; b) allow states to provide income-adjusted purchase of Medicaid benefits to the working poor; and c) similarly allow states to offer purchase of Medicaid benefits to persons closed out of the private insurance market by a pre-existing medical condition or exhaustion of benefits.

The Association views as fundamental to improvement of the health of poor children and other children with special needs, this separation of Medicaid eligibility and cash assistance eligibility. In spite of any desire to provide necessary health care benefits to persons in need, particularly children, states have been hesitant to undertake the required step of an increase in the cash assistance maximum income ceilings so as to extend Medicaid eligibility, because of the financial and social consequences. With such separation, it would not be necessary to "carve out" special populations from Medicaid eligibility standards, to achieve the desirable goals of S.422, discussed above.

There can be no more important action taken by the Committee to enhance the states' ability to meet the health needs of their citizens under the federal poverty level, and the Association urges its early consideration and enactment.

The other proposals of S.1139, to allow states to offer Medicaid buy-in to those above the federal poverty level who do not have health care protection provided to them in their place of employment, deserve similar careful attention. Consideration might be given to amending this proposal so that in the instance of a low-income family where the employed worker receives health benefits as an employment benefit but such benefits are not provided to dependents or are not affordable, Medicaid benefits might be purchased for those dependents. Nearly 30%

of the 11.1 million children without insurance protection live in families where the head of household has employer-provided health insurance.

Welfare Reform

Few initiatives to come before the Congress will have more potential for desirable social and economic change than those concerning reform of the welfare program.

It is our understanding that the Chairman of the Committee's Subcommittee on Social Security and Family Policy will introduce legislation to transform the "inadequate, ineffective, and politically insupportable aid to families with dependent children into a new system of child support."

Essential to the success of such a reform effort will be assurance to persons affected that their health benefits and those of their dependents will continue to be provided through Medicaid for a transition period when such persons move to private sector employment.

NACHRI would urge the Committee, in its consideration of welfare reform, to recognize the importance of continuing Medicaid benefits to the success of the total effort.

Maternal and Child Health Block Grant

The Maternal and Child Health program has a long and successful history of stimulating activities to the benefit of mothers and children. It has provided both funding and incentives to states to improve health care services for mothers and children. Its special programs of regional and national significance (SPRANS) have done much to improve the organization and standards of care, such as programs currently funded in Illinois, Louisiana, and Pennsylvania to develop home-care services for technology dependent infants.

These projects have demonstrated that a significant number of such infants and their families require a prolonged and intensive program of transitional care to prepare infant, family and home, community resources, and sources of payment for the care of these fragile infants in settings other than the high-cost, acute care facilities in which they otherwise will remain.

State maternal and child health programs have frequently provided funds for purchase of services for children with special health needs, when other sources of funds were not available or not adequate.

NACHRI would urge the Committee to continue the essential services provided by the Maternal and Child Health program, and to use its good offices to obtain funding equal to its $557 million authorization.

Further, we would urge continued attention to the special needs of technology dependent infants, initiated by the SPRANS grants, referenced above.

We would recommend funding of demonstration projects which will develop and implement systems of transitional and home and community-based care for such medically fragile infants and their families.

Catastrophic Illness and Children

In recent months, considerable attention has been paid to the catastrophic expense needs of the elderly by this Committee and others. The elderly are not alone in this need. Young families who are just beginning to establish their financial base similarly can be faced with the spectre of overwhelming medical expenses.

In conjunction with other organizations interested in the health care needs of children, NACHRI has developed a proposal to assist families facing financial devastation from the catastrophic illness expense of a child. Modest in comparison to other proposals on catastrophic expense and targeted at the most acute need, we are pleased to have had the opportunity to acquaint Senator Chafee and his staff with it, and look forward to its early introduction for the Committee's consideration.

