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THE HEALTHY START PROGRAM: IMPLEMENTATION LESSONS AND IMPACT ON INFANT MORTALITY

HEARING

BEFORE THE

SUBCOMMITTEE ON HUMAN RESOURCES

OF THE

COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT
HOUSE OF REPRESENTATIVES

ONE HUNDRED FIFTH CONGRESS

FIRST SESSION

MARCH 13, 1997

Serial No. 105–11

Printed for the use of the Committee on Government Reform and Oversight

U.S. GOVERNMENT PRINTING OFFICE

40–482 CC WASHINGTON : 1997

For sale by the Superintendent of Documents, U.S. Government Printing Office
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THE HEALTHY START PROGRAM: IMPLEMENTATION LESSONS AND IMPACT ON INFANT MORTALITY

THURSDAY, MARCH 13, 1997

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HUMAN RESOURCES,
COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT,
Washington, DC.

The subcommittee met, pursuant to notice, at 10:10 a.m., in room 2247, Rayburn House Office Building, Hon. Christopher Shays (chairman of the subcommittee) presiding.

Present: Representatives Shays, Snowbarger, Towns, Kucinich, and Barrett.

Also present: Representatives Cummings, Thompson, and Stokes.

Staff present: Lawrence J. Halloran, staff director and counsel; Doris F. Jacobs, associate counsel; Robert Newman, professional staff member; R. Jared Carpenter, clerk; Ronald Stroman, minority professional staff; and Ellen Rayner, minority chief clerk.

Mr. SHAYS. Good morning. I would like to call this hearing to order and welcome our witnesses and our guests to what is a very important hearing.

Every child deserves a healthy start. That caring principle motivated President Bush in 1989, to make the effort against infant mortality a national priority. Part of that initiative was the Healthy Start Program, a 5-year demonstration begun in 1991 to test innovative, locally driven approaches to reach pregnant women and improve the health of their babies.

Since then, Healthy Start projects in 22 communities have planned their strategies, formed their community organizations, and provided a variety of services to expectant mothers. Through this fiscal year, Congress appropriated and the Department of Health and Human Services, HHS, spent more than $500 million on Healthy Start.

Now the test is over, and it is time to find out what worked and what did not. It is time to analyze as objectively as possible, the impact of Healthy Start initiatives on the leading causes of infant mortality: low birth weight, birth defects, and Sudden Infant Death Syndrome. It is time to determine what Healthy Start demonstrated about the effectiveness and sustainability of community action to improve the health of infants at risk.

Toward that end, HHS is conducting a formal evaluation of the 15 original Healthy Start projects. The study will measure the program's performance in terms of infant mortality data, infant health

records, maternal health records, and public health statistics. The $5 million study will be completed in late 1998 or early 1999.

But the Department believes that enough is already known to justify expansion of the program to 30 more localities. The President's fiscal year 1989 budget requests $96 million for replication of nine successful Healthy Start infant mortality reduction strategies.

The request raises important oversight questions: On what basis did the Department declare the program a success? Can reductions in infant mortality rates be linked directly to Healthy Start initiatives prior to completion of a national evaluation? On what empirical data can communities rely to replicate the successes and avoid the missteps of Healthy Start? Can HHS manage an expanded program effectively?

As much as anyone, I want the answers to confirm that we have found locally supported approaches reduce infant mortality. But the decisions affecting the lives of 30,000 babies each year should be based on facts, not hopes or theories. Federal policies and programs to fight infant mortality must be based on sound research and current data, not anecdotal information and purely local evaluation. When it comes to the care of vulnerable infants, good intentions are no substitute for good health outcomes.

We ask the HHS public health agencies involved in the fight against infant mortality to address these concerns. We also invite Healthy Start project directors to describe their work, to bring local solutions to a national problem.

Your testimony today is an important part of the subcommittee's Healthy Start evaluation. We are very grateful that you came, and we are eager to begin this hearing. And we welcome all of you.

With that, I would like to call on Ed Towns, who is the ranking member of this subcommittee, and I would say without hesitation an equal partner in this process, in this hearing, and in all of the other hearings that we have conducted. Mr. Towns.

Mr. TOWNS. Thank you very much, Mr. Chairman.

Millions of our children are in grave risk because of infant mortality and low birth weight, particularly in our under-served and minority communities.

In 1992, the infant mortality rate was 8.5 deaths per 1,000 births, one of the highest rates of infant mortality among industrialized nations. African-American infants die at a rate more than twice the rate for white infants, with 17.6 infant deaths per 1,000 births, a rate seen in some of the poorest Third World countries.

We are, however, making progress. Since 1970, the infant mortality rate has been cut in half. But the rate is still much too high, particularly in economically disadvantaged neighborhoods. That is why programs like Healthy Start are so important.

Healthy Start was developed by Dr. Louis Sullivan, former Bush administration Secretary for the Department of Health and Human Services. Dr. Sullivan recognized that a one-size-fits-all-approach to infant mortality and low birth weight would not work in underserved areas. Dr. Sulllivan designed Healthy Start to allow local health care providers and community residents to develop individual programs that work best in their communities.

For example, the Bedford Healthy Start Program in my district provides prenatal care, substance abuse prevention, treatment for adolescent drug abuse, a pregnancy program, immunization, of course, nutrition education and counseling, and primary medical care for children.

While a 5-year study to evaluate the success of Healthy Start will not be complete until next year, data from the Healthy Start target areas suggest that the program has helped reduce infant mortality and other pregnancy problems.

According to information that I received from Healthy Start in New York City from 1990 to 1995, infant mortality dropped 43 percent in the Bedford target area compared to a 24 percent decline city-wide. The overall decrease in the other New York Healthy Start target areas was 40 percent.

According to Senator Arlen Specter in testimony that he provided last year in the Senate on the Healthy Start Program, the results of Healthy Start have been extraordinary.

In Pittsburgh, infant mortality has declined 20 percent, and an estimated 61 percent decline for women who have taken advantage of the Healthy Start Program.

Additionally, Gen. Colin Powell has announced that Healthy Start will be a major part of the Corporation of National Service that Presidents Bush, Carter, and Ford will unveil in the coming weeks.

Two days ago, members of my staff visited the Baltimore Healthy Start Program, and talked to health care providers, community leaders, and with women and men who are participating in the program. Everyone they talked with said that the program is well-run, and is dramatically improving pre- and post-natal health care for the women and children in the program. They came back excited.

Like any other program, Healthy Start can be improved. It is my sense that HHS should exercise better oversight over the operations of the program. But this federally-funded, locally-administered program appears to be cost effective.

According to the Office of Technology Assessment, $8 billion was expended in 1987 for the care of low birth weight babies. HHS has estimated that reducing the number of children born of low birth weight by 82,000 births could save between $1.1 million and $2.5 million a year. We are talking about saving money.

If Healthy Start can continue to play a role in reducing infant mortality and low birth weight babies, and help to improve the quality of life for poor women and children in our country, it deserves our strongest support.

The program witnesses that we will hear from today are on the front lines battling infant mortality in communities across this Nation, communities where Healthy Start has made the difference between life and death for thousands of poor American children.

I am hopeful that we will learn enough from their comments to dramatically improve the life expectancy for our country's poorest children.

Thank you very much, Mr. Chairman. And I yield back.

Mr. SHAYS. I thank the gentleman.

Mr. Snowbarger, vice chairman of the subcommittee.

Mr. SNOWBARGER. I have nothing at this time. Thank you.

Mr. SHAYS. Mr. Barrett.

Mr. BARRETT. Thank you, Mr. Chairman. I do have a statement, if I could, please.

Thank you for holding this hearing on the Healthy Start demonstration program. I am a strong supporter of Healthy Start. The program in my district is called the Milwaukee Women and Infants Project. And it has achieved good and solid results in my community by getting pregnant women into prenatal care.

Milwaukee was approved as a Healthy Start site, because we were experiencing alarming infant mortality and low birth weight baby rates. The problems that Healthy Start addresses are typical in my community. And the problems are particularly striking for our African-American community.

For example, in Milwaukee, the average low birth weight for 1988 through 1990 was 14.7 per 1,000 births, with the African-American rate being 18.3. By 1994, the infant mortality rate had decreased by 8 percent for white infants. However, the IMR for non-white infants increased by 20 percent.

I am proud to say that our Milwaukee Healthy Start Program currently reports zero infant deaths among its client population. In addition, it reports a 22 percent increase in the number of women enrolling in prenatal care during their first trimester, and substantial increases in health, immunization, and nutritional access for infants and their mothers.

Mr. Chairman, with the subcommittee's consent, I would like to enter a statement from the Milwaukee Healthy Women and Infants Project into the subcommittee's record.

Mr. SHAYS. Without objection.

[The information referred to follows:]

Milwaukee Healthy Women & Infants Project

2040 W. Wisconsin Ave., Suite 401, Milwaukee, WI 53233 Phone 414. 345.4500 Fax 345.4505

TESTIMONY PROVIDED TO THE UNITED STATES CONGRESSIONAL HEARING ON THE OVERVIEW OF THE NATIONAL HEALTHY START PROGRAM
PROVIDED BY: BRENDA BELL-WHITE, EXECUTIVE DIRECTOR
MILWAUKEE HEALTHY WOMEN & INFANTS PROJECT
MILWAUKEE HEALTHY START
MARCH 13, 1997

I was asked to provide testimony by my Congressman Thomas Barrett - Wisconsin in regard to Milwaukee's Healthy Start Initiative. Our project boundaries are contained within the Districts of Congressmen Tom Barrett and Gerald Kleczka.

Milwaukee Healthy Women & Infants Project (MHWIP) began in 1991, by a group of concerned citizens to respond to a federal RFP for the reduction of Infant Mortality. MHWIP's proposal was approved but unfunded in 1991. In 1992, the National March of Dimes provided funding for 2 years (92/93 and 93/94) to the 6 approved unfunded sites, these sites were known as the National March of Dimes sites.

MHWIP received a matching grant from the Helen Bader Foundation it's second year (93/94). The project was housed at the City of Milwaukee Health Department receiving substantial in-kind services including; office space, postage, telephone and gap funding.

During this 2 year period, MHWIP expanded the consortium which initially consisted of only providers to include consumers and line staff of provider organizations. MHWIP also developed and implemented a *model* consumer involvement program known as the Community Task Force. Community involvement has been redefined in Milwaukee to "community ownership and leadership", which means consumers and providers are equal partners at every level of the organization, i.e., planning, decision making, development and implementation. MHWIP is often asked to share it's model consumer program at national forums as well as to provide training to other Healthy Start sites.

MHWIP has received federal funds since 10-1-94 and is currently in Year 03 of operations as a Healthy Start Initiative-Special Project. MHWIP has been funded at the 1 million dollar level each year, as compared with to the 15 original projects which were funded at various levels but none less than 3 million dollars per annum. MHWIP's level of funding has always been inadequate.

Phase II of Healthy Start will expand this vital initiative to other sites, around the country, unfortunately it also means phase out for many existing sites. The competitive process proposed by the National Healthy Start Office only provides $500,000 for each successful Special Project site. I would be derelict if I did not point out the fact that the seven (7) Special Projects did not have a full year of funding for planning, nor did the Special Projects have five (5) years of implementation as compared to the 15 original sites. Now is not the time to phase out or reduce funding for the Special Projects. Funding should not be reduced but at a minimum maintained at the same level.

MHWIP warrants same level funding or more due to our project's demonstrated successes during Year 02 (10/1/95 - 9/30/96) as follows:

- No infant deaths for our control population during this period
- The Low Birth Weight for our control population was 1% less than our target area
- 15% increase in child health checks provided to children in our control population
- 6% increase in immunizations provided to children in our control population
- 3% increase in the number of clients receiving family planning and preservation services
- 22 % increase in the number of women enrolling in Prenatal care during their 1st trimester of pregnancy
- 8% increase in the number of women and receiving health and nutrition education
- We reduced barriers to health care access with our supportive services as follows:

  We provided 1,738 rides to prenatal, child health check and other medical appointments.

  On-site Child Supervision provided services for 718 children

  Food Pantry nutritional supplement and education to 568 clients

  We have also provided training to approximately 250 Community Task Force members.

  We increased home visits by 28% during this period.

- We have consistently employed target area residents, community task force members and clients throughout our project as follows:

Year 01 (10/1/04 - 9/30/95)	14 - Staff total 22
Year 02 (10/1/95 - 9/30/96	18 - Staff total 24
Year 03 (10/1/96 - 9/30/97	21 - Staff total 27

- Our local evaluator has identified that there must be continued emphasis on reaching and serving African-American women in the Milwaukee community to impact on Low Birth Weight for this population. **Now is not the time to reduce our funding level.**

- Reducing the seven (7) Special Projects funding level for the phase II period contradicts the Senate language and intent of continued funding for the existing projects to maintain initiatives in these existing communities. The Special projects cannot maintain their initiatives with this reduced level of funding.

- MHWIP has provided Technical Assistance to other Healthy Start Projects in several areas i.e., Consumer Involvement, Consumer & Provider Partnerships, Local Evaluation, Case Management and Outreach , Prenatal Care Coordination, Program Development and Implementation.

MHWIP is especially skilled in Consumer Involvement which is a required component for all of the sites. Consumer involvement is not a component that is fully operational or practiced by all sites. Even the federal overseers do not fully understand or integrate consumer involvement (i.e., planning, decision making, development and implementation) in all aspects of programming. As evidenced by the number of projects that call us, as well as, the members of consumer groups from the different sites that contact us; speak to the fact that more must be done in the area of community involvement.

Consumers groups should be held in the same high regard as providers. Unfortunately, this is often not the case, as many consumer groups from various sites feel disenfranchised.

As stated by Dr. Patricia McManus, Executive Director of Black Health Coalition of Wisconsin "the affected communities must be at the center of decisions that impact on the quality of their lives. The community must be seen as a place that has answers to the problem, not only as a source of the problem. In order for people to take personal responsibility for better health outcomes for themselves and their infants, they must be given the information and the power to determine how services will be provided to them."

Thank you for allowing me this opportunity to provide testimony on this important issue, Infant Mortality Reduction. It has been most rewarding professionally and personally to work with this initiative since it's inception in Milwaukee. I encourage members of the committee to continue funding and guarantee healthy outcomes for mothers, children and families in Milwaukee and throughout our nation.

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Mr. BARRETT. Again, I am a strong supporter of Healthy Start. When you look at the babies, who could not be? Healthy Start projects are the type of community-based, locally-designed, and locally-controlled programs that many of my colleagues assert all programs should be.

For that reason, I am puzzled as to why the effectiveness of these projects would be called into question even before a Federal study is completed.

Healthy Start is a good investment. Look at the communities and talk to the clients. The results are evident.

I must also express puzzlement about portions of the Department of Health and Human Service's current funding decisions for the Healthy Start Program. The Healthy Start Program in my district is in the category of projects termed "special projects." It is my understanding that the Department proposes to severely under-fund special project sites.

When the Healthy Start demonstration began in the Bush administration in 1991, Milwaukee was one of seven projects deemed approved, but not funded. Milwaukee and six other projects were federally funded beginning in 1994. Milwaukee has been funded at a level of $1 million annually.

It is my understanding, however, that the seven special project programs will be limited to a maximum of $500,000 under phase II of Healthy Start. My community's Healthy Start project is telling me it will not be able to operate at this funding level, ending services for many of my constituents.

In fact, I have been informed that the so-called "special projects" have always been restricted in access to funding, and have never had the opportunity to apply for the higher funding levels available for the original sites, and for the proposed new sites.

Today, I hope to receive an explanation about the criteria for such administrative funding decisions, because my district needs Healthy Start. I do not want to close it down, because it works.

Thank you.

[The prepared statement of Hon. Thomas M. Barrett follows:]

THOMAS M. BARRETT
5TH DISTRICT, WISCONSIN

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Washington, DC 20515–4905

Statement of Rep. Tom Barrett (WI) to
House Government Reform Subcommittee on Human Resources

March 13, 1997

Thank you Mr. Chairman for holding this Hearing on the "Healthy Start" Demonstration Program. I am a strong supporter of "Healthy Start." The program in my District is called the "Milwaukee Healthy Women & Infants Project," and it has achieved good and solid results in my community by getting pregnant women into prenatal care.

Milwaukee was approved as a "Healthy Start" site because we were experiencing alarming infant mortality and low-birth-weight baby rates. The problems that the "Healthy Start" Program addresses are critical in my community. And the problems are particularly striking for our African-American community.

For example, in Milwaukee, the average Infant Mortality Rate (IMR) for 1988 through 1990 was 14.7 per thousand births, with the African-American rate being 18.3. By 1994, the Infant Mortality Rate had decreased by 8 percent for white infants, however, the IMR for non-white infants increased by 20 percent.

I am proud to say that our Milwaukee "Healthy Start" program currently reports **zero** infant deaths among its client population. In addition, it reports a 22 percent increase in the number of women enrolling in prenatal care during their first trimester, and substantial increases in health, immunization and nutrition access for infants and their mothers. Mr. Chairman, with the Subcommittee's consent, I would like to enter a statement from the Milwaukee Healthy Women & Infants Project into the Subcommittee record.

Again, I am a strong supporter of "Healthy Start." When you look at the babies, who couldn't be? "Healthy Start" projects are the type of community-based, locally designed and locally controlled programs that my Republican colleagues assert all programs should be. I am puzzled why the effectiveness of these projects would be called into question even before a federal study is completed. "Healthy Start" is a good investment. Look at the communities. Talk to the clients. The results are evident.

I also must express puzzlement about portions of the Department of Health and Human Services' current funding decisions for the "Healthy Start" Program. The "Healthy Start" program in my District is in the category of projects termed "Special Projects." It is my understanding that the Department proposes to severely underfund "Special Project" sites. Why?

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When the "Healthy Start" Demonstration began under the Bush Administration in 1991, Milwaukee was one of seven projects deemed "approved, but not funded." Milwaukee and the other six projects were federally funded beginning in 1994. Milwaukee has been funded at a level of $1 million annually.

It is my understanding, however, that the seven "Special Project" programs will be limited to a maximum of $500,000 under Phase II of "Healthy Start." My community's "Healthy Start" project is telling me it will not be able to operate at this funding level, ending services for many of my constituents. In fact, I have been informed that the so-called "Special Projects" have always been restricted in access to funding and have never had the opportunity to apply for the higher funding levels available for the original sites and proposed for the new sites.

Today, I hope to receive an explanation about the criteria for such administrative funding decisions, because my District needs "Healthy Start." I don't want it to close down. It works.

Mr. SHAYS. I thank the gentleman.

If I could, I would like to get some housekeeping out of the way, if I can.

I ask unanimous consent that all members of the subcommittee be permitted to place any opening statement in the record, and that the record remain open for 3 days for that purpose. Without objection, so ordered.

And I also ask unanimous consent that all witnesses be permitted to include their written statements in the record. Without objection, so ordered.

We have two panels that will be coming before us. The first is comprised of officials from the U.S. Department of Health and Human Services. And then we will be having providers in the local communities who will come and testify about their programs.

At this time, I would like to call Audrey Nora, Director of Maternal and Child Health Bureau, Health Resources and Services Administration, accompanied by Thurma McCann, Director of Division of Healthy Start, Maternal and Child Health Bureau. Also, I would call James Marks, Director of the Chronic Disease Center, Centers for Disease Control and Prevention; Duane Alexander, Director of the Institute of Child Health and Human Development, National Institutes of Health; and Lisa Simpson, Acting Administrator, Agency for Health Care Policy and Research.

If you would all just come and stand, as we do swear our witnesses in, even Members of Congress. This is a policy that we have for everyone.

[Witnesses sworn.]

Mr. SHAYS. For the record, everyone has responded in the affirmative. I hope we can fit you at that table. We probably need a table a little wider. I am sorry for that. The important thing is that you have enough space to put your documents down, and have a mike that picks up your voice.

Let me from the outset just apologize and just state for the record. I chair the task force on the Budget Committee on Health Care, and we are making our preliminary decisions on what we are going to report to the full House. And the meeting is now.

I want to weigh in on the very issues that we are talking about in a positive way. So that should give me some license to leave.

I will say that one of the issues that I would like responded to from all participants, is, although I will not be here: it is my understanding that this program was intended to be a program to see the effect of local initiatives. But it was a local-based and local community effort, and that ultimately we would see programs. And it was the expectation, I thought, and the expectation of others, that they would ultimately be self-financing, that we would then seed additional programs. I would love, for the record, the responses. So I've really asked a question up front that I hope others will address.