Analysis of data shows that fully 50% of catastrophic illness expense in children occurs during the first year of life. The consequences of this to young families, frequently in the early stages of developing economic stability, can be devastating. It is such infants and families the proposal would serve. The catastrophic program would be established as a new fund within Title V of the Social Security Act. Its features are these:

Coverage: Children in the first year of life suffering from various conditions such as prematurity, congenital anomolies, neurologic and cardiac disorders, birth trauma and other serious problems;

Covered population: Protection against very high medical costs for the 3.8 million American families with newborns and infants. An estimated 9,643 would incur such costs each year and be eligible for program benefits;

Eligibility: The catastrophic fund will act as the payer of last resort, after exhaustion of all other payment sources when medical bills exceed $50,000, and out-of-pocket liability of 10% of adjusted gross income occurs; coverage in the succeeding year for continued expenses exceeding the 10% out-of-pocket liability;

Emphasis: Care provided in least restrictive setting, with emphasis on home health care; all services provided under a care management program developed by the state Maternal and Child Health (MCH) program, approved by families and attending physicians;

Benefits: Uniform national benefits and federally established payment levels, using current Medicare prospective payment principles where applicable.

Administration: The Office of Maternal and Child Health in conjunction with state MCH programs.

Coupled with the catastrophic fund proposal, and essential to it is a program of grants to state Maternal and Child Health Programs to develop care management services, to be available to all children with high-cost special health care needs, in addition to serving the special needs of those qualifying for the catastrophic fund.

The Association would recommend further the need for more adequate and current data on children with high-cost medical expenses. To that end, we would urge that the Office of Maternal and Child Health be authorized and provided funding to initiate a project for the purpose of studying the incidence, medical expenses, service needs, and adequacy of third-party coverage of children with high-cost medical expenses.

Looking to Children's Future

The Association is pleased to learn that that Committee has proposed for its agenda, an in-depth study of the needs of children, with particular emphasis on those with serious and high-cost health care needs. A part of this activity would be the creation of a distinguished national commission to assist in this challenging undertaking.

NACHRI would respectfully suggest that as part of this effort, the effectiveness and consistency of the federal/state Medicaid program in meeting children's needs, and the past accomplishments and future directions of the Maternal and Child Health program, be assessed.

The Children's Hospitals are substantial participants in the organization and provision of child health services. They will assist in any way possible, and the National Association of Children's Hospitals and Related Institutions will be pleased to facilitate that assistance.

The Association is most appreciative of the opportunity to present these recommendations as the Committee continues its important work on behalf of children.

Senator DURENBERGER. Thank you very much. I now yield to my Democratic colleague.

Senator MOYNIHAN. Mr. Chairman, I welcome Dr. Schiff and Mr. Sweeney, and note that both are speaking, both of you are speaking on the one hand for the physicians and the other for the hospitals, make a point about the extension of Medicaid benefits to families that leave the welfare system—a consequence of finding work.

I guess the single most powerful disincentive we have built into our present welfare system is—unintentionally, as so many things do—when we provided Medicaid to welfare families with all the consequences and mothers concerned with children, and said that the minute you leave welfare you lose that health insurance. It is a deadfall. We have not been in it four months, and we certainly hope in welfare legislation to continue the 6-month provision which, Dr. Schiff, you suggested, and then an 18-month or some such transitional affair. Mr. Sweeney made the same point.

I would like to ask you a general, ask you as a doctor and ask you as someone who is surrounded with children—sources of health are complex, aren't they? What would you make to the general assessment of the consequences on children's health—and our last panel made the point, you know, we have put in all these programs and spent all this money, and things somehow don't get better. What doesn't get better is the family structure. The very thought simultaneously with all this provision, the social provision of medicine and care, there has been a collapse in the social structure. The median, the average American child now lives in a female-headed family before reaching 18. Only in 39 percent live to age 18 with both natural parents.

We can make an estimate that perhaps one-third, somewhere plus or minus 32 percent, plus or minus 3, one-third of American children will be on AFDC before they reach 18. Now this is a social collapse, and it has to have consequences in child health. Does it not? I invite you to tell us. I certainly do not have to tell you.

Dr. SCHIFF. Well, there are a number of ways of examining that particular question. I can also begin by saying that in Suffolk County, in your own State——

Senator MOYNIHAN. You have a study?