We are going to start in the order that I called you, which would be Dr. Nora first and then Dr. Marks, then Dr. Alexander, and then Dr. Simpson, in that order. This will be chaired by Vince Snowbarger, who is the vice chairman of the subcommittee.

Mr. SNOWBARGER [presiding]. Dr. Nora.

STATEMENTS OF AUDREY H. NORA, DIRECTOR, MATERNAL AND CHILD HEALTH BUREAU, HEALTH RESOURCES AND SERVICES ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY THURMA MCCANN, DIRECTOR, DIVISION OF HEALTHY START, MATERNAL AND CHILD HEALTH BUREAU; JAMES S. MARKS, DIRECTOR, NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION, CENTERS FOR DISEASE CONTROL AND PREVENTION, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY MARY ANNE FREEDMAN, DIRECTOR, DIVISION OF VITAL STATISTICS, NATIONAL CENTER FOR HEALTH STATISTICS, CENTERS FOR DISEASE CONTROL AND PREVENTION; DUANE ALEXANDER, DIRECTOR, INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT, NATIONAL INSTITUTES OF HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES; AND LISA SIMPSON, ACTING ADMINISTRATOR, AGENCY FOR HEALTH CARE POLICY AND RESEARCH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. NORA. Mr. Chairman and members of the subcommittee, I am Dr. Audrey H. Nora, Director of the Maternal and Child Health Bureau, Health Resources and Services Administration. I am accompanied this morning by Dr. Thurma McCann, the Director of the Maternal and Child Health Bureau's Division of Healthy Start, who is sitting on my right.

Mr. SNOWBARGER. Dr. Nora, if I could interrupt, before we get into the substance of the testimony, I want to point out, both to the panel and to my colleagues up here, we don't have lights this morning on the timing, and our timing is going to be held over here by a flip chart.

We will try to be generous with the time and understand that it is a little difficult to see that while you're testifying, but I apologize for the inconvenience.

I'm sorry, Dr. Nora. Go ahead.

Dr. NORA. OK. Thank you. I am pleased to share with you our efforts to reduce infant mortality in the United States through Healthy Start. In my testimony today, I will highlight the progress Healthy Start has made toward improving maternal and infant health in 22 communities across the country, and describe how the Department plans to buildupon what we have learned.

In short, we are convinced that the Healthy Start Program is having a positive impact on reduction of infant mortality and morbidity in the areas where the program exists, and we are now planning to replicate these successful efforts in other parts of the country.

Infant mortality, which is defined as the death of babies before their first birthday, is a public health tragedy. Thanks to an intensified national commitment to babies, to giving babies a healthy start in life, the preliminary estimate for the U.S. infant mortality rate is at a historic low of 7.5 deaths per 1,000 live births in 1995, and the proportion of mothers getting early prenatal care is at a record high of 80.2 percent in 1994.

We have also seen declines in some of the risk factors for low birth weight and infant mortality. Teen births dropped for the

fourth straight year in 1995, and smoking among pregnant women has been decreasing in recent years. Nevertheless, when compared to other developed countries, the United States continues to have unacceptably high infant mortality rates with significant disparities among racial and ethnic groups.

In 1991, based on findings by a White House Task Force on Infant Mortality, President Bush recommended that actions be taken to address persistently high infant mortality rates in this Nation, particularly those associated with ethnic and racial populations.

Healthy Start began as a demonstration program in late 1991, with funds appropriated initially under Public Law 102–27, "the Dire Emergency Supplemental Appropriations Act of Fiscal Year 1991," and has been renewed annually since then, in Labor HHS appropriations bills.

The Healthy Start Program was built on the premise that residents of local communities would best know how to overcome these barriers. Thus, new, community-based strategies were needed to attack the causes of infant mortality and low birth weight, especially among high-risk populations.

The National Institutes of Health, the Centers for Disease Control and Prevention, the Agency for Health Care Policy and Research, and many other Federal agencies participated with HRSA in the development of the Healthy Start conceptual framework. They continue to be our allies in addressing health issues affecting our Nation's mothers, infants, children, and their families.

Applicants for Healthy Start grants were sought among both urban and rural communities with infant mortality rates at least one-and-a-half times the national average. In late 1991, 15 applicants—13 urban and 2 rural—were awarded planning grants.

The initial grants supported year-long, comprehensive planning activities through fiscal year 1992. The projects began serving clients in fiscal year 1993.

The overall goal was to reduce infant mortality in the project areas by 50 percent over a 5-year period, focusing on five principles which would assure early prenatal care and appropriate supports for families. These five principles include: innovation, community commitment and involvement, increased access to health care, service integration, and personal responsibility.

In late 1994, seven additional communities—five urban and two rural—received Healthy Start special project grants. These communities also had infant mortality rates greater than one-and-a-half times the national average for infant mortality. The goal for these projects was to significantly reduce infant mortality rates in the target areas over a 2-year period.

In 1993, HRSA entered into a contract with Mathematica Policy Research to conduct an independent, extensive cross-site evaluation of the 15 original Healthy Start projects. This national evaluation, managed by HRSA's Office of Planning and Evaluation, consists of both process and outcome analyses.

The process evaluation will detail the individual characteristics of the 15 original projects, their health and social service infrastructures, organizational characteristics, and descriptive information about the type and scope of local interventions.

The outcome evaluation entails a quantitative analysis of the overall success of the Healthy Start Program through assessment of multiple program outcomes, such as infant mortality rates, low birth weight incidence, and improved maternal and infant health, using client-specific data as well as secondary data sources.

The national evaluation is a 5-year effort with a final report due in 1998. Comparisonsites to the Healthy Start communities will be selected in order to demonstrate the comparative impact of Healthy Start interventions on communities.

While we await the completion of the Mathematica evaluation, results from similar national studies and the impact of community-based service interventions and outcomes from a number of local evaluations at current Healthy Start demonstrationsites are providing useful information.

A recent cross-site successful program to reduce infant mortality in the South was conducted by the School of Public Health, University of North Carolina. The evaluative program, called Healthy Futures/Healthy Generations, used interventions similar to Healthy Start's. It was sponsored, from 1988 to 1993, by the Southern Governors Association, and was co-funded by the Robert Wood Johnson Foundation and the Maternal and Child Health Bureau.

The evaluation compared data from 11 Southern States participating in the Healthy Futures/Healthy Generations program with six States who were not participating, and it attempted to determine if a broad set of perinatal interventions had assisted participating States to reduce infant mortality and expand access to health care services.

Many of the Healthy Futures/Healthy Generations interventions were very like those developed by Healthy Start projects, and included public awareness campaigns for prenatal care services, risk screening protocols, increased obstetric personnel and training of those personnel, improved management of high-risk mothers and newborns, and improved identification and followup of high-risk infants.

Major findings from this evaluation include: improved health outcomes of mothers and infants; enhanced perinatal health care systems; increased utilization of public and private resources, and other efforts which served as a catalyst for a wide range of infant mortality reduction activities. Substantial decline in infant mortality in the South occurred during the Healthy Futures/Healthy Generations period, compared to the pre-program period. For example, at the conclusion, the infant mortality rate was 10 compared to 11.3 infant deaths prior to beginning the program and these infant mortality declines were substantially greater for black populations in the South. There were also increases in the percentage of women who sought prenatal care during their first trimester. There was an increase of .3 percent in the South compared to a .4 percent decrease in early prenatal care nationwide.

Our knowledge of successful community-driven approaches for Healthy Start grantees has been greatly enriched by timely information from 14 of the 15 original projects. Each of the seven special projects has also been required to conduct a local evaluation.

The local evaluations have looked at interventions, such as outreach services, infant mortality reviews, prison initiatives, post-

partum surveys, community ethnographic studies and studies of special populations, such as adolescents and male partners.

The Healthy Start initiative also features an aggressive national and local public information and education component that raises awareness of infant mortality and promotes prenatal care and other healthy behaviors. A new set of public service advertisements, released in February, urges women to avoid putting their babies' health "on the line" by seeking early and regular prenatal care.

The campaign features toll-free numbers for English-speaking callers and Spanish-speaking callers. For the first time, just by calling the hotline, women can reach either their own States' maternal and child health office or a local Healthy Start site, whichever is closer.

Over the 4 operational years of fiscal year 1993 through 1996, information we have learned from the Healthy Start projects has been distilled into nine models of infant mortality reduction strategies which support the concept of community-based service integration.

Mr. SNOWBARGER. Dr. Nora, we're going to have to ask you to sum up quickly here. We have tried to be generous with the time, and we're going to be running late if we allow everyone the same amount of time. Thank you.

Dr. NORA. OK. Thank you. The Maternal and Child Health Bureau and its Division of Healthy Start has provided guidance and oversight to the 22 Healthy Start projects.

Our management of the Healthy Start initiative extends to assisting the grantees in developing and implementing programs and strategies to reduce infant mortality, closely monitoring performance, providing and arranging for the provision of technical assistance, facilitating community consortium development, mediating conflicts, and promoting communication with State Title V agencies.

While the overwhelming majority of Healthy Start sites have experienced minimal problems in the development of consortia, local conflicts have emerged in a few sites. Federal regulations allow HRSA to take corrective action where grantees exhibit serious deficiencies or, "exceptions," in business management or unsuccessful performance in administrative and programmatic management.

Currently, three grantees fall into this "exceptional" category. They are Birmingham, Detroit, and Northwest Indiana.

The Mississippi Delta Futures Project was selected as one of the seven special projects in late 1994. Its project area covers eight counties in the Delta Region. Since inception, the project has experienced difficulties in reaching cohesions within the multi-faceted communities of the project area, establishing effective communications among all stakeholders and timely compliance with grant requirements.

Intensive technical assistance from both Federal staff and private sector resources has been provided. In spite of these efforts, it has been necessary to reduce funding to this project during this fiscal year.

Mr. SNOWBARGER. Dr. Nora, could you conclude fairly quickly here?

Dr. NORA. Yes. Yes. I will.

In conclusion, with encouragement from the Congress, HRSA has established three objectives to operationalize the Healthy Start initiative: No. 1, operationalize successful Healthy Start models through replication; No. 2, establish a peer mentoring program; and No. 3, disseminate nationally information which we have learned.

In closing, I would like to emphasize that we are confident that Healthy Start will continue to be a vital component of the administration's comprehensive national strategy to increase access to prenatal care and to help families care for their infants.

We know that early and continuous prenatal care makes a difference. If children are indeed our future, Healthy Start is a strategic investment in that future.

This concludes my testimony.

[The prepared statement of Dr. Nora follows:]

Testimony of

Audrey H. Nora, M.D., M.P.H.
Assistant Surgeon General
Director, Maternal and Child Health Bureau

Health Resources and Services Administration
Department of Health and Human Services

Before the Committee on Government Reform and Oversight

Subcommittee on Human Resources and Intergovernmental Relations

U.S. House of Representatives

March 13, 1997

Mr. Chairman and Members of the Subcommittee:

I am Audrey H. Nora, M.D., Director of the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA). I am accompanied this morning by Thurma McCann, M.D., Director of MCHB's Division of Healthy Start, which provides leadership and administration to the Healthy Start demonstration program.

I am pleased to share with you our efforts to reduce infant mortality in the United States through the Healthy Start demonstration program. In my testimony today, I will highlight the progress the Healthy Start demonstration program has made toward improving maternal and infant health in 22 communities across the country and describe how the Department plans to build upon what we have learned.

In short, Mr. Chairman, we are convinced that the Healthy Start program is having a positive impact on reduction of infant mortality and morbidity in the areas where the program exists, and we are now planning to replicate these successful efforts in other parts of the country.

Infant mortality--the death of babies before their first birthday--is a public health tragedy. Thanks to an intensified national commitment to giving babies a healthy start in life, the preliminary estimate for the U.S. infant mortality rate is at an historic low of less than 7.5 deaths per 1,000 live births in 1995, and the proportion of mothers getting early prenatal care is at a record high of 80.2 percent in 1994. We have also seen declines in some of the risk factors for

low birthweight and infant mortality: teen births dropped for the fourth straight year in 1995 and smoking among pregnant women has been decreasing in recent years. Nevertheless, when compared to other developed countries, the United States continues to have relatively high infant mortality rates with significant disparities among racial and ethnic groups.

In 1991, based on findings by a White House Task Force on Infant Mortality, President Bush recommended that actions be taken to address persistently high infant mortality rates in this nation, particularly those associated with ethnic and racial populations. The Healthy Start demonstration program began in late 1991, with funds appropriated initially under P.L. 102-27, "The Dire Emergency Supplemental Appropriations Act of FY 1991," and renewed annually since then in Labor-HHS appropriations bills.

At the start of the demonstration, a great deal was already well understood about the chief causes of infant mortality, such as congenital anomalies, complications from low birthweight, and sudden infant death syndrome. There was also longstanding evidence that early and regular prenatal care was essential to healthy pregnancies and birth outcomes. What was not well understood was why more women were not getting the care they needed. Nor had targeted community-level approaches to breaking down such barriers to care as limited availability of health care providers in some urban and rural communities and a lack of accessible transportation to the few providers available, been systematically demonstrated.

The Healthy Start demonstration program was built on the premise that residents of local

communities would best know how to overcome these barriers; thus new community-based strategies were needed to attack the causes of infant mortality and low birthweight, especially among high-risk populations.

The National Institutes of Health, Centers for Disease Control and Prevention, Agency for Health Care Policy and Research, and many other Federal agencies participated with HRSA in the development of the Healthy Start demonstration's conceptual framework. They continue to be our allies in addressing health issues affecting our Nation's mothers, infants, children and their families.

Applicants for Healthy Start demonstration grants were sought among urban and rural communities with infant mortality rates at least 1.5 times the national average. In late 1991, 15 applicants (13 urban and 2 rural) were awarded planning grants. The initial grants supported year-long comprehensive planning activities through FY 1992; the projects began serving clients in FY 1993. The overall goal was to reduce infant mortality in the project areas by 50 percent over a five year period, focusing on five principles which would assure early prenatal care and appropriate supports for families: innovation, community commitment and involvement, increased access to health care, service integration, and personal responsibility.

In late 1994, seven additional communities (five urban and two rural) received Healthy Start demonstration Special Project grants. These communities also had infant mortality rates greater than 1.5 times the national average for infant mortality. The goal for these projects was to

significantly reduce infant mortality rates in the target areas over a two-year period.

Private sector support has been a main ingredient of Healthy Start. In 1992, 11 private sector organizations including Kiwanis International, The Urban League, and the Washington Business Group on Health formed a Healthy Start Steering Group to provide advice to communities in leveraging Federal funds with resources from local companies and foundations. Johnson & Johnson and the March of Dimes co-chaired this Private Sector Steering Group. The partnership went beyond the meeting room with local chapters of the March of Dimes playing an active role within many Healthy Start communities. In 1996, a national summit of community and corporate leaders was co-sponsored by HRSA and Johnson & Johnson to showcase program results and encourage further private sector involvement in national efforts to reduce infant mortality.

In 1993, HRSA entered into a contract with Mathematica Policy Research, Inc. (MPR), to conduct an independent, extensive cross-site evaluation of the 15 original Healthy Start demonstration sites. This **national evaluation** consists of both process and outcome analyses. The process evaluation will detail the individual characteristics of the 15 original projects, their health and social service infrastructures, organizational characteristics, and descriptive information about the type and scope of local interventions. The outcome evaluation entails a quantitative analysis of the overall success of the demonstration program through assessment of multiple program outcomes such as infant mortality, low birthweight incidence, and improved maternal and infant health, using client-specific data as well as secondary data sources. The national

evaluation is a 5-year effort, with a final report due in 1998. Comparison sites to the Healthy Start demonstration communities will be selected in order to demonstrate the comparative impact of Healthy Start demonstration interventions upon communities.

While we await completion of the Mathematica evaluation, results from similar national studies and the impact of community-based service interventions and outcomes from a number of local evaluations at current Healthy Start demonstration sites are providing useful information. A recent cross-site evaluation of a successful program to reduce infant mortality in the South was conducted by the School of Public Health, University of ~~South~~ North Carolina. The evaluated program, "Healthy Futures/Healthy Generations" (HF/HG), used interventions similar to Healthy Start's. It was sponsored from 1988 to 1993 by th Southern Governors' Association, the Robert Wood Johnson Foundation, and MCHB. The evaluation compared data from 11 Southern States participating in the HF/HG program (AL, AR, LA, MD, MS, NC, OK, PR, SC, TX, WV) with six comparison States (DE, FL, GA, MO, TN, and VA) to determine if a broad set of perinatal interventions had assisted participating States to reduce infant mortality and expand access to health care services.

Many of the HF/HG interventions were very like those developed by Healthy Start demonstration projects and included public awareness campaigns for prenatal care services, risk screening protocols, increased obstetric personnel and training, improved management of high-risk mothers and newborns, and improved identification and follow-up of high-risk infants. Major findings from this evaluation include:

- Improved health outcomes of mothers and infants; enhanced perinatal health care systems.
- Increased utilization of public and private resources, and other efforts which served as a catalyst for a wide-range of infant mortality reduction activities.
- Substantial decline in infant mortality in the South during the HF/HG period compared to the pre-Program period (10.0 compared to 11.3 infant death rate respectively). These infant mortality declines were substantially greater for Black populations in the South.
- Substantial improvement in prenatal care utilization during the HF/HG Program period from the pre-Program period (61.5% for pre-Program and 66.5% for Program period, and,
- Increases in the percentage of women who sought prenatal care during their first trimester (an increase of 0.3% in the South compared to a 0.4% decrease nation-wide).

Our knowledge of what community-driven approaches are working for Healthy Start grantees has been greatly enriched by timely information from 14 of the 15 original projects, which are conducting local evaluations. Each of the 7 Special Projects has also been required to conduct a local evaluation. The local evaluations have looked at interventions, such as outreach services, infant mortality reviews, prison initiatives, postpartum surveys, community ethnographic studie, and studies of special populations such as adolescents and male partners. Examples of outcomes of local evaluations include:

- In Pittsburgh, the rate of infant deaths for pregnant women receiving case management and home visiting is 7.8 per 1,000 live births, 50% lower than the rate of 15.6 for women not participating in Healthy Start programs but also living in the project area.

- Boston's local evaluation has tracked Sexually Transmitted Diseases (STDs) as an indicator of adolescent high risk behaviors and found that the proportion of teen STDs had declined by 81%.
- The Florida Panhandle project's home visiting program has been instrumental in systemic changes, including increasing the participation rate of prenatal care providers in screening pregnant women and newborn for risk factors, facilitating community provider forums on the effect of managed care on maternal and child health care, and participating in the review of the contracts with HMOs.

The Healthy Start demonstration also features an aggressive **national and local public information and education component** that raises awareness of infant mortality and promotes prenatal care and other healthy behaviors. A new set of public service advertisements, released in February, urges women to avoid putting their babies' health "on the line" by seeking early and regular prenatal care. The campaign features toll-free numbers for English-speaking callers and Spanish-speaking callers. For the first time, just by calling the hot line, women can reach either their own State's maternal and child health office or a local Healthy Start site, whichever is closer.

Over the four operational years of FY 1993-1996, information we have learned from the Healthy Start projects has been distilled into nine models of infant mortality reduction strategies which support the concept of community-based service integration. Each of these strategies has been tailored to address unique community needs and to overcome barriers to care:

1. **Community-based consortia**- Use a community-based advisory body to provide a means of communication between the project and the community.
2. **Outreach and client recruitment**- Provide case finding services that actively reach into the community to recruit perinatal clients.
3. **Care coordination/case management**- Coordinate services across providers to meet a

client's identified needs.

4. **Family resource centers**- Provide a comprehensive array of co-located client services.
5. **Enhanced clinical services**- Improve quality, availability, utilization, and linkage with perinatal systems.
6. **Risk prevention and reduction**- Provide specialized services to reduce, modify, or eliminate stressors or unhealthy client behaviors.
7. **Facilitating services**- Provide enabling services such as translation, transportation, and child care to clients receiving services and participating in infant mortality reduction programs.
8. **Training and education**- Provide education and public information to address infant mortality risk factors.
9. **Adolescent programs**- Provide services that are focused on the unique needs of adolescents to help them understand the complexities of childbearing and the need for pregnancy prevention.