Dr. SCHIFF [continuing]. Yes. I was involved with that study as the chairman of the Advisory Committee. One observation that was made, and I don't think we can quote this in any statistically sound fashion, but one observation that was made by the physicians there is that this particular program in Suffolk County enabled parents to go out and seek work and not lose the Medicaid program that they were already part of, because of the specific provisions there.

So in a sense, one could say that one was enhancing the esteem of the family structure by this particular approach.

Senator MOYNIHAN. Your problem is it is in medicine. I mean experimenting with human beings is hard. You can't have a controlled group which you deny childcare.

Dr. SCHIFF. Yes, but I think in general, however, I think that we are concerned about the break-up and the decline of the family as you are already suggesting is occurring. And we recognize that and we see that.

What happens, actually, so often is that we get into the major problem of providing care for children during the day as a very important part of this problem—the daycare problem. We know that there are health problems associated with daycare, and there is the additional separation of the whole family structure.

But, I think that what we anticipate is that this isn't going to change in the near future, and that what we are trying to do is adapt and provide increased information and care for children in daycare so that their health will not be impaired.

Senator MOYNIHAN. Good. But it really would help if we learned more from the pediatricians about this. If we know anything about health, it is that the most important things happen before people get sick and preventing them from doing and what mothers spend their lives doing—is seeing that children don't swallow things and so forth.

Dr. SCHIFF. Yes.

Senator MOYNIHAN. To the degree that that preventative structure is collapsing, the follow-on therapeutic structure becomes, it is overway, overstressed. Is it not? Is something like that going on?

Dr. SCHIFF. Well, I think that there are no greater advocates of prevention than physicians who care for children, mostly pediatricians. And certainly in the way you have described, accident prevention programs are a very major responsibility. Certainly, if you have people who are kind of lose about watching——

Senator MOYNIHAN. Most mothers are walking accident prevention programs.

Dr. SCHIFF [continuing]. Yes, they are.

Senator MOYNIHAN. They are pretty industrious.

Dr. SCHIFF. They are very dedicated to that. We have helped them with specific programs.

Mr. SWEENEY. If I may, Senator, from the hospitals' perspective and the organized delivery of care we see some very basic manifestations of the problems caused by this changing organization of the family. A very practical one is a working mother is not available to take her child to a physician or to a clinic or to a hospital when required.

Senator MOYNIHAN. Yes.

Mr. SWEENEY. Some of our institutions have tried to address this by having evening clinic hours and weekend clinic hours and that sort of thing. The question of the use of daycare, one of the downsides of the increased use of daycare is that we are exposing very young children to kind of a germ pool that they would not be exposed to were they in home, cared for by a mother. That is another consideration that has to be thought about.

Senator MOYNIHAN. So that all turn to working mothers and daycare is unexamined with respect to something as simple as that. I mean, traditionally, children live in a germ pool of their own family—now they go into those across the street.

Mr. SWEENEY. I think perhaps the biggest consequence, however, is that you have got a new type family unit that is trying to get along on much less income.

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

Senator DURENBERGER. Thank you. Senator Chafee.

Senator CHAFEE. Thank you, Mr. Chairman. First, I want to apologize to Dr. Schiff, Mr. Sweeney, and Ms. Rosenbaum and the others who testified before, because I was not here. I will just explain briefly my absence, and you might approve of it.

I was offering an amendment on the floor to deny tobacco an export subsidy. We now have a program in existence which is what we call a "no net cost" for tobacco. In 1982, we nearly eliminated all the support programs, but we decided then there would be no net cost for them. In this trade bill there is a provision from the Agricultural Committee that provided that tobacco would be subsidized in the export section, which keeps the whole industry going—or helps with it.

I moved to strike, that is to eliminate, the subsidy for tobacco, and I regret to say I was unsuccessful, but I am pleased to note that both of my colleagues supported my efforts. We got 42 votes and the other side got 51, I think.

Dr. SCHIFF. Sorry to hear that.