Today, you will be hearing from several Healthy Start projects about their implementation of some of these models. In addition, Attachment A presents infant mortality statistics for the 15 original Healthy Start projects. Attachment B presents the status of performance by Healthy Start projects, which are contributing to:

- Significantly reduced infant mortality.
- Effective models of intervention.
- Institutionalized collaboration and consortia.
- Integrated more cost-effective services.
- Increased access to services.
- Increased job training, education, and employment opportunities.
- Strengthened local leadership, capacity, and community-based organizations.

- A new framework of program advocates and staff composed of former clients.
- New management information systems that are local-based and perinatal-focused.

MCHB and its Division of Healthy Start provide guidance and oversight to the 22 Healthy Start projects. Our management of the Healthy Start Initiative extends to assisting the grantees in developing and implementing programs and strategies to reduce infant mortality; closely monitoring performance; providing and arranging for the provision of technical assistance; facilitating community consortium development; mediating conflicts; promoting communication with State Title V agencies; and providing performance-based grant awards.

Building the community infrastructures for carrying out successful efforts to improve pregnancy outcomes is time consuming and can be frustrating for community leaders. While the overwhelming majority of Healthy Start sites have experienced minimal problems in the development of consortia, local conflicts have arisen in a few sites. Federal regulations allow HRSA to take corrective action where grantees exhibit serious deficiencies, or "exceptions", in business management or unsuccessful performance in administrative and programmatic management. Currently, three grantees fall into this category -- Birmingham, Detroit, and Northwest Indiana. The "exceptional" designation allows the MCHB to provide intensive technical assistance, monitor progress more closely and provide detailed guidance to help grantees in addressing their deficiencies. Although not all deficiencies have been resolved, both Northwest Indiana and Birmingham have made significant improvements in the internal management of service provision, contract monitoring, and in meeting project objectives. The Northern Plains project, previously an "exceptional" grantee, successfully remedied its difficulties; its "exceptional" status was lifted in FY95.

The Mississippi Delta Futures project was selected as one of the seven Special Projects in late 1994. Its project area covers eight counties in the Delta region. Since inception, the project has experienced difficulties inachieving cohesion within the multi-faceted communities of the project area; establishing effective communications among all stake holders; and timely compliance with grant requirements. Intensive technical assistance regarding program implementation as well as conflict mediation has been provided by MCHB, using Federal staff and private sector resources. In spite of these efforts, it has been necessary to reduce funding to the project in this fiscal year.

The Healthy Start demonstration is in the final year of piloting strategies to reduce infant mortality. HRSA is providing technical assistance to the projects in a number of ways designed to sustain and operationalize the successful models. This includes packaging effective infant mortality reduction strategies and promoting them to health care providers, including managed care organizations; and, assistance in developing enduring public and private sector partnerships with corporations, foundations, and other business entities.

This year, with encouragement from the Congress, HRSA has established three objectives to operationalize the Healthy Start demonstration:

1. **Operationalize successful Healthy Start models through replication.** HRSA will soon review competing applications for projects from new communities. Approximately 30 new communities will be targeted under the replication phase. These communities are expected to have the following characteristics: infant mortality problems are most severe, resources can be

concentrated, implementation is manageable, linkage with State and local perinatal systems is strong, and progress can be measured.

2. **Establish a peer mentoring program.** HRSA will provide technical assistance to existing demonstration projects to facilitate transformation to peer mentors capable of sharing knowledge with newer Healthy Start communities and other health care providers. Support of these projects for the continuation of their successful strategies will also be provided by HRSA. The continued funding of successful strategies and mentoring activities at a reduced level will be limited to two years.

3. **Disseminate nationally information on lessons learned.** HRSA intends to document all lessons learned, both positive and negative, and share these with States, communities, academics, professionals, and other organizations. National dissemination will include technical assistance materials as well as local and national studies and reports.

In closing, I would like to emphasize that the Healthy Start demonstration has been an important component of the Administration's comprehensive national strategy to increase access to prenatal care and to help families care for their infants. We know that early and continuous prenatal care makes a difference. This concludes my testimony.

Attachment A

HEALTHY START INITIATIVE - 15 ORIGINAL PROJECTS
INFANT MORTALITY RATE PER 1,000 LIVE BIRTHS*

Data Source: May 1996 Healthy Start Continuation Grant Applications

10 YEAR TREND

PROJECT COMMUNITY	1984-88 BASELINE	1988-90 AVERAGE	1990-92 AVERAGE	1992-94 AVERAGE
Baltimore	20.1	15.6	17.8	15.3
Birmingham	18.4	19.7	18.4	17.2
Boston	17.1	14.3	11.6	10.6
Chicago	19.6	20.5	19.3	16.7
Cleveland	21.4	21.4	20.8	19.7
Detroit	26.3	26.9	23.0	20.2
District of Columbia	23.2	24.0	22.0	22.0
New Orleans	23.3	21.9	18.1	14.4
New York	19.4	20.2	17.3	14.6
Northern Plains	18.7	18.4	16.8	13.5
Northwest Indiana	16.2	15.1	12.5	13.0
Oakland	17.9	15.6	11.2	9.4
Pee Dee	15.9	14.5	14.8	12.1
Philadelphia	22.3	19.5	18.8	18.1
Pittsburgh	20.2	19.8	16.7	16.2
United States	10.5	9.7	8.9	8.3

* Infant Mortality Rate Per 1,000 Live Births is defined by the National Center for Health Statistics as the number of infant deaths in a period divided by the number of live births during the same period, multiplied by 1,000.
(Ref.: *NCHS Healthy People 2000 Statistical Notes*, Winter 1991, Vol.1, No.2, p.2)

ATTACHMENT B

HEALTHY START INITIATIVE

STATUS OF PERFORMANCE--DEMONSTRATION PHASE

Data Sources: Healthy Start Continuation Grant Applications and Local Evaluation Reports (May 1996);
FY96 Final Progress Reports for 15 Original Projects; December 1996 Status Reports for 7 Special Projects
To be updated upon receipt of Continuation Grant Application, 4-15-97

Although the 22 sites vary widely, nine intervention models have taken shape over the course of the five-year demonstration. These models will be Healthy Start's legacy. The table below characterizes the annual performance indicators reported on by the projects for the models of intervention emerging from the demonstration phase.[1],[2]

Page

Healthy Start Organizational Model: Community-based Consortium. 2
Healthy Start Service Intervention Model: Care Coordination/Case Management 4
Healthy Start Service Intervention Model: Outreach & Client Recruitment 9
Healthy Start Service Intervention Model: Family Resource Centers 12
Healthy Start Service Intervention Model: Enhanced Clinical Services 15
Healthy Start Service Intervention Model: Risk Prevention and Reduction 17
Healthy Start Service Intervention Model: Facilitating Services 19
Healthy Start Service Intervention Model: Education and Training 21
Healthy Start Service Intervention Model: Adolescent Programs 24

[1] It should be noted that over the period of the demonstration phase, projects had the flexibility to refine annual performance indicators. In many cases. the refinement moved from more process indicators to health outcome oriented indicators; in other cases, the precipitating reason for this refinement was the loss of secondary data sources available to projects for tracking annual performance. As a consequence of these factors and the difference in implementation schedules for the 22 projects, the baseline year for each performance indicator identified differs. Some of the performance measures are common to several models.

[2] Percent of Change Over Time Analysis: the baseline value is subtracted from the current value and that quantity is divided by the baseline value. The results are multiplied by 100 for readability. The "percent change" figure has been rounded to the nearest whole number.

CONSORTIUM

Definition: Use of a local community-based consortium/advisory board of consumers (i.e. recipients of project services residing in the catchment area), providers, public and private health and social services agencies, community action agencies, religious organizations, schools, businesses, and others in an advisory capacity for program planning, operations, monitoring and evaluation.

Purpose: To partner with the community to reduce infant mortality by providing a formal means of two way communication between the project and the community throughout the life of the project.

PERFORMANCE MEASURE	PROJECT	PERFORMANCE INDICATOR	BASELINE[1]	CURRENT	PERCENT CHANGE[2]
Increased understanding of infant mortality and the contributing factors to it in their community.	Birmingham	Increased understanding of infant mortality and the contributing factors to it in their community.	Pretest	Matched post-test: shows improvement by 69% of participants	69%
	No. Plains	Service areas will host at least one forum regarding their health status (i.e. what does infant mortality mean to me and my community) and programs available to address concerns.	0%	100%	
Level of community participation and leadership.	Boston	Increase community participation and leadership in Healthy Start planning and management activities.	17%	65%	282%
	Boston	Increase community participation in the Consortium's Executive Committee and subcommittees.	17%	70%	312%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Plan for continuing program services without federal funding.	Dallas	Collaboration to continue services beyond HS funding period; Collaborate to enhance current service staffing.	None	• Dallas Enterprise Zone and 'Success by Six' • Utilizing Vista and Americorps volunteers	
Evidence of service integration, including number of joint staff training across agencies, shared data, and common data systems.	Chicago	Increase service integration: Subcommittee developed and consortium approved uniform case management protocols and Family Center protocols/scope of services for 5 FCs each operated by different community-based organizations; monthly joint staff training.	None: 8 case management agencies; no Family Resource Centers (FRCs)	All community based case agencies management and 5 new Family Resource Centers	
Number of consumers consistently attending consortium meetings.	Boston	Increase the proportion of non-provider community members actively participating in the Consortium.	17%	65%	282%
	Cleveland	Increase average number of active Neighborhood Consortia participants.	9	20	33%
	Milwaukee	Increase average monthly attendance at Community Task Force (consumer branch of Consortium Organization) which has 260 members.			
	Dallas	Increase teen participation - Teen Advisory Committee of the Project's Consortium.	0	60 teens	

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Evidence of partnerships/linkages with related initiatives to address economic, job, housing and safety issues affecting the perinatal period.	Chicago	Consortium Economic Development committee representing over 11 community agencies, relevant state and city departments and business organizations will implement a joint strategy to maximize employment opportunities for families served by the project.	No joint initiative in place	• Executive Service Corporation will assist; • employment training program and job bank have been established.	

Care Coordination/Case Management

Definition: The coordination of services across providers to meet a client's identified needs through client assessment, monitoring, facilitation, and follow-up on utilization of needed services.

Purpose: To coordinate services from multiple providers to assure that each family's individual needs are met to the extent resources are available, and the client agrees with the scope of planned services.

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Level of infant mortality rate (IMR) in participants in relation to infant mortality rate in non-participants.	Chicago	Decrease infant mortality rate in the project area in contrast to decreases city-wide and in the state.			
		• Project Area IMR	21.3	15.0	30%
		• Citywide IMR	15.6	12.6	19%
		• State IMR	10.7	9.3	14%
	DC	Decrease infant mortality rate in case- managed participants in relation to infant mortality rate in project area			
		• IMR for participants	23.2	5.1	78%
		• IMR for project area	23.2	20.2	13%
	Mississippi	Reduce by 25% the infant mortality rate.	15.5	10.9	30%
	NYC	Decrease infant mortality rate in the project area in contrast to city-wide decrease:			
		• Project Area IMR	20.4	12.3	16.0%
		• Citywide IMR	11.6	8.8	

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
	Pittsburgh	Decrease infant mortality rate in case managed participants in relation to infant mortality rate in project area: • IMR for participants • IMR in non-participants	 20.2 20.2	 7.8 15.6	 61% 23%
Level of infant mortality rate in participants in relation to infant mortality rate in non-participants.	Richmond	Reduce the infant mortality rate.	16.5	15.2	8%
	Savannah	Reduce the infant mortality rate for clients: • Black IMR • White IMR	 22.0 12.6	 12.0 3.5	 45% 72%
	Tallahassee	Reduce the rate of infant mortality in the project area	14.51	9.6	34%
Percentage of live births with birth weights less than 2,500 grams (5 lbs. 8 oz.), i.e., Low birthweight.	NYC	Reduce LBW for prenatal women receiving HS/NYC case management services.	15.0%	12.4%	17 %
	Savannah	Reduce Low Birthweight in target subpopulations (Black LBW babies).	16.8%	12.0%	29%
Number of people who received a risk reduction intervention or completed referral in relation to the number of people from the target population who were identified with risk behavior(s).	Baltimore	Increase the percentage of women enrolled in case management services (Maternal and Infant program) who will: • receive home based education on smoking cessation or be referred to smoking cessation programs • be referred to alcohol and drug treatment	 85% 75%	 100% 90%	 18% 20%
	Boston	Increase the percentage of Healthy Start prenatal clients who do not smoke during pregnancy.	81%	91%	12%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
	Dallas	Increase number of participants screened as having inadequate diet during pregnancy and referred for counseling.	0	1,965 clients referred (=50 % of those screened)	
	NYC	Increase the proportion of eligible women who are enrolled in WIC.	43.9%	59.5%	36%
Number of people who received a risk reduction intervention or completed referral in relation to the number of people from the target population who were identified with risk behavior(s).	NYC	Increase the number of prenatal women and women of childbearing age who receive substance abuse counseling, treatment, referrals and preventive services.	200	1,568	684%
	NYC	Reduce the rate of reported prenatal drug use.	6.3%	4.2%	33%
	No. Plains	Increase the percentage of participants Provide infant car seats and/or education on the importance of car seat utilization to Healthy Start participants.	50%	90%	80%
	No. Plains	Increase the number of participants who receive screening and education on maternal substance abuse.	24%	100%	317%
	No. Plains	Increase the number of males and/or fathers who are involved in prenatal and post partum care of women and infants.	17%	25%	47%
	Pittsburgh	Reduce the percentage of women who smoke during pregnancy.	33.5%	31%	8%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Number of women who receive adequate prenatal care, as measured by the Kotelchuck Scale or Kessner Index in relation to the total number of pregnant participants.	Baltimore	Increase the percentage of pregnant women in project area with "adequate" level of prenatal care in the project area according to the Kessner index .	58%	69.7%	20%
	Boston	Increase the proportion of women who receive adequate prenatal care.	62%	74%	19%
	Chicago	Increase the proportion of pregnant women in target area with "adequate" levels of prenatal care according to the Kessner index.	41.5%	55%	33%
	No. Plains	Increase the proportion of women who are Healthy Start participants who attain at least 8 prenatal contacts.	57%	75%	32%
Number of women who receive adequate prenatal care.	Philadelphia	Increase the average number of prenatal visits for women in the project area.	8.1	9.5	17%
Number of women who enter prenatal care, by trimester, also including the number of women who receive no prenatal care.	Milwaukee	Increase number of women receiving prenatal care services in first trimester.	45	58	22%
	NYC	Reduce the proportion of women who do not receive prenatal care by the end of the second trimester.	22.2%	13.2%	40.5%
	No. Plains	Increase the proportion of women entering prenatal care in the first trimester.	32%	65%	103%
	Tallahassee	Increase percentage of women enrolling for prenatal care in their first trimester.	84.5 %	87.5%	3%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Number of women who receive continuous prenatal services in relation to the total number of women receiving care coordination/case management services.	Boston	Increase the proportion of high risk pregnant and post partum women either enrolled or receiving services in a case management or a pregnancy and parenting support/health education program.	39%	64%	64%
Number of pregnant women who are connected to needed service agencies in relation to the number of pregnant women identified in need of supportive services.	Baltimore	Number of women enrolled in case management services (Maternal and Infant program) receiving information and advocacy regarding entitlements for themselves and their children.	0	100%	
	Detroit	Reduce incidence of Congenital Anomalies.	7.9/1000 live births	2.8/1000 live births	65%
Number of infants enrolled in a medical home in relation to the number of infants receiving care coordination/case management services.	Baltimore	Increase the proportion of infants born to Healthy Start prenatal participants who receive a 2-week pediatric visit.	54%	68.2%	26%
	Pittsburgh	Increase percentage of infants who receive continuing care, including immunizations.	61%	97%	59%
Number of encounters per provider (encounter is defined as a contact between an individual client and an individual provider via fact to face or telephone communication not including exchanging phone messages nor group sessions).	Tallahassee	The home visitors will achieve a face to face meeting of at least 80% of their caseload each week : • average number of women served per month • home visits attempted	 0 0	 187 1,364	
Percentage of new mothers with early discharge who home visit.	Boston	Increase the proportion of project area clients (new mothers who are discharged early from a hospital) who receive a home visit within 72 hours.	0	85%	

Outreach & Client Recruitment

Definition: Provision of case finding services which actively reach out into the community to recruit perinatal clients.

Purpose: To identify and enroll clients most in need of Healthy Start services.

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Number of women who enter prenatal care, by trimester, also including the number of women who receive no prenatal care.	Baltimore	Increase the proportion of women in target area who enter prenatal care in first trimester.	66.9%	70.9%	6%
	Boston	Increase the proportion of women in the project area who receive prenatal care in the first trimester.	73%	81%	11%
	Birmingham	Increase the percentage of women in target area who enter prenatal care in first trimester.	64.4%	74.4%	16%
	Northwest Indiana	Increase the number of Healthy Start enrollees who enter prenatal care early:			
		• first	39.7%	47.5%	20%
		• second	33.8%	31.6%	7%
		• third	23.0%	10.7%	53%
	Pee Dee	Decrease number of women entering prenatal care in the third trimester.	9.7%	5.0%	48%
	Philadelphia	Decrease the proportion of women in the project area who do not receive any prenatal care.	9.4%	3.8%	60%
Percentage of live births with birth weights less than 2,500 grams (5 lbs. 8 oz.), i.e. low birthweight infants (LBW).	Baltimore	Reduce LBW in target area with aggressive door to door canvassing, referral and follow-up to ensure prenatal care was received.	17.7%	15.9%	10%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
	Boston	Reduce the percentage of LBW in the project area through case management and a variety of other activities.	11.0%	10.7%	3%
Percentage of live births with birth weights less than 2,500 grams (5 lbs. 8 oz.), i.e. low birthweight infants (LBW).	DC	Reduce LBW in the project area.	20%	5.8%	71%
	Pee Dee	Reduce LBW in project area.	10.2%	9.0%	12%
	Philadelphia	Reduce LBW in project area.	14.3%	14.1%	1%
Percentage of live births with birth weights less than 1,500 grams (3 lbs. 5 oz.), i.e., Very Low Birthweight (VLBW) infants.	Baltimore	Reduce VLBW in target area with aggressive door to door canvassing, referral and follow-up to ensure entry into prenatal care.	3.9%	2.0%	49 %
	DC	Reduce VLBW in project area.	20.0%	5.8%	72%
Infant mortality rate in participants in relation to infant mortality rate in comparable nonparticipants.	Cleveland	IMR for infants whose mother were enrolled in outreach in relation to IMR for project area mothers not enrolled • enrolled • not enrolled	21.4	11.3 25.8	47% 21%
Number of indigenous workers trained and working in the community.	Milwaukee	Increase the number of indigenous workers trained and working with the project.	14	21	33%
Number who are connected to prenatal care services in relation to the total number of pregnant women recruited and identified as needing a prenatal provider.	Pee Dee	Increase the percentage of lower income pregnant women receiving risk appropriate care (includes delivery at appropriate Level III hospitals).	77.5%	95.0%	23%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Number of women who are connected to the appropriate health care provider in relation to the number identified as needing interconceptional care.	Birmingham	Increase the percentage of women who had a live birth who receive interconceptional counseling.	53.7%	55%	2%
Increase client satisfaction.	Detroit	Increase client satisfaction with Outreach.		91.2%	
Number of infants who are connected to the appropriate health care provider with completed immunizations appropriate for age.	Birmingham	Increase the rate of completed immunizations among one year olds.	49.6%	80.0%	61%
	DC	Increase the proportion of Project Area infants who receive all appropriate immunizations during their first year of life.	40%	70%	75%
	New Orleans	Increase the number of infants tracked for compliance with immunizations.	0%	20%	
	Savannah	Increase the percentage of children fully immunized by age 2.	73.1%	80.4%	10%
	Tallahassee	Increase the percentage of children immunized by age 2.	94.1%	95.8%	2%
Number of people who were recruited, indicated a need and have a complete referral for a risk treatment program.	Birmingham	Increase the percentage of pregnant women who abstain from:			
		• tobacco use	72%	82.9%	15%
		• drug use	88.9%	92.3%	4%
		Increase the number of pregnane women who achieve the minimum recommended weight gain.	63.8%	64.3%	1%

FAMILY RESOURCE CENTERS

Definition: Provision of a community-driven array of client services at a single, accessible community location.

Purpose: To provide access to related services in one central location.