Senator CHAFEE. Well, I would like to ask both of you gentlemen some questions. It seems to me, and see if you agree, you have got wide practices and wide knowledge: is it safe to say that there is no better investment in preventive medicine, that will produce such substantial results, as proper prenatal care and proper care for young children. Is that a safe statement? Dr. Schiff, you touched on it there.

Dr. SCHIFF. I would certainly be happy to support that. I mean, I would endorse it.

Senator CHAFEE. But dollar for dollar, if we want to make an investment in preventive medicine to keep people healthy, the greatest single return we can get is to take care of all mothers, but we are directing it to impoverished mothers here, that they get fed right, eat right, and counselled properly in their, during the prenatal period.

Dr. SCHIFF. A particularly vulnerable group are teenage mothers, which we are seeing more and more. And certainly if we can prevent a premature birth, we may save $100,000 on an individual pregnancy. So I would agree with you wholeheartedly.

Senator CHAFEE. Would you agree with that, Mr. Sweeney?

Mr. SWEENEY. Indeed. The Institute of Medicine, of course, reports this in the study they have done on this question. They say every dollar spent for effective prenatal care and management of the pregnancy is going to have a return of $3.38. There is another report that the lack of adequate prenatal care for poor women costs the Federal Government $360 million a year in program costs to attempt to correct the results of this.

As Mr. Nugent, I believe it was, mentioned earlier this morning in your absence, Senator, I think we need to look far down the road, because a child who suffers neurological damage or oxygen deprivation as a result of a difficult pregnancy that otherwise could have been managed, that child can cost $1 million in institutionalization in it's lifetime. It is just the most shortsighted thing that this nation can do to not provide adequate funding and care for mothers and infants. It just, in a business sense, makes no sense. And in a humane sense, it is sinful.

Senator CHAFEE. That is a very elegant statement. I wish we could all scream this from the housetops. I guess the Children's Defense Fund does that, thank goodness, and all the rest of you good folks do it likewise. We try to do it here. And as you mentioned, during the various Reconciliation measures, we have been able to extend the Medicaid and will continue doing that.

Next, I would like to thank you, gentlemen, and the previous speakers who said good words about the efforts we have been making here and I have been making with MedAmerica and the Community and Family Living Amendments, and I want to thank the chairman for the kind comments that he made in my absence as I understand.

Sorry I wasn't around. I love to hear nice things said. Let me ask you, Mr. Sweeney. In MedAmerica, which is based upon people purchasing at an income-adjusted premium Medicaid coverage. Do you think people would be interested in doing that? Do you think individuals would buy coverage?

Mr. SWEENEY. I think there is no question that people would do it. There are many families that are unable to afford insurance protection in the private sector because of their income level. There are many others to whom it is not available. We have got to remember that the private insurance business is, in fact, a business. I have heard it stated that insurance companies are in the business of avoiding risk, not protecting against risk.

Pre-existing conditions, as so frequently can happen with a youngster in the family, a youngster that has had a difficult early stage of life, can preclude or make prohibitively expensive the purchase of private sector insurance. I am quite sure and I think Senator Durenberger has recognized this in legislation I understand he will be proposing for families with children with special health care needs, they have got to have this made available to them.

Senator CHAFEE. I want to say I couldn't agree with you more. I guess it was Dr. Schiff that said that separating out the income payments, AFDC, from Medicaid is important. I think that is absolutely essential for the reasons that have been cited most recently by Senator Moynihan right here—that people fear getting off AFDC because they lose their coverage.

Now, here is one program that would give them the possibility to continue Medicaid coverage. You agree with that, the disincentive factor that was mentioned?

Dr. SCHIFF. Oh, yes. Right. I have one small concern about the buying in of the Medicaid.

Senator CHAFEE. Yes.

Dr. SCHIFF. That is that we must be sure that the cost to the individual family is cut low enough to make it affordable. I think this is an issue that must be addressed carefully.

Senator CHAFEE. Well, I think you are right. We are dealing with the community that probably isn't very used to insurance to start with.

Dr. SCHIFF. And can't afford it.