PERFORMANCE MEASURE	PROJECT	PERFORMANCE INDICATOR	BASELINE[1]	CURRENT	PERCENT CHANGE[2]
Number of clients served through FRCs who have access to needed services in a timely manner.	Chicago	Decrease the proportion of pregnant/parenting women served by Family Center (FC) who fail to keep appointments due to a lack of child care or transportation services.	34%	5.1%	85%
	Essex	Strive to serve 250 prenatal clients annually.	114	150	28%
Percent of clients surveyed who report increased satisfaction with co-located services.	Chicago	Percent of clients surveyed who report satisfaction with overall services.	No services	98.1% satisfied	
Number of women who enter prenatal care, by trimester, also including the number of women who receive no prenatal care.	Baltimore	Increase the number of women in target area who enter prenatal care in first trimester .	66.9%	70.9%	6%
	Northwest Indiana	Decrease the number of women: • with no prenatal care • entering care in third trimester	 4.11% 4.81%	 2.99% 3.43%	 27% 29%
Number who are connected to prenatal care services in relation to the total number of pregnant women recruited and identified in need of a provider.	Baltimore	Increase during the perinatal period the number of women in target area enrolled in the Neighborhood Healthy Start Center (NHSC).	80%	97%	21%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Percentage of live births with birth weights less than 1,500 grams (3 lbs. oz.), i.e., Very Low birthweight infants (VLBW).	Northwest Indiana	Reduce the incidence of VLBW.	2.49%	2.01%	19%
Number of women who receive adequate prenatal care, as measured by the Kotelchuck Scale or Kessner Index in relation to the total number of pregnant participants.	Baltimore	Increase the percentage of pregnant women in target area with "adequate" levels of prenatal care according to the Kessner index.	36%	64.4%	79%
	Chicago	Increase the percentage of pregnant women in target area with "adequate" levels of prenatal care according to the Kessner index in service areas where Family Centers have been in operation more than 12 months.	45.1%	60%	33%
Number of infants enrolled in a medical home in relation to the number of infants receiving care coordination/case management services.	Oakland	Increase the number of high-risk infants utilizing Healthy Start FRC's, who are enrolled in case coordination/case management programs.	411	542	32%
Number of infants who are connected to the appropriate health care provider in relation to the number identified needing services.	Chicago	Increase the percentage of infants residing in the project who participate in Early Periodic Screening Diagnosis and Treatment (EPSDT) program.	30%	72%	140%
Increase the proportion of Project Area infants who receive all appropriate immunizations during their first year of life.	Oakland	Increase the number of infants utilizing Healthy Start FRC's who complete their basic immunization series.	145	292	101%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Number of women who are connected to the appropriate health care provider in relation to the number identified as needing interconceptional care.	Baltimore	Reduce the fertility rate of women of childbearing age (WCBA) 15-44 years of age in target area.	104/1000	76.4/1000	27%
	Chicago	Increase the number of family planning visits.	499	4596	821%
Percent of pregnant clients who had HIV testing when indicated	Essex	Increase the percentage of pregnant clients who had HIV testing when indicated.	86%	100%	16%
Number of people who received a risk reduction intervention or completed referral in relation to the number of people from the target population who were identified with risk behavior(s).	Baltimore	Increase the percentage of pregnant enrolled Neighborhood Family Service Centers' women who achieve the minimum weight gain during pregnancy;	59.7%	64.6%	8%
		Increase the % of NHSC pregnant women breastfeeding for at least 6 weeks after delivery;	less than 1%	12.5%	1289%
		Increase the percentage of women assessed as in need of substance abuse intervention referred to ongoing HS substance abuse support groups or a substance abuse treatment program.	-- 20%	40.3%	102%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
	Chicago	Increase the percentage of pregnant women whose diets are assessed as nutritionally optimal;	38.2%	40%	244.0%
		Decrease the percentage of infants born with positive drug screen whose mothers were enrolled in HS;	22%	10%	
		Increase the number of Healthy Start clients in the FC employment training program who were:			
		• placed in jobs;	25	84	
		• referred for employment	149	531	

ENHANCED CLINICAL SERVICES

Definition: Improvement of quality, availability and access, and utilization of clinical services that are usually offered by providers such as health department clinicas, hospitals, and community clinics.

Purpose: To improve accessibility, quality, and client satisfaction of existing perinatal health services.

PERFORMANCE MEASURE	PROJECT	PERFORMANCE INDICATOR	BASELINE[1]	CURRENT	PERCENT CHANGE[2]
Number of women receiving adequate prenatal care, as measured by the Kotelchuk Scale or the Kessner Index.	New Orleans	Reduce the percentage of Hispanic women receiving inadequate prenatal care.	27%	13.5%	50%
Number of women who enter prenatal care, by trimester, also including the number of women who receive no prenatal care.	Detroit	Increase the percentage of women who enroll in prenatal care in the first trimester;	64.1%	72.7%	13%
Number of clients screened for medical risk factors	New Orleans	Increase the percentage of clients screened for medical risk factors, and of those found to be high risk, provide case management and consultation from a Perinatologist.	23%	50.4%	135%
Number of clients using new providers who were hired to fill gaps in services identified by the project.	New Orleans	Increase the percentage of clients who receive prenatal services in a contracted clinic that participate in prenatal classes;	68.2%	77.8%	14%
		Increase the percentage of clients who receive family planning services at the CHCs.	11.6%	26%	124%
	Pittsburgh	Increase the percentage of women who receive family planning services.	61.4%	83.4%	36%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Number of postpartum women who receive appropriate care.	Detroit	Increase the percentage of women receiving annual PAP smear.	82.2%	88.7%	8%
Number of infants appropriately immunized by age in relation to the total number of infant participants.	Savannah	Increase the percentage of children fully immunized by age 2.	73.1%	80.4%	10%
Increased number of physicians and/or midlevel practitioners serving infants of low income women.	Pee Dee	Increase the number of pediatricians or other physicians and/or mid-level practitioners serving infants, including low income families.	10.5	33.	217%
Increased client satisfaction	Baltimore	Increase the number of participating medical reform providers who have a mechanism for community and patient feedback in place;	11 of 18	16 of 18	45%
		Increase percentage of client satisfaction with prenatal clinics (measured by 13 service characteristics);	74-97%	81-98%	9% to 1%
		Increase percentage of client satisfaction with pediatric clinics (measured by 12 service characteristics).	84-96% with over 95% in 2 areas	79-98% with over 95% in 6 areas	6% to 2% 200%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Increase client satisfaction.	Detroit	Increase percentage of client satisfaction with Enhanced Clinics;		100%	
		Decrease average waiting time for prenatal appointments.	13 days	9.5 days	27%
Enhance linkages among providers.	Boston	Establish coordination and linkage among health and human service providers funded by HS.	0	100%	
Improved practice measures at clinics/ambulatory care centers.	Boston	Introduce enhanced prenatal risk assessment protocol in project area health centers.	0	13	

Risk Prevention and Reduction

Definition: Provision of specialized services which address population-based or system-oriented issues to reduce, modify, or eliminate specific stressors or unhealthy behaviors that threaten childbearing women and their families.

Purpose: To reduce risks particularly associated with infant mortality in specific communities.

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Number of participants who report decreased practice of risk behaviors such as smoking, substance abuse, family violence, and behaviors leading to inadequate prenatal weight gain in relation to the total number originally identified with the behaviors:	Boston	Increase the percentage of Healthy Start prenatal clients who do not smoke during pregnancy.	81%	91%	12%
	Boston	Increase the percentage of pregnant and post-partum women in the project area receiving needed treatment for substance abuse.	8%	21%	163%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
	DC	Increase the percentage of abstinence from alcohol use reported by pregnant women;	8.1%	3.0%	63%
		Increase abstinence from drug use by pregnant women;	21.6%	6.4%	71%
		Reduce the proportion of smoking in pregnant females.	8.1%	3.8%	54%
	Pittsburgh	Increase the percentage of project area women who achieve the minimum weight gain during pregnancy;	62.7%	64.6%	3%
		Reduce the percentage of women who smoke during pregnancy.	35.5%	31%	13%
Ratio of those participants identified with risk behaviors that participate in program in relation to in relation to total number of those identified with behaviors.	Boston	Identify, counsel and make adequate referrals for pregnant women in the project area at risk for domestic violence.	Uncertain (low %)	66%	
	NYC	Assist families and/or individuals to improve their living conditions by helping them obtain better housing opportunities.	700 families/ individuals	1,131 families/ individuals	38%
	Richmond	Increase the number of pregnant women or postpartum with children receiving residential treatment for substance abuse by increasing the number of slots.	0	15	
	Pittsburgh	Ensure that all enrollees have access to needed community-based mental health	0	309	

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Number of participants who report increased knowledge about risk taking behaviors.	New Orleans	Increase the number of clients who participate in parenting classes.	61.4%	73.9%	20%
Reduced incidence of contributing risk factors (e.g. smoking, substance abuse, family violence) currently identified among families of in project area.	Pee Dee	Create new or expanded businesses for the 6-county project area.	49	93	90%

FACILITATING SERVICES

Definition: Provision of enabling services such as translation, transportation, and child care to assist clients in receiving services and participation in infant mortality programs.

Purpose: To reduce logistical barriers to accessing services and activities.

PERFORMANCE MEASURE	PROJECT	PERFORMANCE INDICATOR	BASELINE[1]	CURRENT	PERCENT CHANGE[2]
Success rate of keeping appointments for all care.	Boston	Decrease the proportion of pregnant and parenting women in the project area who fail to keep or make prenatal and/or pediatric appointments due to lack of child care and/or transportation.	30%	10%	67%
Utilization rate of facilitating services by those who identified lack of transportation, child care, and/or translation services as barriers.	Dallas	Expand ridership of Mom-Mobile transportation program.	150	4200	2700%
	Detroit	Increase utilization of participant support services:			
		• WIC participation	61.5%	73.8%	20%
		• Clinic Transportation	9.3%	18%	94%
		• Healthy Baby Van Transportation	4.2%	9.8%	133%
	Pee Dee	Establish/ increase number of sites offering short term child care services for project area women.	0 sites	7 sites	
	Pittsburgh	Increase utilization of participant support services:			
		• Transportation			
		• Child Care	0	6117 trips	
		• Tangible Goods		954 families	
				2182	

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Increased understanding of infant mortality and the contributing factors to it in their community.	Birmingham	Increased understanding of infant mortality and the contributing factors to it in their community.	Pretest	Matched post-test: shows improvement by 69% of participants	69%
	No. Plains	Service areas will host at least one forum regarding their health status (i.e. what does infant mortality mean to me and my community) and programs available to address concerns.	0%	100%	

EDUCATION AND TRAINING

Definition: Provision of planned education and public information to address risk factors associated with infant mortality, and to improve individual and community health.

Purpose: To educate the public, clients, and providers regarding health issues and other topics that promote perinatal health and/or enhance the delivery of perinatal care.

PERFORMANCE MEASURE	PROJECT	PERFORMANCE INDICATOR	BASELINE[1]	CURRENT	PERCENT CHANGE[2]
Increased understanding of infant mortality and the contributing factors to it in their community.	Birmingham	Increased understanding of infant mortality and the contributing factors to it in their community as measured by pretest and post-test	Pretest	Matched post-test: shows improvement by 69% of participants	69%
Number of indigenous workers trained and working in the community.	Baltimore	% of employees of neighborhood family centers who are indigenous workers/residents of target area.	0%	29%	
	Boston	Increase job training opportunities and employment available to project area residents.	243	927	281%
	Boston	Increase the capacity of Adult Basic Education and English as a Second Language programs. • % client enrolled • Number enrolled	 12% 720	 18% 888	 50%
Number of providers trained and utilizing training in the community.	Boston	Train project area service providers in: • Communication skills, risk assessment and infant mortality prevention; • Cultural competency.	 0 0	 519 197	

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Number of indigenous workers trained and working in the community.	Florida	Train 16 community members as home visitors.	0	16	
Percentage of project area residents aware of HS program, its' purpose and services.	Northwest Indiana	Increase the percentage of residents from project area who are: • aware of the program • aware of services • used the service or knew someone who had	0	58% 44% 31%	
Number of recipients trained and utilizing training in the community.	NYC	Provide training to facilities providing prenatal care and other services to women to begin or enhance smoking cessation programs. • Number of facilities • Number implementing new/enhanced existing prenatal smoking cessation programs	1	41 21	4000%
	NYC	Increase number of participating residents by increasing number of programs providing educational opportunities and job skills training to project area residents.	700	1,867	167%
	NYC	Increase training to health care and social service providers to improve their ability to interact effectively with women of diverse backgrounds and identify domestic violence.	1 training program	16 programs 1,402 providers	1500%
	Pittsburgh	Increase the number of women who are enrolled in educational/training program.		2, 314	
Number of hotline clients who reported being referred by the PSA.	Pittsburgh	Increase the percentage of Project area women who have heard of HS.		93.5%	

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
	No. Plains	Service areas will host at least one forum regarding their health status (i.e. what does infant mortality mean) and programs available to address concerns.	0%	100%	

Adolescent Programs

Definition: Provision of services which focus on the unique needs of adolescents to help them understand the complexities of childbearing and the need for pregnancy prevention.

Purpose: To decrease adolescent pregnancy and to improve health care and parenting skills for pregnant and parenting adolescents.

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
Rate of births to teens for two groups: fourteen and under and fifteen through seventeen.	Birmingham	Reduce the fertility rate of women 10-18 years of age.	42/100	42/100	0%
	Mississippi	Increase the percentage of births to teens ages 10-19.	29.2%	15%	49%
	Pittsburgh	Reduce percentage of births among women 17 and younger.	9.0%	8.7%	3%
	Savannah	Increase the percentage of birth to teens 15 to 17.	7.5%	5.4%	28%
Incidence of STDs.	Boston	Decrease the prevalence of risk-taking behaviors among teens (using STDs as an indicator) who participate in Healthy Start programs.	14.0%	1.9%	86%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
	Pittsburgh	Decrease the incidence of gonorrhea and other STD's in adolescents 15-19.	3,620 cases/ 100,000	1,700 cases/ 100,000	53%
Number of teenage participants who are referred to prenatal and family planning service providers.	New Orleans	Increase the percentage of teens, aged 14-17 years, referred into the CHC network of prenatal and family planning service providers.	0%	21.7%	
Number of teens utilizing Healthy Start sites who receive a specific source of on-going health care, including STD screening, family planning, health services, and support services.	Oakland	Increase the number of teens with access to health care and support services.	117	241	106%
Number of teens who are connected to the appropriate health care provider.	Boston	Increase the percentage of project area teens who have accessed adolescent health services.	22%	64%	191%
Number of participants who report increased knowledge about risk taking behaviors.	Richmond	Provide resources to nine churches in order to facilitate a pregnancy prevention program. (City Wide).	No such program existed in 1993	All nine churches received resources	
Ratio of those teens identified with risk behaviors that participate in program in relation to in relation to total number of those identified with behaviors.	NYC	Increase the number of parenting adolescents and/or care givers of high risk children who receive parenting education and training.	700	3,031	333%

Performance Measure	Project	Performance Indicator	Baseline[1]	Current	Percent Change[2]
	Chicago	Increase the percentage of pregnant women whose diets are assessed as nutritionally optimal;	38.2%	40%	244.0%
		Decrease the percentage of infants born with positive drug screen whose mothers were enrolled in HS;	22%	10%	
		Increase the number of Healthy Start clients in the FC employment training program who were:			
		• placed in jobs;	25	84	
		• referred for employment	149	531	

It should be noted that over the period of the demonstration phase, projects had the flexibility to refine annual performance indicators. In many cases, the refinement moved from more process indicators to health outcome oriented indicators; in other cases, the precipitating reason for this refinement was the loss of secondary data sources available to projects for tracking annual performance. As a consequence of these factors and the difference in implementation schedules for the 22 projects, the baseline year for each performance indicator identified differs. Some of the performance measures are common to several models.

Percent of Change Over Time Analysis: the baseline value is subtracted from the current value and that quantity is divided by the baseline value. The results are multiplied by 100 for readability. The "percent change" figure has been rounded to the nearest whole number.

Mr. SNOWBARGER. Thank you, Dr. Nora. Dr. Marks.

Dr. MARKS. Thank you, Mr. Chairman. Good morning. I am Dr. James Marks from the National Center for Chronic Disease Prevention and Health Promotion at the Centers for Disease Control.

I am pleased to be here to discuss some of our agency's activities related to infant mortality and prenatal care, including the National Vital Statistics System. I will summarize my written testimony on this work and also discuss the timeliness and accuracy of the data, and some of our other activities in this area.

As Dr. Nora has mentioned, the infant mortality rate in the United States has declined steadily over the last quarter century, reaching 7.5 deaths per 1,000 live births in 1995, the lowest rate ever recorded. Slightly over 30,000 infants die in the United States each year, with the leading causes of death being birth defects, disorders related to prematurity and low birth weight, Sudden Infant Death Syndrome, and Respiratory Distress Syndrome.

However, the relatively poor international ranking of the United States in infant mortality and the large differential in infant mortality among the U.S. population subgroups presents cause for concern.

The vital statistics system maintained by CDC's National Center for Health Statistics is the source of the Nation's official vital statistics. These statistics are provided through State-operated registration systems and are based on vital records filed in the State offices. Detailed annual birth and death data are available for the United States as a whole, for States, for counties, and cities of greater than 100,000.

CDC believes this State data on low birth weight and infant mortality to be highly accurate. All of the States have adopted laws requiring registration of live births and deaths, and CDC relies on information provided by the States to complete the national files. An example: the States were able to link about 98 percent of all infant death records to their corresponding birth certificates, one of the ways that they are encouraged to check on completeness of registration.

With regard to timelines, the vital statistics system is in transition, with a shift toward electronic collection and transmission of data. This is dramatically improving timeliness. In 1995, almost 70 percent of births were registered electronically, although most States were still processing a paper legal record.

In October 1996, CDC released preliminary data for calendar year 1995, including preliminary infant mortality rates, by cause of death and race. This was an almost 12-month improvement over previous data releases.

CDC is working further with the States to continue to improve timeliness of vital statistics in general, and especially timeliness of the linked birth and death data.

In addition to collecting the vital statistics, CDC conducts epidemiologic research into the risks and causes of infant mortality and supports the States to gather and better use their data to assess their infant health problems and target their resources. I will now describe some of this work in a little detail.

For example, one measure that is of great importance is that of early prenatal care, defined as having the initial prenatal visit within the first 3 months of pregnancy.

In 1994, about 80 percent of all women received early prenatal care, but there is substantial variation among our largest cities, with the cities that have the lowest rates averaging slightly over 50 percent, and those with the highest rates having over 80 percent of women receiving early prenatal care.

Another way that we use vital statistics is in examination of ethnic and racial disparities in infant mortality. As you have heard, African-American infants have over twice the rate of infant mortality as do white infants.

It is found that this is principally due to the very low birth weight rate, which contributes to almost two-thirds of the disparity and the concomitive higher mortality of those very small infants.

Although these very low birth weight infants represent only a tiny fraction of all the births in the United States—about 2.3 percent of the births to African-Americans and only .8 percent among whites—because of their high mortality, they account for this excess.

Further, when you look at the risk of death to college-educated African-American women, compared with college-educated white women, we find that the excess remains. We would assume, for these college-educated groups, that access to quality care would be much more nearly equal than for the population as a whole, yet the excess remains.

Therefore, CDC has begun to examine the psychological, social, cultural, and environmental factors that may contribute to preterm delivery, using a community participatory approach in Harlem and Los Angeles. We are working with the communities to understand how they view the infant mortality and the risks and protective factors influencing maternal health and pregnancy outcomes.

CDC also works heavily in the area of birth defects, the leading cause of infant mortality, where it is surveillance and epidemiologic capabilities have enabled us to conduct research that has led, for example, to show that the consumption of the vitamin, folic acid, could prevent 50 to 70 percent of cases of neural tube defects, a very serious birth defect.

Our efforts, along with those of others, contributed to the FDA's decision to require fortification of the food supply with low levels of folic acid.

I would now like to just briefly mention our work with the States and communities.

The Maternal and Child Health Epidemiology Program is collaborative between CDC and HRSA. We support about 15 States to increase their analytic capability through the assignment of epidemiologists and support for specific analytic projects.

For example, Georgia evaluated the efficacy of prenatal care case management funded by Medicaid and found that it does get high-risk women into care earlier. This evaluation influenced the State to continue to provide case management services when it was an area under review.

The other is the Pregnancy Risk Assessment Monitoring System, or PRAMS, which is an ongoing population-based surveillance system designed to identify and monitor selected material behaviors and experiences that occur before, during, and after a pregnancy.

Again, in fiscal year 1996, we funded 15 States for this. It is designed to supplement data from vital records and asks a sample of women who have recently delivered about their behaviors and experiences, such as access and use of care, alcohol use, smoking, violence during pregnancy, et cetera.

An example of how this was used: in Oklahoma, they found that half of all women with Medicaid coverage, who had their first prenatal visit after the first trimester, indicated that they began care as early as they wanted to. Thus, awareness of the importance of prenatal care remains a barrier to receiving early prenatal care, particularly among women with Medicaid coverage.

In conclusion, continued progress in reducing the Nation's infant mortality rate and eliminating the racial and ethnic differences in pregnancy outcomes will occur if the national, State, and local commitment to improving birth outcomes also continues. It is increasingly clear that infant mortality is a problem that needs broad community-based, as well as medical interventions. The Healthy Start demonstration projects and the complementary work that we are engaged in at CDC we hope will contribute to reducing infant mortality in the future.

Thank you. I will be pleased to respond to any questions you might have.

[The prepared statement of Dr. Marks follows:]

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

TESTIMONY OF

JAMES S. MARKS, M.D., M.P.H.

NATIONAL CENTER FOR CHRONIC DISEASE
PREVENTION AND HEALTH PROMOTION

CENTERS FOR DISEASE CONTROL AND PREVENTION

PUBLIC HEALTH SERVICE

BEFORE THE

COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT

SUBCOMMITTEE ON HUMAN RESOURCES AND
INTERGOVERNMENTAL RELATIONS

U.S. HOUSE OF REPRESENTATIVES

MARCH 13, 1997

Good Morning, I am James Marks, M.D., Director of the National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention (CDC). I am accompanied today by Mary Anne Freedman, Director of the Division of Vital Statistics in CDC's National Center for Health Statistics. I am pleased to be here to discuss some of our agency's activities related to infant mortality and prenatal care, including the National Vital Statistics System. In response to the Subcommittee's request, I will give a brief overview of the infant mortality and birthweight data maintained by CDC, discuss the timeliness and accuracy of the data, and describe some of CDC's activities in the area of infant health and mortality.

The infant mortality rate in the United States has declined steadily over the last quarter century, reaching 7.5 deaths per 1,000 live births in 1995 (based on preliminary data) -- the lowest rate ever recorded in the United States. However, the relatively poor international ranking of the United States in infant mortality (22nd in 1992) and the large differential in infant mortality among the United States' population subgroups present cause for concern. Approximately 30,000 infants die in the United States each year. The leading causes of death for infants are birth defects, disorders relating to prematurity and low birth weight, and sudden infant death syndrome.

I. NATIONAL VITAL STATISTICS SYSTEM

The National Vital Statistics System - maintained by CDC's National Center for Health Statistics - is the source for the Nation's official vital statistics. The registration of vital events, including births and deaths is a State function governed by State laws. Thus, the Nation's vital statistics are

based on State vital statistics records and are generated through State-operated registration systems. CDC collaborates with the States to develop standard forms for data collection and model procedures to ensure uniform registration of the vital events. CDC shares the costs incurred by the States in providing vital statistics data for national use.

Detailed annual data on births and deaths are available for the United States as a whole, and for States, counties, and cities of greater than 100,000 population. In addition to maintaining data files on births and deaths, CDC maintains files which "link" birth and infant death data. These files link information from the birth certificate (such as birthweight, prenatal care, and mother's age) and the death certificate (such as cause and age of death), and enable us to explore the complex relationships between infant deaths and factors present at birth. The linked files are particularly useful in examining racial and ethnic disparities in infant mortality.

Existing data on low birthweight and infant mortality are highly accurate. For the 1991 birth cohort, for example, CDC and the States were able to match 97.7 percent of all infant death records to their corresponding birth certificates. In addition, data timeliness is improving dramatically as a result of electronic collection and transmission of data. CDC, thus is now able to publish birth and death rates more timely. In October 1996, CDC released preliminary data for calendar year 1995, including preliminary infant mortality rates by cause of death and race. This represents an almost 12 month improvement over previous data releases. CDC is also accelerating the publication schedule for the linked birth and infant death files, which provide

valuable information on the causes of infant mortality. Release of the 1995 linked file is expected in September 1997.

II. CDC INFANT HEALTH AND MORTALITY ACTIVITIES

Numerous activities and research projects are underway at CDC to promote infant health and assist in the prevention of infant mortality and morbidity. The following provide examples:

• **Analyses of Vital Statistics Data**: The data maintained by the National Vital Statistics System is critical to many of the analyses CDC conducts to further understanding of the factors affecting infant mortality, low birthweight, and related indicators of pregnancy outcome. Let me summarize two examples:

Data by Cities: CDC has developed an information system to increase access to comparative vital statistics on prenatal care, low birthweight and infant mortality in cities in the United States. This system facilitates the comparison of maternal and child health indicators among cities. While the maternal and child health status of cities in general is lower than the U.S. as a whole, it is important to realize that there is much inter-city variation in measures of maternal and child health. For instance:

• One measure of maternal and child health is early prenatal care - defined as having the initial prenatal visit within the first three months of pregnancy. In 1994, the most recent year

for which final data are available, approximately 80 percent of all U.S. women received early prenatal care (this represents a 1 percent increase over the previous year). Among the 23 largest U.S. cities *(1990 Census population >500,000)*, only about 50 percent of women received early prenatal care in New York City, El Paso, and Washington, DC. Conversely, more than 80 percent of women in Columbus, San Francisco, and Boston received early prenatal care.

• Similarly, inter-city variation also occurs with measures of infant health, such as low-birthweight *(birthweight <2500 grams, or approximately 5 1/2 pounds)*. In 1994, 7.3 percent of infants were born with low-birthweight in the U.S.. Among the large U.S. cities, the percentage of infants born with low-birthweight was as low as 6 percent in Seattle, San Diego, and San Jose, and over 13 percent in Memphis, Baltimore, Detroit, and Washington, DC.

Racial/Ethnic Variation: The main contributors to the excess mortality among African-American infants are the high rate of very low birthweight (<1500g) and the excess rate of postneonatal mortality among normal birthweight babies. Although very low birthweight infants represent a tiny fraction of all live births in the United States (2.3 percent of singleton births among African-Americans and 0.8 percent among whites), they account for almost two-thirds of the disparity in infant mortality between African-Americans and whites. The majority of all very low birthweight infants are born as a result of a preterm delivery. Moreover, the more premature an infant is, the more difficult medical treatment becomes.

Another 25 percent of the gap in infant mortality between African-Americans and whites derives from deaths among normal birthweight babies, many of whom survive the first 28 days of life but die during the postneonatal period. Patterns of postneonatal mortality suggested that with a few exceptions, such as certain congenital birth defects, excess deaths among normal birthweight black infants generally resulted from potentially preventable causes such as infections, injuries, and sudden infant death syndrome (SIDS).

The infant mortality and birthweight data were also used to study the experience of African-American infants born to families in which women are college educated and presumably have occupational stability, health insurance, access to services, and early entry into care. African-American and white infants born to college educated parents had similar infant mortality rates for many causes, including sudden infant death syndrome (SIDS), injuries, and respiratory diseases. However, among infants born to this highly educated group of parents, those born to African-American college graduates had an 80 percent higher risk of dying during their first year of life than babies born to white college graduates. This excess was related most notably to a three times higher rate of very low birthweight in the African-American than in the white college educated population. Thus, the disparity in the very low birthweight rate for infants of African-American college-educated parents is almost as large for the general population.

• **The Maternal and Child Health Epidemiology Program (MCHEP):** The Maternal and Child Health Epidemiology Program (MCHEP), a collaborative effort between CDC and the

Health Resources and Services Administration (HRSA), provides support to State maternal and child health (MCH) programs. Its primary objectives are (1) to assist States in identifying and collecting the data needed to assess and protect the health of mothers and infants, (2) to conduct epidemiologic analyses of maternal and infant health service and policy issues essential for State program planning, policy development and priority setting, and (3) to support State efforts to use information effectively to make decisions about the health of mothers and infants.

Numerous examples exist to document the improvement in programs and changes in policy that resulted from this epidemiologic support. Through the MCHEP program, for example, the State of Georgia evaluated the efficacy of prenatal care case management funded by Medicaid and found that it does get high risk women into care earlier. This evaluation influenced the state to continue providing case management services.

• **Pregnancy Risk Assessment Monitoring Systems (PRAMS):** PRAMS is a surveillance system designed to identify and monitor selected maternal behaviors and experiences that occur before, during, and after pregnancy. In particular, PRAMS was designed to supplement data from vital records and to generate data for planning and assessing perinatal health programs in participating States (presently 15 States). States select a sample of mothers who are asked about behaviors and experiences such as access to, and use of, prenatal and infant care, alcohol use, smoking, and violence during pregnancy. These data are meant to be used to enhance understanding of maternal risk factors and their relationship with adverse pregnancy outcomes and aid in the development and assessment of programs designed to identify high-risk

pregnancies and reduce adverse outcomes, including low birthweight and infant mortality. According to the PRAMS group in Oklahoma, "Half of all women with Medicaid coverage who had their first prenatal care visit after the first trimester indicated that they began care as early as they wanted, nearly twice the rate among non-Medicaid women. Awareness of the importance of prenatal care remains a barrier to received early care, particularly among women with Medicaid coverage."

• **Prenatal Care:** Early initiation of prenatal care is believed to promote heathy pregnancy outcomes. However, in the United States in 1994, approximately 20 percent of the infants were delivered to women who had received prenatal care after the first trimester of pregnancy or received no prenatal care at all. Wide differences exist in rates of delayed initiation of prenatal care by State, county, ward, and neighborhood. Moreover, studies have demonstrated an association between delayed prenatal care initiation and various demographic characteristics. Research aimed at identifying and understanding the barriers to early prenatal care initiation will assist in developing strategies to alleviate these barriers. Presently, CDC is conducting research to explore the reasons for the delay in initiating early prenatal care, using both PRAMS data and national and State-based vital statistics data.

• **Prenatal Smoking Cessation (PSC):** Smoking during pregnancy has been identified as the most important potentially preventable cause of low birthweight in the United States. It is estimated that perhaps 25 percent of low birthweight in the United States can be attributed to maternal smoking. The purpose of CDC's Prenatal Smoking Cessation program is to develop and

enhance the capacity of maternal and child health programs to reduce the effects of smoking among women of reproductive age and their families. Since 1986, CDC has provided funding and technical assistance to State health departments in the development, implementation and evaluation of prenatal smoking cessation interventions. Since 1993, CDC also has collaborated with the Association of Maternal and Child Health Programs (AMCHP) to promote smoking cessation during pregnancy.

• **Birth Defects:** Birth defects are the leading cause of infant mortality in the United States and the primary cause of nearly 7,000 or 20 percent of all infant deaths each year. The commonly held belief that birth defects, developmental disabilities, and genetic diseases are rare occurrences that cannot be prevented is far from accurate. Each year, factors in the periconceptional and prenatal environment result in major birth defects that affect 120,000 babies. Already, we know the causes of about 25 percent of these birth defects, and as a result, prevention is possible in some cases. CDC's surveillance and epidemiologic capabilities have enabled us to take a leadership role in monitoring trends in birth defects, developmental disabilities, and genetic diseases; in linking these health outcomes with the factors in the environment that increase risk; and in identifying effective means of reducing that risk.

CDC has established Centers for Birth Defects Prevention Research in 6 States which have initiated unique national collaborative research into the causes of birth defects. The causes of about 75 percent of all birth defects are unknown. The role of environmental pollutants, drugs, specific behaviors, or genetic susceptibilities in causing birth defects, developmental disabilities, or

other adverse reproductive outcomes is being explored. These new Centers will accelerate the process of finding the causes and risk factors for birth defects.

CDC's research and efforts on folic acid is an excellent example of CDC's working with its partners on birth defects prevention. In 1991, research by CDC and others showed that the vitamin, folic acid, could prevent 50-70 percent of the U.S. cases of neural tube defects, spina bifida and anencephaly. Each year in the United States, 2,000 cases of spina bifida and anencephaly can be prevented by consumption of adequate amounts of folic acid by women of childbearing age. CDC's efforts contributed significantly to the Food and Drug Administration's decision to require low-level fortification of the food supply in order to prevent neural tube defects. CDC also works to increase the percentage of women consuming folic acid supplements in order to prevent neural tube defects, and provides advice and technical assistance to many states that are initiating folic acid programs.

• **Sudden Infant Death Syndrome (SIDS):** In the United States, 4,000 to 5,000 infant deaths occur due to SIDS annually. SIDS is the leading cause of infant deaths between 1 month and 1 year of age and accounts for a third of these deaths. Although the cause (s) of SIDS is unknown, many modifiable risk factors have been identified, including prone (face down) sleeping position, in utero and environmental tobacco exposure, not breast-feeding, and soft bedding.

CDC has several major activities related to SIDS. For example, CDC plays a key role in SIDS mortality surveillance and monitoring of changes in risk factors over time (tobacco use, breast-

feeding, prone sleep). CDC also has issued the first national guidelines for death scene investigation of SIDS, which are designed to help State and local medical examiners and coroners to conduct a standardized and uniform investigation of SIDS. In addition, in collaboration with NIH-NICHD, CDC is supporting two research projects in Chicago and the Aberdeen Area of the Indian Health Service designed to examine the association between social, environmental, and medical risk factors and SIDS.

• **Preterm Delivery**: Preterm delivery, the birth of an infant before completion of 37 weeks of gestation, is one of the predominant proximate causes of low birthweight and, together with low birthweight, is the third leading cause of infant mortality in the United States. The percent of preterm births has risen steadily from 9.4 in 1981 to 11.0 in 1994. African-American women experience twice the risk of preterm delivery as white women. The reason for the disparity in preterm delivery between African-American and white women remain unexplained. Therefore, CDC has begun to examine psychological, social, cultural, and environmental factors that may contribute to preterm delivery. In particular, CDC is supporting community-based prevention research to improve understanding of both risk and protective factors influencing maternal health and pregnancy outcomes. In addition, because high levels of exposure to such factors as stressful life experiences put African-American women at increased risk for adverse reproductive outcomes, CDC is examining the validity and reliability of stressful life event scales in African-American women.

III. CONCLUSION

Continued progress in reducing the Nation's infant mortality rate and eliminating the racial and ethnic differences in pregnancy outcomes will occur if the national, State and local commitment to improving birth outcomes and maintaining healthy infants also continues. It is increasingly clear that infant mortality is a problem that needs community-based as well as medical interventions. The Healthy Start demonstration program and the complementary work that CDC is engaged in on community-based prevention research are both innovative approaches that contribute to reducing infant mortality in communities that still have an excess burden of infant deaths. CDC will continue to work with its partners - federal, state, local and private - to strengthen surveillance efforts, to conduct prevention research, and to disseminate information about what works to prevent infant mortality.

Mr. SNOWBARGER. Thank you, Dr. Marks. Dr. Alexander.

Dr. ALEXANDER. Mr. Vice Chairman, members of the subcommittee, I thank you for the opportunity to testify here today. I am Duane Alexander, Director of the National Institute of Child Health and Human Development at the National Institutes of Health.

The Congress charged my institute, the NICHD, with supporting and conducting biomedical and behavioral research on maternal and child health, the population sciences, and medical rehabilitation. When my institute was founded in 1962, it was given a special mandate to address the significant problem of infant mortality in the United States, which was actually on the rise at the time. Since then, the U.S. infant mortality rate has declined by 70 percent.

NICHD-supported research advances have played a major role in that reduction, particularly improvements in preventing and treating Respiratory Distress Syndrome and the "Back-to-Sleep" campaign aimed at reducing the risk of Sudden Infant Death Syndrome.

Since 1990, three major research findings have significantly affected and accelerated the continuing decline in the U.S. infant mortality rate.

First is the development and use of surfactant to treat newborns afflicted with Respiratory Distress Syndrome. Our research had previously revealed that infants with RDS lacked surfactant, a surface factor that keeps the insides of the lungs from sticking together and makes breathing easier.

The development and administration of surfactant has markedly reduced deaths due to RDS and saves almost $90 million a year in medical costs.

To illustrate the significance of this advance, in 1963—the year after NICHD was founded—President Kennedy's infant son Patrick was born prematurely and died of Respiratory Distress Syndrome. Despite all his advantages, his doctors and his parents could only watch helplessly as Patrick struggled to breathe, because the cause of RDS was not yet understood and there was no treatment.

Now, with surfactant treatment, new respirators, better isolettes, and advanced intravenous fluid therapy, all developed through research, premature babies have a far better chance to live. When Patrick was born, an infant with RDS, at his weight and gestational age, had a 95 percent chance of dying. Today, an infant at that weight and age has a 95 percent chance of living.

Second, in 1994, an NICHD-supported Consensus Development Conference concluded that use of antenatal steroids to treat women in preterm labor would result in a 50 to 60 percent reduction in the baby's risk of death or suffering complications.

As a result of our targeted dissemination of the recommendations from that consensus panel, the use of antenatal steroids in high-risk women has increased from 15 percent of such patients to about 60 percent, potentially saving the lives of several thousand very low birth weight infants each year, plus as much as $160 million annually in medical expenditures.

Further increases in the application of these recommendations will result in additional savings in both infant lives and costs.

The third and perhaps most dramatic research finding that has reduced infant mortality in the United States in the 1990's is the realization that placing infants on their backs to sleep, rather than the common practice of on their stomachs, reduces the risk of Sudden Infant Death Syndrome.

For many years, SIDS had been the leading cause of death in infants from between 1 month and 1 year of age. Deaths due to SIDS have fallen by more than 30 percent nationwide in the past 3 years. Some States are reporting reductions of over 60 percent in SIDS deaths.

Such declines can be traced to the success of the research-based "Back-to-Sleep" campaign designed to encourage back sleeping for infants.

The "Back-to-Sleep" campaign is led by NICHD with the Maternal and Child Health Bureau and the American Academy of Pediatrics, in collaboration with SIDS parents and professional groups. Since the campaign began, it is estimated that 1,600 fewer babies a year die of SIDS.

Despite these major research advances and their direct impact on reducing infant mortality, the rate of death during the first year of life is still too high, and remains an important public health problem for the Nation. We continue to support a major research program on reducing infant mortality and anticipate that our expenditures in this area during this current fiscal year will exceed $94 million.

Recognizing that obstetric and neonatal practice was hampered by a lack of clinical trials of sufficient size to give clear indications rapidly of the effectiveness of various treatment approaches, several years ago we established two networks for multisite clinical trials in maternal-fetal medicine and neonatology.

These networks develop common protocols, conduct the trial, and present the results jointly. To date, these networks have successfully identified both effective and ineffective interventions and widely disseminated the results for clinicians.

Our infant mortality research effort is placing special emphasis on the leading cause of infant mortality, birth defects, and the problems of prematurity, especially low birth weight. For some time, we have explored questions about possible links between maternal infections and premature birth.

Using the most promising lead we have at the present time for reducing prematurity, our maternal-fetal medicine network launched a clinical trial in August 1996 to determine whether screening pregnant women for a marker of bacterial vaginosis called fetal fibronectin, and treating them with an antibiotic to eliminate this infection would reduce the rate of premature delivery.

This large-scale clinical trial is based on evidence that bacterial vaginosis triggers premature labor and on small studies suggesting that antibiotic treatment markedly lowers that risk.

Because large numbers of women, particularly African-American women, have this common infection and are unaware of it, the development of an inexpensive and easy means of eliminating it could have a major impact on the incidence of prematurity and infant mortality.

Mr. Vice Chairman, our Institute is proud of its record in helping to reduce the rate of infant mortality in our country, and remains committed to continuing to contribute to this effort in the future.

I will be glad to respond to any questions that you or members of the subcommittee have.

[The prepared statement of Dr. Alexander follows:]

Statement of

Duane Alexander, M.D.

Director, National Institute of Child Health
and Human Development

National Institutes of Health

Before the

Subcommittee on Human Resources

Committee on Government Reform and Oversight

U.S. House of Representatives

Thursday, March 13, 1997

Mr. Chairman and members of the Subcommittee:

I am Dr. Duane Alexander, Director of the National Institute of Child Health and Human Development (NICHD) at the National Institutes of Health (NIH). In response to your invitation to Dr. Harold Varmus, Director of the NIH, I have been asked to testify about research focused on the causes of infant morbidity and mortality, especially low birth weight, premature birth, and sudden infant death syndrome.