Senator CHAFEE. Can't afford it, suspicious of it, think that it belongs to some other income group—not them, haven't thought about it. And so I would see some problems in getting them interested.

Dr. **Schiff**. It is well worth the effort, though.

Senator **Chafee**. I think so.

Mr. **Sweeney**. Senator, if I may just make a comment on that question you have asked. I think that we are getting to the point, however, in the entire Medicaid program that we have also got to look at the disparity of the coverages of the various state Medicaid programs.

For example, the working poor family that is allowed to buy into Medicaid in Rhode Island or in Minnesota will be well protected as a consequence of that. The working poor family that is allowed to buy into Medicaid in the State of Alabama will be buying 12 days of hospital protection, separated by a 31-day period of non-hospitalization, and then perhaps another 12 days, and might be entitled to 10 or 12 outpatient visits per year.

Now, I'm not sure how valuable that buy-in is going to be to that family in Alabama. So I think we have to start looking at the disparity of the value of the Medicaid programs State to State.

Senator **Chafee**. Well, I think that is a good point, and we certainly have got to bear that in mind as we go forward with this.

Well, I would just like to thank each of you for the help you have given us in working with our staff, and Ms. Rosenbaum and the others for what they have done. We are trying to press ahead with these different proposals. Senator Durenberger has one, as you know, I am involved with MedAmerica and the community and family living arrangements.

All of them evolve around Medicaid. And that is the program that we are latching onto. Thank you, Mr. Chairman.

Senator **Durenberger**. Thank you. Gentlemen, one would expect, given the nature of this panel, the doctors and the hospitals, that you are going to support all this stuff—it is good for business. The more care we can provide, the more care we can finance, the more care you can provide.

Let me ask both of you a question about the advent of something called case management. We are dealing with that, beginning to deal with that in other areas. Employers are beginning to be concerned about managing the access of their employees to the health care system. Trying to control the selection of providers or utilization of the system, as we call it.

We have, and hopefully they stay there—six little demonstration projects in the Medicare Catastrophic bill to show us what we can learn about case management for the access of the very sick elderly who are at the catastrophic end of that program, so that we don't get to $1,000 or $1,500 or $1,700 and then it is, welcome to the hospital, welcome to the doctor, use as much service as you want.

Now obviously, when we are dealing in an area in which we are forced to prioritize we can't do all we would like to do. We can't do all we should do. That is a tough thing from your standpoint and a tough thing from ours.

The introduction of the notion of case management into the system is important, but it is also important that it be looked at appropriately. When we introduced it into the Medicaid area, and we have done this at various State levels through gate keeper programs and things like that, it is possible that it can be used as a way to keep people away from health care.

So I am just curious to know, from your own experiences or your observations, what your views are on the necessity of case management, and if we are moving in that direction, how should we as the payer try to shape the case management systems so that it helps the people we care most about who are the consumers of health care.

Dr. SCHIFF. Well, I think that I can speak from personal experience, because in private practice I was a case manager of my practice having to do with the HMO patients which I cared for. And I think that the observations that have been made have varied enormously.

What I mean by that is that I think that one can case manage in a cost effective way, which I think we are all concerned with and interested in doing, and yet provide quality care. But I think there is a danger which we must recognize and which we must be very careful about, and that is the danger of underutilization and over-control and over-rationing.

I think that this is an extraordinarily difficult area that is with us today and will continue to be with us as time goes on, because this issue of the proper balance of utilization versus underutilization is one that is often in the eye of the holder. Consequently, I think the issue of peer review by physicians is a critical part of this particular program. I am very concerned that the choice of case manager and the program of case management be carefully thought out and be placed on either a pilot program or that we use the experience which is already in existence in the various HMOs in this country. And various HMOs do case management in various ways.

But I think there is wealth of experience there already, at various ages, and I think that again, if we spread this out across the country that it must be done in a very careful way so that we do not impose upon this country a system which will be costly and ineffective.

Senator DURENBERGER. Mr. Sweeney.

Mr. SWEENEY. Senator, we like to use the term care management, particularly in relation to children. Case management we see as a manila folder. Care is our goal with the children.