The Congress has charged the NICHD to conduct and support biomedical and behavioral research on maternal and child health, the population sciences, and medical rehabilitation. The Institute supports a wide range of research approaches to these areas, including the latest in molecular biology, clinical trials, epidemiologic surveys of various populations in our society, and development of new assistive technologies. When NICHD was founded in 1962, it was given a special mandate to address the significant problem of infant mortality in the United States. Since the Institute was established 35 years ago, the U.S. infant mortality rate has declined by 70 percent. NICHD-supported research advances have played a major role in that reduction, particularly improvements in treating respiratory distress syndrome (RDS), and the "Back to Sleep" campaign aimed at reducing the risk of sudden infant death syndrome (SIDS).

Since 1990, three major research findings have significantly affected the continuing decline in the U.S. infant mortality rate:

First is the development and use of surfactant to treat newborns afflicted with respiratory distress syndrome. Many premature infants have trouble breathing. NICHD research previously revealed that such infants lack surfactant, a surface factor that keeps the inside of the lungs from sticking together and makes breathing easier. The development and administration of surfactant has markedly reduced deaths due to RDS and saves about $90 million a year in medical costs. To illustrate the significance of this advance, in 1963--the year after the NICHD was founded--President Kennedy's son Patrick was born prematurely and died of respiratory distress syndrome.

Despite all his advantages, his doctors and his parents could only watch helplessly as Patrick struggled to breathe, because the cause of RDS was not yet understood and there was no treatment. Now, with surfactant treatment, new respirators, better isolettes, and advanced intravenous fluid therapy, premature babies have a far better chance to live. When Patrick was born, an infant with RDS at his weight and gestational age had a 95 percent chance of dying; today, an infant at that weight and age has a 95 percent chance of living.

Second, in 1994, an NICHD-sponsored Consensus Development Conference found that the use of antenatal steroids to treat women in preterm labor would result in a 50 to 60 percent reduction in the baby's risk of death or suffering complications such as brain hemorrhage, respiratory distress syndrome, and chronic lung disease. As a result of NICHD's targeted dissemination of the recommendations from that consensus panel, the use of antenatal steroids in high-risk women has increased from 15 percent of such patients to 60 percent, potentially saving the lives of several thousand very low birth weight infants each year, plus as much as $160 million annually in medical expenditures. Further increases in the application of these recommendations will result in additional savings in both infant lives and care costs.

The third, and perhaps most dramatic, research finding that has reduced U.S. infant mortality in the 1990s, is the realization that placing infants on their backs to sleep, rather than the common practice of on their stomachs, reduces the risk of sudden infant death syndrome (SIDS). For many years, SIDS has been the leading cause of death in infants between one month and one year of life. Deaths due to SIDS have fallen by more than 30 percent in the past three years. Some states are reporting reductions over 60 percent in SIDS deaths. Such declines can be traced to the success of the research-based "Back-to-Sleep" campaign designed to encourage back sleeping for infants. The "Back-to-Sleep" campaign is led by NICHD, along with the Maternal and Child Health Bureau and the American Academy of Pediatrics, in collaboration with SIDS parents and professional groups. Prior to the campaign, about 5,000 to 6,000 babies were lost to SIDS each year. Since the campaign began, it is estimated that each year between 1,500 and 1,600 fewer babies die of SIDS.

Despite these major research advances and their direct impact on the reduction of infant mortality, the rate of death during the first year of life is still much too high and remains an important public health problem to the Nation. The NICHD continues to support a major research program on reducing infant mortality. We anticipate that NICHD expenditures in this area during Fiscal Year 1997 will exceed $94 million.

Recognizing that obstetric and neonatal practice was hampered by a lack of clinical trials of sufficient size to rapidly give clear indications of the effectiveness of various treatment approaches, several years ago the NICHD established two networks for multisite clinical trials in maternal-fetal medicine and neonatology. These effective networks, funded by a new cooperative agreement mechanism, collaborate with NICHD staff to identify topics for study, develop common protocols, conduct the clinical trial, and present the results jointly. To date these networks have successfully identified both effective and ineffective interventions and widely disseminated the results to clinicians.

The NICHD's infant mortality research effort is placing special emphasis on the leading cause of infant mortality, birth defects, and the problems of prematurity, especially low birth weight. Birth defects alone account for 1 in 5 infant deaths. Approximately 120,000 babies are born with major birth defects each year, requiring estimated annual care costs of more than $8 billion. Vitamins and dietary micronutrients may hold important answers for prevention of some birth defects. NICHD scientists played a key role in the discovery of genetic abnormalities that help to explain why low folate intake increases the risk of neural tube defects such as spina bifida. Due to action by the Centers for Disease Control and Prevention and the U.S. Food and Drug Administration, grain and cereal foods are now being fortified with folic acid, helping to ensure that it is present in a woman's diet before conception to reduce the risk of spina bifida.

The process of development from a cell to a complex embryo is governed by intricate systems controlled by genes that turn on and off cell activities and direct that various organs and limbs be developed. When things go wrong during embryonic development, they often cause birth

defects. NICHD scientists and their collaborators have discovered that certain genes, the LIM-homeobox genes, are critical to the correct development of the brain and the central nervous system. Last year's Nobel Prize for Medicine or Physiology went to two scientists whose basic research on embryonic development had been funded by NICHD for decades. Critical, exciting basic research on embryonic development continues in NICHD's laboratories today.

For some time, the Institute has explored questions about possible links between maternal infections and premature birth. Using the most promising lead we have at the present time for reducing premature birth, the NICHD Maternal Fetal Medicine Network launched a clinical trial in August of 1996 to determine whether screening pregnant women for a marker of bacterial vaginosis (fibronectin), and treating them with an antibiotic to eliminate the infection, will reduce the rate of premature delivery. This large-scale clinical trial is based on evidence that bacterial vaginosis triggers premature labor, and on small studies suggesting that antibiotic treatment markedly lowers that risk. Because large numbers of women, particularly African-American women, have this common infection and are unaware of it, the development of an inexpensive and easy means of eliminating it could have a major impact on the incidence of prematurity.

Mr. Chairman, the NICHD is proud of its record in helping to reduce the rate on infant mortality in our country, and remains committed to continuing to contribute to this effort in the future. I will be glad to respond to any questions that you or the members of the Subcommittee may have.

Mr. SNOWBARGER. Thank you, Dr. Alexander. Dr. Simpson.

Dr. SIMPSON. Good morning, Mr. Vice Chairman and members of the subcommittee. It is my pleasure to be here. I'm Lisa Simpson. I'm the Acting Administrator of the Agency for Health Care Policy and Research.

I take particular pleasure in being able to testify here this morning, both as a pediatrician, as my colleagues, but also a former director of maternal and child health for the State of Hawaii.

There are three major points that I would like to leave you with today from our Agency's perspective.

First, that we share the Healthy Start Program's goal of trying to reduce infant mortality and to do that through research. However, our research programs have never directly assessed the effectiveness of the Healthy Start Program.

The second point is that health services research, which is the research that we sponsor, has contributed to our understanding of the effectiveness and cost-effectiveness of interventions to improve low birth weight outcomes.

Third, many clinical services today, whether used for pregnant women, children, or adults, and are considered the standard of practice, actually lack a strong evidence or scientific base, and to create that scientific base and to use it to promote evidence-based practice is a key strategy for improving clinical care in this country.

The Agency's research emphasis, which stems from our legislative mandate, has been on issues and conditions which are common, costly, and for which there is substantial variation in practice.

Perinatal care, which is the care of a mother before delivery and of herself and her baby after delivery, is clearly one of these issues. Let me give you some examples.

Each year in this country, the costs of hospital admission for childbirth exceed $20 billion. Each year, the incremental costs of low birth weight are close to $4 billion. To put this in perspective, the annual direct costs of low birth weight continue to exceed the cost of AIDS.

AHCPR has a series of studies underway on perinatal care. Projects include studies of the management of childbirth and patient outcomes, variations in practice related to prenatal care, and strategies to improve the outcomes for very low birth weight infants.

In 1992, the Agency funded a comprehensive 5-year research project to investigate the components of obstetrical care. The project, which is titled the Low Birth Weight Patient Outcomes Research Team, or PORT, is headed by Dr. Robert Goldenberg, a national authority on low birth weight at the University of Alabama.

This project is now in its last year, and has already yielded several key findings, and my written testimony includes several highlights from this project, but let me just mention one or two, because I think they exemplify how health services research complements the biomedical and epidemiologic research that are conducted by other agencies in the Department.

One of the most important and, frankly, controversial findings of this study is the lack of evidence for the effectiveness of prescribing

bed rest for pregnant women considered to be at risk for a number of adverse perinatal outcomes.

In fact, there is not much consensus about when bed rest should be used, for whom, or for how long, and yet a growing body of research is showing that bed rest may, in some cases, actually be harmful. Still, almost 20 percent of pregnancies are recommended bed rest today.

So there is clearly a gap, a critical gap, between what we know from research and what is going on day-to-day in clinical practice.

Another important finding from this study is that high-risk babies have an increased chance of survival, with no significant increase in cost, if they are delivered in hospitals with a high volume of deliveries in specialized neonatal intensive care units, or NICUs.

This finding is from California, and it is my understanding that the California Children's Service, which oversees neonatal intensive care in that States's Medicaid population, is already looking to these results to recommend revisions for their State guidelines on neonatal intensive care.

Overall, this study has already produced 77 published articles and abstracts in leading peer review journals on these key findings. Mr. Vice Chairman, I respectfully request that a cumulative bibliography of these articles be submitted for the record.

Other findings from this study have influenced the practice recommendations that have been disseminated by the Centers for Disease Control and Prevention and the National Institutes of Health.

For example, this study's findings on cost effectiveness of the maternal screening and treatment for the prevention of a disease neonatal Group B streptococcal sepsis were used by the Centers for Disease Control in formulating their recently released screening and treatment recommendations.

Other findings from Dr. Goldenberg's study were also used by the National Institutes of Health in what Dr. Alexander just mentioned, their consensus development conference on the use of corticosteroids for fetal maturation and improving birth outcomes.

But health services research also goes beyond looking at the clinical services themselves to examine how you organize and finance health care services and to determine which of these approaches result in improved quality, better outcomes, and lower costs.

For example, our researchers have estimated that, in 1987, health care expenditures for infants totaled $12.6 billion and were greater on a per capita basis than those of any other age group younger than 65.

The source of this type of data is the agency's Medical Expenditure Panel Survey, which collects detailed information on the use and payment for health care services from a nationally representative sample of Americans. Many questions remain unanswered today about the many changes in the health care system, such as the impact of managed care and what will happen to the delivery of services at the community level.

This survey, or MEPS, is one source of information that will be able to shed some light on these questions in the years ahead. Because this survey is now an annual survey, we will be able to provide you with much more current data on a yearly basis, beginning in 1998.

To conclude, Mr. Vice Chairman, there are a number of interventions being used today to reduce the rate of infant mortality, and there is wide agreement that prenatal care is a key strategy, but we need to continue to build the science base behind these clinical interventions.

We need to give policymakers, physicians, patients and, increasingly, purchasers and health plans information on which specific interventions are the most effective and the most cost effective in reducing low birth weight and infant mortality.

While our agency is helping to bridge some of the gaps in this area, in other words, between what is known about effective treatment and the use of these treatments in everyday practice, a lot of work remains.

I am pleased to say that we are one of the Federal agencies collaborating with the others at the table and private sector groups in sponsoring a conference this fall that is going to bring together national experts on preterm, and really try to chart the course for research for the next decade in this area.

Thank you.

[The prepared statement of Dr. Simpson follows:]

Statement of
Lisa Simpson, M.B., B.Ch.
Acting Administrator
Agency for Health Care Policy and Research
before the
House Subcommittee on Human Resources and Intergovernmental Affairs

Introduction

Good morning, Mr. Chairman and members of the Subcommittee. I want to thank you for giving me this opportunity to discuss the Agency for Health Care Policy and Research's work in the area of low birth weight. I am pleased to address this critical issue, not only as the Acting Administrator of AHCPR, but also as a pediatrician and the former director of maternal and child health for the State of Hawaii.

There are three major points that I want to leave you with today:

First, while our work has never directly assessed the effectiveness of care provided under the Healthy Start program, we share the Program's goal of reducing the rate of infant mortality.

Second, health services research -- the type of research that the Agency funds -- has contributed to our understanding of the effectiveness and cost-effectiveness of strategies to improve low birth weight outcomes.

Third, like in all aspects of medical care, many individual clinical services which are considered the standard of practice today actually lack a strong scientific base. I believe that creating that scientific foundation and promoting evidence-based practice is a key strategy in improving health

care in this country.

As you may know, AHCPR was created in 1989 to provide policymakers, patients, physicians, health plans, and purchasers with the scientific information needed to make informed decisions on what works best in our health care system. The mission of the Agency for Health Care Policy and Research, an operating division of the Department for Health and Human Services, is to generate and disseminate information that improves the delivery of health care, including goals that determine what works best in clinical practice; improve the cost-effective use of health care resources; help consumers make more informed choices; and measure and improve the quality of care.

The Agency's research is uniquely designed to focus on the delivery of services in real world settings and answer questions about their quality, outcomes, and cost-effectiveness. Our emphasis -- which stems from our legislative mandate -- has been on issues and conditions that are common, costly, and for which there is a substantial variation in practice. Perinatal care (the care of a mother during pregnancy and of both mother and baby for a month following delivery) is clearly one of these issues.

Research on Perinatal Care

Hospital admissions for childbirth account for 12.7% of all admissions at a cost of nearly $20 billion (Keeler and Brodie, 1993). Approximately 35% of the cost of care for infants -- or $4 billion -- is due to the incremental costs incurred by low birth weight infants. To put this in perspective, the annual direct cost of low birth weight continues to exceed the cost of AIDS (Lewit, Baker, Corman, and Shiono, 1995). Finally, variation is also common in this area of medical care as evidenced by the wide variation in C-section rates by type of insurance and level of reimbursement, with rates as low as 15% and as high as 29% (Keeler and Brodie, 1993). Clearly, perinatal care is common, costly, and exhibits wide variation.

AHCPR has underway a series of studies on perinatal care These studies begin to look at some, but not all, aspects of the multifaceted set of services that make up comprehensive perinatal care. The projects include studies of the management of childbirth and patient outcomes, practice variation in prenatal care, the relationship between a physician's practice style and his/her malpractice experience, the effects of policy changes (e.g., reimbursement) on physician's practice styles, low-income women's satisfaction with prenatal care, strategies for care of very low birth weight infants, aspects of practice and outcome variation in neonatal intensive care units, and the long term developmental outcomes of very low birth weight infants.

Today, I would like to give you more details from one of these studies, because it exemplifies the contributions that health services research is making to our understanding of how to improve health care. First, the study assessed the effectiveness of discrete clinical interventions, second, it is studying ways in which to use this evidence to inform physician decisions, and finally it is looking at the effectiveness of one way of organizing services to improve outcomes. In 1992, AHCPR funded a comprehensive 5 year research project on discrete components of obstetrical care for which there is a wide variation and little evidence supporting these practices. The project, the Low Birth Weight Patient Outcomes Research Team or PORT, headed by Dr. Robert Goldenberg, at the University of Alabama is now in its last year, and has already yielded several key findings.

Key Findings

One of the most important and controversial findings, for example, is the lack of effectiveness of bed rest in preventing a number of adverse perinatal outcomes. This finding, which was published in 1994 and covered extensively in the press, found that bed rest did not appear to avert a variety of poor outcomes, including low birth weight, preterm delivery, and other complications associated with a high-risk pregnancies. Yet, bed rest has been recommended in as many as 20% of all pregnancies. Nor is there much consensus among physicians about when bed rest should be ordered or for whom or for how long. Moreover, there has been a growing body of research that

suggests that bed rest may actually be harmful for pregnant women, including physical and psychological consequences.

Clearly, as in many other areas of medicine, there is critical gap between what we know about an intervention and what is being prescribed in clinical practice.

Another important finding from the study is that high-risk babies have an increased chance of survival, with no significant increase in cost of care, if they are delivered in hospitals with highly specialized, level III, neonatal intensive care units (NICU) with a high volume. The research suggests that the emergence of competing and less specialized NICUs in California in the 1980s may have resulted in a higher infant mortality rate than if high risk deliveries had been concentrated in hospitals with existing level III units.

In addition, the findings suggest that referral and/ or transport of high-risk expectant women to hospitals with level III NICUs will yield better outcomes than later transport of infants. It is my understanding that the California Children's Service, which oversees NICU care for the Medi-Cal population, is considering using the results from this study to recommend revisions in the state's guidelines for neonatal intensive care for Medi-Cal patients.

Other key findings from the low birthweight study include: further evidence of the strong relationship between bacterial vaginosis (an infection of the vagina) in pregnancy and preterm delivery; the fact that African American women have the highest risk of bacterial vaginosis; the effectiveness of zinc supplementation for improving birthweight of the babies of African American women; and the effectiveness and cost effectiveness of prenatal corticosteroids in improving outcomes of preterm newborns. The study has already produced 77 published articles and abstracts in the leading peer-reviewed journals on these key findings. Mr. Chairman, I respectfully request that a cumulative bibliography on these articles be submitted for the record.

Putting Science Into Practice

In addition to publication in the professional literature and press, the findings from this study have influenced practice recommendations disseminated by the Centers for Disease Control (CDC) and National Institutes for Health (NIH). For example, the finding on the cost-effectiveness of maternal screening and treatment strategies for the prevention of neonatal group B streptococcal sepsis were used by CDC in formulating recently released screening and treatment recommendations. Other findings from Dr. Goldenberg's study were also used by NIH in their Consensus Development Conference on the Effect of Corticosteroids for Fetal Maturation on Perinatal Outcomes, which developed strategies to enhance corticosteroid use.

Dr. Goldenberg's work does not end here however. His ongoing work is focusing on translating the findings on the effectiveness of corticosteroids in reducing respiratory distress and neonatal mortality into clinical practice. In addition, the PORT will conduct a study to assess the relative contributions of three primary interventions in reducing low birthweight. These interventions are: (1) frequent high quality obstetrical care, (2) a smoking cessation program, and (3) a nutritional program focusing on both weight gain and good nutrients.

Dr. Goldenberg's study is an excellent example of the outcomes research that this Agency sponsors. In today's health care system where the cost pressures are mounting and providers and plans are struggling to provide high quality care at a reasonable cost, it is essential to determine which services are effective at improving outcomes. We must also make this information available to practitioners in ways that make it easy for them to practice evidence-based care.

Understanding Changes in the Health Care System

Health services research also looks beyond the clinical services themselves to examine the organization and financing of health care to determine which approaches result in improved

quality, better outcomes, and lower costs. In addition to the many outcomes research projects we sponsor in perinatal care, AHCPR also conducts studies of the cost and financing of care, including perinatal care. These have shown that medical care during pregnancy, childbirth, and infancy is a major source of health care expenditures. In addition to the data I mentioned earlier on the costs of perinatal care, our researchers have estimated that in 1987, the total charges for obstetrical care were over $15 billion, and that health care expenditures on infants totaled $12.6 billion and were greater, on a per capita basis, than those of any other age group except those 65 years of age and older (Lewit and Monheit, 1992).

The data source for many of these studies is the Agency's Medical Expenditure Panel Survey (MEPS) which collects detailed information on the use and payment for health care services from a Nationally representative sample of Americans. This survey's predecessor was the National Medical Expenditure Survey (NMES) and was last conducted in 1987. The survey provides detailed information on health care expenditures and services used by Americans at the household level for families and individuals; the cost, scope, and breadth of private health insurance coverage held by and available to the U.S. population; and the specific services that are purchased through out-of-pocket and/or third party payments.

The use of MEPS is important to the public and private sectors in developing National and regional estimates of the impact of changes in financing, coverage and reimbursement policies and estimates of who benefits and who bears the cost of a change in policy. It is also the source of information for examining the utilization of medical services, their quality and cost, and recent changes in these measures.

The current "revolution" we are witnessing in health care with the spread of managed care strategies is dramatically altering the delivery of services at the community level. This is notably so for low income, underserved populations, who have relied on Medicaid and other public programs for their care, including prenatal care. Many questions remain unanswered about the impact these changes will have. MEPS is one source of information that will be able to shed some

light on these questions in the years ahead. Because MEPS is an annual survey, we will be able to provide you with much more current data, on an annual basis, beginning in 1998.