Senator DURENBERGER. From now on I'm going to use that. It sounds much more sensitive.

Mr. SWEENEY. I think care management is particulary indicated in children with special health needs. The effort is at the effective coordination of services provided by a variety of care givers.

Principal to the development of that care management program are two entities. One, of course, is the parents.

The second is the attending physician. If we attempt to supplant or replace either of those two by a computer somewhere, kids are not going to get the kind of care that they deserve.

The pediatrician, in my experience—and I was thinking you were suggesting a little surprise that the hospitals and the doctors sat down here together this morning, as if it were the lion and the lamb—but pediatricians are very effective care managers in the handling of their patients.

I have been in this business 30 years. I'm not sure I could say that for every physician I have seen. But pediatricians, as a group, don't like to hospitalize children—they like to get them out as soon as they can. They tend to observe the child and take advantage of the child's natural defenses and such, instead of reach for the needle or reach for the scalpel.

I know that there is no great risk of pediatricians overutilizing services in their treatment of children. Coordination, perhaps, is the area where we need an organized approach.

Senator DURENBERGER. Thank you both very much for those comments. John.

Senator CHAFEE. Just a couple of final points. First, Mr. Sweeney, I want to thank you for your help in working with us on the catastrophic care for children under the Maternal and Child Health Block Grants, I appreciate that a great deal.

Mr. SWEENEY. I appreciate that.

Senator CHAFEE. Secondly, and this is a rather philosophical question, I quess. Each year we come up here during Reconciliation and we put our finger in the dike and try to plug it as far as taking of it, extending Medicaid for children, or prenatal care, doing something along those lines.

Do you think we ought to take a look at this whole medical delivery system, health delivery system—I don't want to say medical, because it involves more than traditional medical care—and see whether we are on the right track in this country? Do you think there is any merit? I mean, I know this stepping back and seeing where we want to go.

I'm asking you a question, so I don't want to put my own views too much into this question. But, I'm curious whether you think that we are on the right track or whether we ought to step back and review the whole situation. I will start with you, Dr. Schiff.

Dr. SCHIFF. Well, I must confess that I am always looking for better answers than what we have right now. I think that there are so many deficits and problems in our current health system that I would applaud and appreciate an effort of that sort. And, in fact, if I may just make an aside, I want to thank you for your support and introduction of the Chirp Bill. But that is, that is only part of it.

I think it would be very wise if we did step back a bit and look more broadly at our health care system. I don't know what form it should take. I don't think we should prejudge that at all, but I like to think of myself as a scientist in a way, as well as a humanitarian. I applaud any look at the issues, again, to see if we are on the right track. I would certainly support that.

Senator CHAFEE. What do you say to that, Mr. Sweeney?

Mr. SWEENEY. Senator, I think one of the problems is we all work under such a tight time line. Here we are with the reconciliation process and you have got to move through quickly and merge together what you can determine are the best priorities for the available funds.

Particularly in regard to the two programs we are discussing this morning, the Maternal and Child Health Programs and the Medicaid program as they relate to children, I think it would be of extreme value to this committee in an oversight function to step back and say, now what is it that we are accomplishing for children with these programs? What is it we are attempting to accomplish?

What needs are we missing? Can these programs be redesigned and reinforced in order to do the job better with the amount of funds that we have at hand?

We would support that effort 105 percent.

Senator CHAFEE. I want to thank you for that encouragement. And then, it wouldn't be just for children. But children are, I think, the most critical part of the missing links in the equation here. As you have cited, the decline in the coverage of Medicaid for children, the fact that so many children are totally uninsured, have no access to medical assistance in so many respects. There is just something wrong.

I mean, in this country of ours that is so wealthy, for poor mothers to not receive proper prenatal care just seems to me to be fiscal insanity, but beyond that insanity in every other respect, as you so elegantly point out—both of you.

It would be a big thing to do. This committee is like every other committee. And like you folks, we are always rush, rush—meet the deadline—the tyranny of the urgent. But I hope we can do something about a long-range view of where we are to go with health care systems in this country. Thank you. Thank you, Mr. Chairman.

Senator DURENBERGER. John, gentlemen, thanks to you all, and to all the witnesses. We very much appreciate your being here today. The hearing is concluded.

[Whereupon, at 11:46 a.m., the hearing was concluded.]

[By direction of the chairman the following communications were made a part of the hearing record:]

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STATEMENT OF THE ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS

SUBMITTED FOR THE RECORD ON JULY 15, 1987

TO THE SENATE FINANCE COMMITTEE

REGARDING MEDICAID, THE MATERNAL AND CHILD HEALTH BLOCK GRANT, AND OTHER MATTERS PENDING IN THE FY 1988 BUDGET RECONCILIATION PROCESS

The Association of Maternal and Child Health Programs appreciates the opportunity to submit this statement to the Committee on Finance of the United States Senate. We are submitting this statement to supplement the testimony that the Committee received during its hearings to consider Fiscal Year 1988 Budget Reconciliation issues affecting Medicare, Medicaid and Maternal and Child Health Block Grant programs.

The Association's members are persons responsible for and concerned with the administration of State and Territorial Maternal and Child Health Programs, and Programs for Children With Special Health Needs. The programs have a fifty year history of improving the ability of mothers and children to obtain appropriate and effective health care, and of establishing systems of coordination with other health, social service, and education programs to enhance the health and well-being of mothers and children.

Formerly the ASSOCIATION of MATERNAL and CHILD HEALTH and CRIPPLED CHILDREN'S PROGRAMS

Within recent years, a growing proportion of American children live in families who have inadequate health insurance to protect them from the high costs of chronic or catastrophic illness. Nearly one in five children, and one in three poor children, were uninsured in 1984. Sulvetta, M. and Swartz, K. Uninsured and Uncompensated Care. Urban Institute, 1986. Children are uninsured whenever a parent does not receive health insurance as a benefit of employment and cannot afford to purchase private coverage, and a child is not eligible for a public program, such as Medicaid.

The lack of necessary financing of care leads to several adverse circumstances. Many children do not receive necessary health services due to prenatal anxiety about charges. Other children do receive care but their families experience severe financial and emotional stress. Further, resources can become inaccessible to families without insurance or other means of financing health care since providers no longer readily shift unreimbursed costs to other payors.

The Association strongly believes that a public responsibility exists to assure that all children have access to necessary health care and services. With regard to catastrophic health care costs, the Association fully supports the proposal to establish a special Title V program to develop care management plans for children who have high cost illnesses and disabilities, as well as financial support for newborns and infants who incur health care costs in excess of $50,000 a year. The establishment of a fund to address the catastrophic costs of those children under one year, and a thoughtful care management system for all children with annual health costs exceeding $5,000 would assist significant numbers of families to remain intact.

As medical technology improved the life expectancy of children with special health care needs, Title V programs around the country developed expertise in coordinating services and funding from both private and public programs. The goal of these programs has been to help the child achieve his or her maximum potential and maximum independence and integration in the community. The care management programs which have succeeded have been those which have successfully balanced the dual responsibilities of advocacy and cost effectiveness. With additional funds addressed towards systematizing such care management programs, they will be able to assist significantly larger numbers of children.

In addition to urging the Committee to address children's catastrophic health care needs, the Association wholeheartedly supports each of the recommendations listed in the testimony of the Children's Defense Fund. They are to enact the Infant Mortality Amendments of 1987, to require all states to include SSI children in their Medicaid programs, to mandate Medicaid coverage of all "Katie Beckett" children, to coordinate

Medicaid coverage with P.L. 99-457 coverage at least for children under 200% of the federal poverty level, to enact Medicaid improvements for working poor families leaving AFDC, to increase the Title XX Social Services Block Grant, and to establish a National Commission on Children.

The Title V Maternal and Child Health Block Grant program is the only federal program devoted exclusively to improving the health of mothers and children. Until there is universal health care coverage, the Association believes that adoption of the recommendations listed above will significantly improve the health of this Nation's mothers and children.

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