Conclusion

Mr Chairman, there are a number of interventions being used to reduce the rate of infant mortality. While there is widespread agreement that prenatal care can help reduce the rate of infant mortality, we still need to build the science base to provide policymakers, physicians, patients, purchasers, and plans with the information on what specific interventions are most effective and cost-effective in reducing low birth weight and infant mortality. While AHCPR is helping to bridge the gap in this area -- between what is known about effective treatments and the use of effective treatments in everyday practice -- a lot of work remains.

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MEDTEP
MEDICAL TREATMENT EFFECTIVENESS PROGRAM

Low Birthweight PORT

Principal Investigator: Robert L. Goldenberg, M.D.
Grant Number: 290-92-0055

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Mr. SNOWBARGER. Thank you very much. We will now go to questioning for the panel, and I would like to begin by reminding panelists—maybe that's the best way to do it—reminding panelists of the chairman's question before he left. This may really just be for Dr. Nora. I'm not sure. If others want to respond, that's fine.

My understanding was his question was concerning the legislation that was passed about the nature of the programs, maybe beginning at the Federal level but, sooner or later, becoming local programs that were self-financed.

Dr. Nora, could you respond to the chairman's concern?

Dr. NORA. Yes. I would be happy to. We refer to this as sustainability. And, in the third year of the program, we sponsored a national conference addressing this issue.

All of the grantees participated in it, as did some of our other Federal partners. The private sector was involved. The State Title V maternal and child health directors were included, as well as local interest groups.

The grantees have been working on sustainability since that time. We likewise anticipate that Federal funding will not continue forever.

Mr. SNOWBARGER. Those of you who have been around the committee before know that I like to take advantage of my freshman status and claim ignorance on a lot of things.

Mr. TOWNS. Only this year. [Laughter.]

Mr. SNOWBARGER. I know. I know. Like I said before, I'm going to take advantage of it.

I am not so sure we are concerned, necessarily, about Federal funds running out, but it seems to me that there is a need to expand this to other areas and, rather than expand the program as a whole, I would think there would be a desire to establish programs in certain geographic areas and then move on to continue expanding the program nationwide.

Is that the course this is taking? Do we find any of the programs that are anywhere near self-sustaining at this point?

Dr. NORA. Well, our intent is to expand the area into approximately 30 other geographic areas, which would address the criteria that have been identified. In addition, those communities must have one-and-a-half times the national average of infant mortality rates to be eligible.

We anticipate that many of the current existing Healthy Start sites would serve as mentors to assist the new sites in using the kinds of interventions that have been successful.

Mr. SNOWBARGER. I guess the question still is: is anybody coming close to sustainability at this point? What steps have been taken in that direction with any of the programs?

Dr. NORA. I would like to ask Dr. McCann to provide more detail on the sustainability.

Mr. SNOWBARGER. That would be fine.

Dr. MCCANN. I guess as a result of the conference that Dr. Nora mentioned, as well as many of the efforts that are going on locally, there are several of the Healthy Start Programs which have been able to find other funding for the currently funded interventions.

As a result, when we are starting this next phase which we are calling replication, and asking these current grantees to mentor, we

have given them the option of applying for whatever model they wish to mentor, so that those that they have found other funding for they would not be coming in to ask requests for Federal funding.

In that way, we feel that they will be able to sustain many of the existing interventions and models that are currently going on, as well as getting support from us to help them with those that they have not currently found funding for.

Mr. SNOWBARGER. So all of the programs that we currently have in place will continue to receive funding?

Dr. MCCANN. Some funding.

Mr. SNOWBARGER. Some funding.

Dr. MCCANN. But not to the level that it will fund all of the interventions that they currently have supported.

Mr. SNOWBARGER. OK. I'm not sure who to address this question to, but one of the questions that came up as I was listening to all of you speak is trying to get a handle on how infant mortality, low birth weight, et cetera—it seems like it has been going down nationwide.

Do we have some comparison between how programs in these cities have fared versus the nationwide averages, as they have gone down?

Dr. NORA. We have some results from the local evaluations that would give us some information on that. Dr. McCann, do you have the details?

Dr. MCCANN. Yes. We have trends that we have been following among all of our grantees, in terms of what their infant mortality rates are, but we are not attributing those infant mortality rate drops entirely to the Healthy Start Program, because we plan to wait for the outcomes of the national evaluation to really point that out to us in a much more technical manner.

However, through the local evaluations, many of our grantees are reporting outcomes which suggest that they have increasing enrollment in the first trimester, that they are seeing more women during their pregnancy for prenatal care, that low birth weight seems to be declining in many of the sites and, you know, they have identified which clients have received case management or outreach, and those clients whom have been case-managed have reduced low birth weight rates.

So we are beginning to start to see some declining numbers within the specific population that is affected through the Healthy Start Program, but we cannot report that the decreases are entirely due to the Healthy Start Program right now.

Mr. SNOWBARGER. You don't have any basis for saying that the reductions are greater where the programs are in place than they would be nationwide?

Dr. MCCANN. We can't say that, no.

Mr. SNOWBARGER. Dr. Marks, do you have any basis for answering that question?

Dr. MARKS. No. Really, the evaluation being done by Mathematica will allow that to be looked at more thoroughly, in that, in many of the cities, the Healthy Start has selected certain areas of the cities so, overall city statistics might not adequately reflect what is going on in the Healthy Start areas. But the data

that we have from Vital Statistics is being made available for the evaluation, as they need it.

Mr. SNOWBARGER. If I can follow through on one question, that has to do with the statistical analysis here by Mathematica, apparently they were brought on board in 1993. I understand that this is going to be a 5-year study and we'll study the first full implementation here.

Is there any provision, though, in their contract or in your arrangements with them, for interim reports, so that we have some preliminary findings before the end of 1998? If I understand this correctly, we're talking about this program ending, in theory, in September 1997, and it's going to be a full year, a year and 3 months later, before we can find out whether or not the program has been successful.

Dr. NORA. Well, it's certainly true that the national evaluation will not be available until 1998, but I think there is some preliminary evidence in the local evaluations that are showing changes in the communities where these programs are located. I think you will hear about some of those from the next panel.

Mr. SNOWBARGER. All right.

Dr. MCCANN. In addition, there are reports that are being released that have begun earlier.

As Dr. Nora reported, there are not only outcome portions for the national evaluation, but there is also process analysis going on that some of these reports are being prepared at present, they are undergoing the process that is set in place for review by the grantees and other professionals prior to being released. So some reports are available.

We also have what we refer to as special reports that have been completed. One has been done on the outreach workers in Healthy Start; another has been done on the adolescent services in Healthy Start. Those reports are out and available at this point in time.

Mr. SNOWBARGER. Thank you. Mr. Towns.

Mr. TOWNS. Thank you very much. Let me make certain I'm hearing you right.

In your testimony, you indicated in Pittsburgh the rate of infant deaths for pregnant women receiving case management and home visiting is 7.8 per 1,000 birth rate, 50 percent lower than the rate of 15.6 for women not participating in the Healthy Start Program, but also living in the housing development.

Now, what do you mean by that?

Dr. MCCANN. Well, what you're reading are data that are reported by the grantees in their applications that they present to us on an annual basis, which really provides an opportunity for us to monitor the progress of the project.

There are other kinds of interventions going on in each of the Healthy Start communities, other than the Healthy Start interventions.

By looking at comparisonsites, which will be part of the contract with Mathematica, we would be able to tell more directly exactly what impact the Healthy Start Program has had on these communities, and that's the part of the evaluation that we are awaiting.

But, in the meantime, the grantees have taken a very close look at their specific interventions, such as the one that you're referring

to in Pittsburgh, where they have taken a look at their case managed population and just taken a look at what's going on with infant mortality and low birth weight.

Mr. TOWNS. So, in other words—I mean, let me just make sure I fully understand—you say there are reasons for me to be excited about this?

Dr. MCCANN. There are reasons for you to be excited about it. We are very happy about it.

Mr. TOWNS. OK.

Dr. MCCANN. We think that it's pointing in the right direction, and we are awaiting the comparisonsite evaluation by Mathematica to support what we've seen preliminarily.

Mr. TOWNS. OK. That's very clear. Let me just sort of ask a general question to, I guess, all of you. If we were to eliminate local community-based programs, like Healthy Start, what would be the impact of the underserved communities currently benefiting from the program? What would happen? We've seen enough to be able to make a general assessment, haven't we?

Dr. NORA. Well, we feel that Healthy Start was the glue that pulls together the services that are existing within the community, and we feel that it has strengthened the foundation that is there and has made the community more aware of what needs to be done; so we feel that it is important to be able to bring this about.

In many of the projects, for example, there have been efforts to integrate the services from across agencies, such as WIC, the Infant Feeding Program, enrolling women in Medicaid, and the outreach services that you mentioned earlier.

So it's an effort to pull all of these together to address the problems of the entire woman and her pregnancy and the baby.

Mr. TOWNS. Thank you. Dr. Marks, I think you mentioned in terms of working with the community.

Dr. MARKS. Yes.

Mr. TOWNS. I think I heard you say that. What do you mean by that, when you say working with the community?

Dr. MARKS. Sure. We've used the community approach in a lot of areas, and not just in the infant mortality area, but we have the projects that I mentioned in Harlem and in Los Angeles.

One of the issues in working with the community is find out how—as I mentioned before, we found that Medicaid women in Oklahoma got care as early as they wanted. We need to find out what are the sort of, the local issues that have people not getting the care when it is available to them, what are the issues that they see are important as barriers to care, whether it's transportation, whether it's being encouraged and helped to change behaviors that contribute to poor infant outcomes.

What we are doing in ours is to spend a lot of time with focus groups and working with the community to see how they frame the issues of infant and mothers' health, and then whether we can, in fact, by what we learn by talking with them, modify the systems that exist in their communities so that they are more responsive and more specific for the kinds of concerns that they have.

In those discussions, we spend time saying what we know about the medical risks, what we know about the behavioral risks, so that they understand what we do know, but especially in the area

of the gap between African-Americans and white Americans infant health.

Whenever we do that analysis on just the medical factors, we can explain some of that gap, but not all of it, so we have to look for other interventions, and we think that some of that may come from the community and what they perceive as the issues and problems that they have to deal with.

Mr. TOWNS. Thank you very much, Mr. Chairman. I yield back.

Mr. SNOWBARGER. Thank you. Let me just try to close up this panel with some questions about coordination between the agencies that we have here.

We've heard research telling us new ways to deal with problems, to what extent is Healthy Start, you know, monitoring those changes and implementing those changes within their communities, to what extent does the CDC monitor what Healthy Start may be doing.

Is there any coordination or interfocus here between the groups about how we're dealing with these infant problems in high-risk areas, I guess is the best way to put it?

Dr. NORA. I think one very clear example is Sudden Infant Death Syndrome and the "Back-to-Sleep" campaign. All of the Federal agencies participated in this, and we continue to work together on this campaign and share expenses; and I think it's made a lot of difference as far as infants dying with sudden infant death.

Maybe Dr. Alexander would like to add something else.

Dr. ALEXANDER. Yes, I think that the SIDS experience is an excellent example of agencies working together. The epidemiologic findings clearly indicated that sleep position was associated with Sudden Infant Death Syndrome and that back was safer. All of us worked together in putting together the "Back-to-Sleep" campaign.

In addition, the Centers for Disease Control worked together with us in the research community to develop a protocol for a death scene evaluation that helps in establishing the cause, that SIDS is, in fact, the attributable cause of death or not.

All of us have worked cooperatively in developing materials and getting the message out, and this message has been picked up, it is my understanding, in the Healthy Start sites and implemented very effectively in those communities where Healthy Start exists.

Mr. SNOWBARGER. Thank you. Are there any more questions?

[No response.]

Mr. SNOWBARGER. If not, I thank the panel for coming this morning and for presenting their testimony. And just to assure, I can't remember who it was that asked, but all of your written testimony will be included in the record. So thank you.

I think I would like to call the next panel forward: Thomas Coyle, Melanie Williams, Barbara Hatcher, and Juan Molina Crespo as well, by the way, as Dr. Guyer and Robert Pugh.

I apologize for letting you sit down first. We need to swear you in, so if you could, all stand and raise your hand.

[Witnesses sworn.]

Mr. SNOWBARGER. I would like to recognize one of our colleagues, Representative Cummings, at this time.

Mr. CUMMINGS. Thank you very much, Mr. Chairman and our ranking member. Thank you.

Mr. Chairman, I would like to introduce two esteemed guests from my congressional district of Baltimore, and make some brief remarks regarding the Healthy Start Program.

Historically, the 7th Congressional District of Baltimore has experienced an exceedingly high rate of infant mortality. Many high-risk areas in the city had twice the national average of infant deaths. However, with the implementation of the Healthy Start Program in 1993, Baltimore has drastically reduced the number of babies born with low birth weights and severely reduced the number of infant mortalities.

The Healthy Start staff, in conjunction with the Mayor's Office and the surrounding community, are committed to ensuring that all babies have a strong and healthy beginning, by providing important prenatal care to high-risk mothers who need it most.

Our city's infant mortality rate has dropped 31 percent since the implementation of the Healthy Start Program. In the two neighborhoods where Baltimore's Healthy Start Centers are located, the infant mortality rate has been slashed by a staggering 61 percent. The Baltimore example is truly a success story.

We have targeted the program services to the poorest areas of the city, which are at the highest risk. The staff is mostly comprised of community residents who have been hired and trained through the program, thereby providing important employment opportunities to the community.

I might add, Mr. Chairman and members of the committee, I have had an opportunity to meet many of those people who work in the program. They are very dedicated. They give much of their time and effort, going beyond the normal 8-hour day, to assist people in lifting themselves up and lifting their children up.

Mr. Chairman, this program is working, and I decry any attempt to reduce its funding level.

I would now like to recognize Dr. Bernard Guyer and Mr. Thomas Coyle. I am very pleased that they are able to testify as to the merits of the Healthy Start Program in Baltimore.

Dr. Guyer is chair of the Maryland Commission on Infant Mortality Prevention, and professor and chair of the Department of Maternal and Child Health of the Johns Hopkins University School of Public Health and Hygiene.

Mr. Coyle is currently the assistant commissioner for maternal and infant care and special projects, of the Baltimore City Health Department. He is responsible for all maternal and infant programs managed by the Baltimore City Health Department. He also serves as project director for the Federal Healthy Start Program.

I am so proud of the work that these gentlemen do on behalf of so many. Mr. Chairman, I thank you for the opportunity to be here with them and I look forward to hearing their testimony.

Mr. SNOWBARGER. Thank you, Representative Cummings. And, with that, Mr. Coyle, we will turn the microphone over to you.

STATEMENTS OF THOMAS COYLE, ASSISTANT COMMISSIONER, BALTIMORE CITY HEALTH DEPARTMENT, MATERNAL AND INFANT CARE AND SPECIAL PROJECTS, ACCOMPANIED BY BERNARD GUYER, CHAIRMAN, DEPARTMENT OF MATERNAL AND CHILD HEALTH, JOHNS HOPKINS SCHOOL OF HYGIENE AND PUBLIC HEALTH; MELANIE WILLIAMS, PROJECT DIRECTOR, MISSISSIPPI DELTA FUTURES HEALTHY START, ACCOMPANIED BY ROBERT PUGH, EXECUTIVE DIRECTOR MISSISSIPPI PRIMARY HEALTH CARE ASSOCIATION; BARBARA HATCHER, PROJECT DIRECTOR, DISTRICT OF COLUMBIA HEALTHY START PROGRAM; AND JUAN MOLINA CRESPO, PROJECT DIRECTOR, CLEVELAND DEPARTMENT OF PUBLIC HEALTH

Mr. COYLE. Thank you, Congressman, and good morning, Mr. Vice Chairman and members of the subcommittee.

We welcome the opportunity to be here today to testify about the National Healthy Start Program. I have submitted my testimony earlier this week, and we will try to summarize that today.

I am joined here on my left by Dr. Bernard Guyer, who Congressman Cummings has already introduced. I had listed out all of Dr. Guyer's titles and several other things, but I'm going to have to pass on this, since the Congressman has already done that.

Because our time is limited, and because the focus of this hearing is on evaluation, and because Baltimore City has dramatic results in terms of the local evaluation, I am asking Dr. Guyer, whose department has overseen this evaluation for over 6 years, to do most of the testimony.

Bernie.

[The prepared statement of Mr. Coyle follows:]

TESTIMONY
Before the Subcommittee on Human Resources
Thomas P. Coyle
Assistant Commissioner
Baltimore City Health Department
Maternal and Infant Care and Special Projects

Good morning Representative Shays and other members of the Committee. Thank you for inviting me and Dr. Bernard Guyer, Chairman of the Department of Maternal and Child Health, Johns Hopkins School of Hygiene and Public Health, to testify today. Also with us, is Mr. Joseph Jones, the Director of our Healthy Start Men's Services Program.

During the last past few years, we have had many visitors come to see our Baltimore City Healthy Start Program. Invariably, they leave the visit with the conviction that they have seen a comprehensive, coordinated, community-based program that truly serves the needs of our poorest citizens. This is not by accident. Our Healthy Start staff works hard at making this program effective.

The reason so many visitors are impressed with what they witness at

Baltimore City Healthy Start is due to the foresight and wisdom of the federal government. The Department of Health and Human Services (HHS) has created a program that allows communities the flexibility to address all of the needs of the family in a comprehensive manner, and, has provided the resources to do so.

In addition, HHS staff has required each of the Healthy Start sites to undertake a local evaluation of its efforts. These local evaluations, in conjunction with the national evaluation being conducted by Mathamatica, Inc., will provide valuable insights into the overall effectiveness of the Healthy Start Program. However, because the results of the national evaluation are still two years away, the local evaluations take on more importance in the short run.

In the past, infant mortality and low birth weight have been viewed primarily as medical issues. What Healthy Start has demonstrated is that, in our poorest inner city neighborhoods -- which have the highest incidences of infant mortality and low birth weight in the United States --

these problems are not solely medical, but are rooted in a complex set of health, social, and economic issues. And, in my opinion, the devastating consequences of infant mortality and low birth weight will only be solved through the broad, comprehensive approach that Healthy Start Programs around the country represent. The traditional, categorical approach of federal programs will not get the job done.

Another unique feature of Healthy Start is that it is outcome driven. This means that we are directly accountable to all of you in this room for actually reducing the incidence of infant mortality in our poorest communities. In fact, the federal government established one of the most ambitious goals ever for a new initiative, that is, reduce infant mortality by 50% over a five-year period. I don't need to tell members of this committee how ambitious that outcome goal is! Would that other federal initiatives set similar goals of reducing the incidences of child abuse, teen pregnancy, and substance abuse in our major cities.

The really good news is that the Baltimore City Healthy Start

Program -- and other Healthy Start Programs across the country -- are well positioned to meet this objective. Prior to the initiation of Healthy Start in Baltimore, the infant mortality rate in our poorest communities was 20.1 -- meaning that a little over 20 infants out of a 1,000 died before their first birthday. The infant mortality rate now is 13.0, representing a 35 percent reduction.

But, there is even better news. The objective of Healthy Start is not only to keep babies alive, it is also to decrease the number of low birth weight and very low birth weight babies. I am delighted to tell you that the Baltimore City Healthy Start Program has very strong data indicating significant reductions in the rates of low birth weight, very low birth weight, and preterm deliveries among our clients[1]. These data have been confirmed by our evaluation team at the Johns Hopkins School of Hygiene and Public Health.

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[1]LBW:<2500g or 5.5 lbs.
LBW:<1500g or 3.3 lbs.
LBW:< 37 weeks gestation

We have compared the birth outcomes between the pregnant enrolled women in our program with comparable women who did not receive Healthy Start services during their pregnancy. The rates of low birth weight births, and preterm delivery were significantly lower among the women who participated in Neighborhood Healthy Start Center services while pregnant. Women who did not participate in Healthy Start while pregnant were more than twice as likely to experience a low birth weight birth and preterm delivery. More significantly, women who did not participate in Healthy Start while pregnant were also three and a half times more likely to experience a very low birth weight birth. Said differently, the rate of very low birth weight births among Healthy Start participants was 67% lower than the rate for those women who did not receive healthy Start case management and support services during their pregnancy.

We did these same comparisons for a subset of our clients -- the approximately 35% of our clients who are substance abusers -- obviously our highest risk mothers. The same results of improved rates of low birth

weight births, very low birth weight births, and preterm labor were found when comparing these women with a comparable group of substance abusing women who did not participate in Healthy Start while pregnant.

Low birth weight babies may live beyong their first birthday, but may have physical and mental disabilities for a lifetime, with the likelihood of great suffering for themselves and their families. The human cost -- in terms of suffering and loss of quality of life -- are very real and difficult to put a price tag on. We know, however, the cost that the Federal Government, the State of Maryland and our medical systems incur from the births of these very small infants. In Baltimore City, where the greatest number of low birth weight and very low birth weight babies are African American, the average hospital charge for a very low birth weight African American Medicaid birth in 1996 was $63,089. Applying the reductions in very low birth weight births achieved by Healthy Start, we estimate that we can save a Medicaid Managed Care Organization with 1,200 annual births between $1.1 and $1.8 million per year just in infant hospitalization

costs. Additional costs savings would result from lower average length of stay for the mother at time of delivery; reduced outpatient, ancillary and treatment costs; reduced hospital readmissions, and, certainly, there would be costs savings in regard to special education the child would probably need as well.

One of the major reasons for these impressive results is the Neighborhood Healthy Start Center staff, the people who work most closely with our pregnant clients to effect this change, are community residents themselves. We have made a special effort to "deprofessionalize" many of our outreach and homevisiting services by hiring residents from the neighborhood to carry our this work. The vast majority of these residents are women who are or were on welfare. Second, by definition, maternal and child health programs have left out the fathers -- with devastating consequences. Healthy Start has created a special fathers' initiative called the Men's Services Program. This program is directed by Mr. Joseph Jones, who was introduced earlier. Mr. Jones and his staff take

the highest-risk dads and transform them into nurturing parents through an intensive support and case management process.

One of the most impressive aspects of our Men's Services program is it's emphasis on providing real employment opportunities for our male participants. We have integrated a lead abatement grant from the Department of Housing and Urban Development into the Men's Services program and are able to guarantee employment in the construction field for those men who are committed to turning their lives around.

Finally, a preliminary cost-benefit analysis of the Men's Services program has shown that the program has already paid for itself in reduced incarceration costs alone. Moreover, it has dramatically benefited the young fathers and their families in East and West Baltimore in terms of expected future wages, given the program's emphasis of linking the male participants to livable wage employment.

In short, Healthy Start is a unique and wise investment. I hope it continues.

Mr. SNOWBARGER. Dr. Guyer.

Dr. GUYER. Thank you, Mr. Vice Chairman. I am pleased to be asked to come here today by Tom Coyle and the Baltimore Healthy Start Project. This is a wonderful collaboration between faculty at Johns Hopkins and our colleagues in the Baltimore City Health Department.

I have a handout that I put on the table with some of these earlier results, for the committee. Let me just summarize briefly the findings.

This committee is obviously very well-informed on issues of infant mortality and low birth weight, and I won't go into any of the background to that. What I want to provide you with is some early evidence of the evaluation from the Baltimore Healthy Start Project.

These data come from more than 600 women who participated in the Baltimore Healthy Start Project during their pregnancies, and they are compared to more than 500 women who became known to the Baltimore Healthy Start Project, but only after they delivered their babies.

In summary, the data show that the women who did not have the Healthy Start services prenatally were more than twice as likely to have a low birth weight baby, more than three times as likely to have a very low birth weight baby, and more than twice as likely to have a pre-term delivery.

Clearly, there is something going on with exposure to the Healthy Start interventions during the pregnancy that gives these women advantages over those who get to Healthy Start after the baby is born.

The faculty at Johns Hopkins has been taking a careful look at this data, trying to dissect it and understand what factors account for these kinds of differences. But one thing that they have done immediately was to look at women who are substance abusers in both groups—those who get Healthy Start services before the baby is born, during pregnancy, and those who only become available afterwards. These findings hold up even among women who are substance abusers.

I do not have hard answers for you on the causes and the difference that Healthy Start makes, but I want to point you in a particular direction that I think is important from the Baltimore experience. Now, we know that low birth weight is an important precursor of infant mortality.

It is influenced by a whole set of medical factors, but it is also, as often is said, it is a social problem, and the Healthy Start intervention in Baltimore, in particular, provides social support, housing, job preparation, education, case management to these women, and it may be that what we are seeing among the Baltimore Healthy Start participants is the added benefit of all those intensive services in reducing low birth weight.

We have had very few studies in the past that have made this level of intensive investment in these high-risk pregnancies to try to see whether they could have these kinds of effects on the difficult outcomes like very low birth weight and low birth weight.

There are lots more analysis that need to be done with these data to be able to come up with definitive findings, but the early findings are very positive. Thank you.

[The prepared statement of Dr. Guyer follows:]

Preliminary Outcome Evaluation Results
Baltimore City Healthy Start
February 7, 1997

Background

The purpose of these preliminary analyses was to examine the effect of participation in the services at the Neighborhood Healthy Start Center on pregnancy outcome. The hypothesis was that program participants would have lower rates of inadequate pregnancy weight gain as well as lower rates of inadequate prenatal care utilization as compared with rates in a comparison group of non-participants. In addition, it was hypothesized the program participants would have lower rates of low birth weight, very low birth weight, and preterm delivery.

Methods

Data were drawn from the client database for the Neighborhood Healthy Start centers and included all cases recorded in the database between May 1993 and June 1996. These data included 1348 clients who were enrolled in center services during their pregnancy during this time period. Of these clients, 898 of them had given birth as of June 30, 1996, and of these, 611 cases had been linked to birth certificate data. These 611 cases form the sample of treatment cases for these analysis.

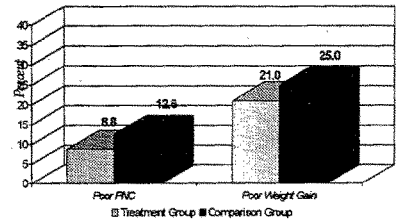
Although a number of comparison groups will be considered in future analyses, these analyses focus on a comparison group of postpartum enrollees in the Neighborhood Healthy Start centers. Between May 1993 and June 1996, 886 clients were enrolled in center services during the postpartum period. Of these, 545 cases were linked to birth certificate data.

The treatment and comparison groups were compared in terms of the following outcome variables: adequacy of prenatal care (as defined by the Kessner index), adequacy of pregnancy weight gain (≥20 pounds), low birth weight, very low birth weight, and preterm delivery.

Results

The percentage of women who were classified as having inadequate prenatal care utilization and/or inadequate pregnancy weight gain for the treatment and comparison groups is displayed in Figure 1 below.

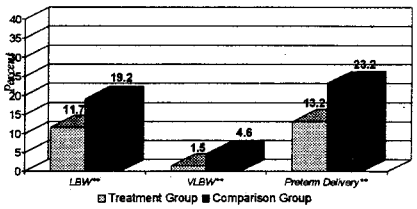
Figure 1. The Effect of Healthy Start Participation: Intermediate Outcomes



As can be seen in the Figure, although the rate of poor prenatal care utilization and inadequate pregnancy weight gain was lower in the treatment group, the differences were not statistically significant.

The treatment and comparison groups were also compared in terms of rates of low birth weight, very low birth weight and preterm delivery. These rates are displayed in Figure 2.

Figure 2. The Effect of Healthy Start Participation on Pregnancy Outcome



**p<.01

The rate of low birth weight births, very low birth weight births, and preterm delivery were significantly lower among the treatment women who participated in Neighborhood Healthy Start Center (NHSC) services during their pregnancy. Although they support the positive effects of NHSC services, these results should be interpreted with caution. Because women were not assigned at random to receive NHSC services, it is possible that the differences in outcome are the result of other differences between the two groups. For example, women in the comparison group, those who enrolled postpartum, may be a higher risk group in general compared with the treatment group. This higher risk could explain the higher rates of poor pregnancy outcome observed in this group. To examine this issue further, the two groups were compared in terms of a variety of demographic and pregnancy-related risk factors. These comparisons are displayed in Table 1. The women in the comparison group were higher risk in terms of a variety of risk factors. They were more likely to be substance users and less likely to have ever been employed. In addition, they were more likely to have had a short interpregnancy interval and more likely to have higher parity. Finally, there was a trend towards a higher rate of first trimester prenatal care initiation among treatment women. Such a trend could indicate that women in the treatment group were more motivated for wellness in general, and this difference could explain the improved pregnancy outcomes in this group.

Table 1. Demographic Differences: Treatment vs. Comparison Women

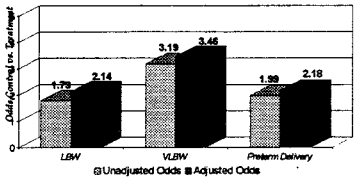
	Treatment	Comparison
	%	%
Age 17 or less**	25.8	20.3
< 12 years education	60.5	59.4
Substance users*	33.0	39.7
Ever employed*	65.8	60.6
Below 100% poverty	98.5	98.6
< 18 mos since last birth**	2.9	6.9
Parity 3 or more**	17.8	24.3
Initiated PNC 1st trimester*	76.7	70.2

*p<.10 *p<.05 **p<.01

In order to control for these differences, a series of logistic regressions were conducted for each of the outcomes of low birth weight, very low birth weight, and preterm delivery. For each logistic regression model, a binary variable

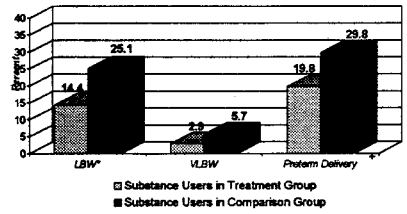
indicating group membership (comparison vs. treatment) was entered first. Next, maternal age, substance use, employment status, interpregnancy interval, parity, and prenatal care initiation were entered into the model to control for group differences. The results of these analyses are shown in Figure 3. Women in the comparison group were more than twice as likely as the treatment group to experience a low birth weight birth and/or preterm delivery, even after adjusting for differences in risk status between the two groups. Women in the comparison group were almost 3.8 times as likely to experience a very low birth weight birth.

Figure 3. The Effect of Healthy Start Participation on Pregnancy Outcome



A related evaluation question is whether or not these differences would also be observed among higher risk subgroups of NHSC clients. To answer this question, the comparison was restricted to the subsample of treatment and comparison clients who were identified as substance users. The comparison between these two groups in terms of low birth weight, very low birth weight, and preterm delivery rates is displayed in Figure 4. Substance users in the treatment group were significantly less likely to experience a low birth weight birth and/or a preterm delivery. Although the difference between the treatment and comparison groups in terms of very low birth weight rates was not significant, this may be the result of the small sample sizes for this subgroup analysis. Because of the small sample sizes, adjusted analyses for substance users will have to wait until additional data are available.

Figure 4. The Effect of Healthy Start Participation on Pregnancy Outcome: Substance Users



*p<.10 **p<.05

Additional analyses

As we presented these early results to various audiences we received important feedback that helps us to further examine whether the encouraging results are valid. Various audiences have raised three important questions that we went on to explore to determine whether the results held after addressing specific issues. The questions, analyses conducted to explore the questions, and the impact upon the results presented above are briefly discussed in this section.

1. Is the prenatal group better off because there are large numbers of women who enrolled late in pregnancy (i.e., too late to experience a VLBW or preterm delivery birth?) To answer this question we undertook analyses that compared postpartum enrollees to a subset of the prenatal enrollees who enrolled early (<32 weeks gestation). We then compared the two groups on the primary outcomes (prenatal care, LBW, VLBW and preterm delivery). If the late enrollees (>=32 weeks gestation) were biasing the original results toward having good outcomes, this new comparison would show that the "prenatal enrollees who enrolled <32 weeks" would have similar rates of outcomes as the postpartum enrollees. *Results:* Comparison of these two groups indicate that prenatal enrollees >=32 weeks were not biasing the results. The LBW, VLBW, and preterm delivery rates for "prenatal enrollees who enrolled <32 weeks" compared to the postpartum enrollees were 9.2% vs. 19.2%; 0% vs. 4.6%; and 9% vs. 23.2%, respectively. These differences between prenatal and postpartum enrollees were even greater than those presented in Figure 1.

2. Are the differences observed due to other confounding factors that were not presented in Table 1? Although we do not have access to many more confounders at this early point in our data collection and processing we were able to examine differences in the presence of medical risk factors as reported on the birth certificates and the initial interviews (self-report). We found that adjustment for medical risk factors did not change the odds ratios presented in Figure 3.

3. There was interest in whether our choice of inclusion criteria in our treatment and comparison groups may have biased the results. Specifically, the treatment group as presented in Figures 1-4 were based upon women who were *recruited and enrolled* prenataly. Women who were recruited prenatally but enrolled postpartum were excluded from our original prenatal enrollee group. Exclusion of these women may have biased the results such that a high proportion of preterm or VLBW births were excluded. We ran the analyses presented in Figure 1 again including the prenatal recruited but enrolled postpartum women along with the prenatal enrolled and recruited (the original treatment sample). Results were similar to those presented in Figure 1. That is, exclusion of this group was not responsible for the observed differences.

Another exclusion criteria was of interest to some audiences: those women who were recruited but never enrolled. Women who are recruited but not enrolled may be higher risk than women who are recruited and enrolled in HS. Although this applies to both the prenatal and postpartum groups, there is concern that their exclusion may decrease differences between prenatal and postpartum enrollees. Moreover, including these women in the two comparison samples are consistent with the "intention to treat" models of evaluation. We re-ran the analyses in Figure 1 by adding into the prenatal and postpartum groups the women who were recruited but not enrolled. Because of low rates of birth certificate matching to the group who was recruited but not enrolled, the overall sample sizes for each group did not increase substantially. The results of this analysis indicates that the addition of the non-enrolled women did not significantly change the results presented in Figure 1.

The exploration of the three issues presented in this section did not change our original results presented in Figures 1-3.

Conclusions and Next Steps

The results of these preliminary analyses are encouraging. Women who participate during their pregnancy in the services provided by the NHSC appear to have lower rates of low birth weight, very low birth weight, and preterm delivery. However, further analyses need to be conducted to determine the robustness of this relationship. Although the analyses reported here controlled for a number of demographic and pregnancy-related differences between the treatment and comparison groups and we ran additional analyses to explore specific questions regarding the potential biases, the comparability of these two groups needs to be explored even further. We are also in the process of re-matching the birth certificate data to the participation data so that we can do the comparisons on a 100% or near 100% sample of prenatal and postpartum enrollees. In addition, similar comparisons in pregnancy outcomes need to be made with other appropriate

comparison groups. These analyses are ongoing. In addition, future analyses will explore more fully potential mechanisms by which NHSC services may be translated into improved pregnancy outcome. For example, the relation between service intensity and outcome will be explored as well as the effect of NHSC services on health behaviors, knowledge, and attitudes. Finally, the moderating affect of the context of the program will be examined by integrating community factors into the analyses.

Mr. SNOWBARGER. Thank you, Dr. Guyer. Mr. Coyle, does that complete your testimony?

Mr. COYLE. Yes.

Mr. SNOWBARGER. Thank you. With that, I would like to call on another of our colleagues, Representative Thompson, at this time.

Mr. THOMPSON. Thank you, Mr. Chairman, and other members of this subcommittee. I am happy to come and introduce someone to you who is project director for our Delta Futures Healthy Start Initiative in Mississippi and one of the few rural projects we have across the country. But my support for this project is 100 percent. They operate presently in the 2d District of Mississippi, which for the record is the State with the highest infant-mortality rate. It ranks No. 1.

And I am honored to introduce Ms. Melanie Williams, the distinguished project director of the Delta Futures Healthy Start Initiative. Ms. Williams has done outstanding work administering this program in Mississippi and is due much credit for its success. A licensed, master-level social worker of 10 years, she has demonstrated extensive leadership and administrative ability through the development and implementation of innovative programs dealing primarily with maternal and child-health issues.

I also again want to say that my experience with this project indicates that it is an excellent project, Mr. Chairman, and I hope from the testimony that you will receive from Ms. Williams and others here you will see that it is well worth the investment.

And, once again, I would like to thank the committee for allowing me to introduce Ms. Williams, and I present Ms. Williams to you at this point.

Mr. SNOWBARGER. Thank you, Representative Thompson. Ms. Williams.

Ms. WILLIAMS. Mr. Vice Chairman and members of the subcommittee, thank you today for the opportunity to address your organization about Delta Futures, and I bring you greetings from the Mississippi Delta. Delta Futures was funded in 1994 as one of the seven special projects added to the Healthy Start Initiative. We began with an infant mortality rate of 15.5 percent, which was a 3-year average over 1998 to 1990.

The project was formed around two primary goals: one, to reduce the infant mortality rate by 20 percent; and the second, to establish community-based groups and organizations that could provide input and guidance into program planning and implementation.

We attacked the infant mortality rate problem by developing a number of strategies that we have implemented throughout our eight-county project area. We have worked to develop programs that enhance existing clinical services by providing prenatal care providers to areas where those types of services did not exist. We worked to reduce risk for pregnant and parenting women by promoting healthy deliveries and enhancing parenting skills.

We have also worked to provide facilitative services that help to provide better access to prenatal care services by providing transportation and child care for women who are trying to access prenatal care services.

We have provided a great deal of training and education that helps to raise public awareness. We have developed public service

announcements, brochures, and videotapes that are made available to a wide variety of community groups and organizations throughout the project area.

A lot of our efforts have focused on programs that target adolescents and the gateway problem of teen pregnancy. We have worked to develop efforts that boost self-esteem among young people and encourage them to delay sexual activity until they are ready for that responsibility.

Our infant mortality rate has dropped 10.6 percent in 1995, which was a decline of 30 percent. I am not certain that we can target Delta Futures with that full responsibility for that decline. Our project has only been in existence for 2 years, and many of our programming efforts focus on more long-term outcomes.

The second component that we worked on was the development of community-based groups and organizations that can help to provide input into program planning and implementation; this has been the most challenging and rewarding component of our project. We believe that communities best know how to solve their own problems, and it is simply our job to help them determine what their needs might be and to help them craft strategies that they think will work in their communities.

This has not been without its share of conflict. Sometimes communities tell us things that we do not necessarily want to hear, or want to implement strategies that we know cannot work or cannot be done. They may come to the table with their own agenda and their own ideas that may not necessarily relate to infant mortality reduction.

We have worked very hard to increase the capacity of our communities and to build infrastructure and to encourage collaboration among existing groups and organizations. We have been successful in developing an RFP process that has put over $840,000 back into local community-based organizations for the development of infant mortality reduction strategies.

We have worked to provide training in leadership development, consortium building and maintenance, and conflict resolution to these local groups and organizations.

The Division of Healthy Start has been very helpful to Delta Futures with implementation of this initiative. Through site visits and technical assistance during critical periods of our implementation, the Division has demonstrated a commitment to fostering successful achievement of project goals.

It should be noted, however, that while expansion of infant mortality prevention initiatives to new communities is important, it is equally important to assist currently funded Healthy Start projects to sustain and continue effective services as well.

Healthy Start should balance use of available funding for both the maintenance of service levels for current projects and seeding of new projects. Delta Futures is a unique Healthy Start initiative, inasmuch as it is only one of three rural projects. Our experience has been that expectations or objectives oftentimes are somewhat ambitious for rural communities.

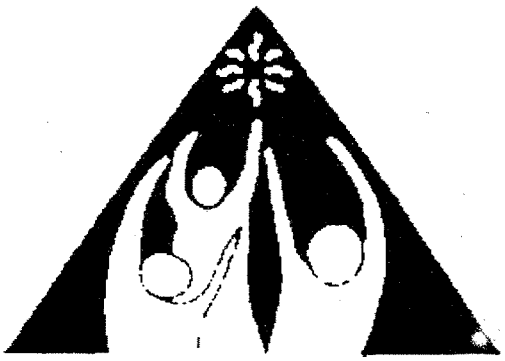
Many systems and organizations that are readily available in urban areas often do not exist in rural communities. Much of Delta Futures' efforts have focused on building infrastructure and

strengthening communities' capacities to meet the challenges of dealing with these complex issues. Because of these challenges, our progress oftentimes seems slow or fraught with conflict.

We are strengthened, however, by the ever increasing commitment, enthusiasm, and willingness of the communities we serve to reduce infant mortality, and as a result of our efforts we believe that not only will we have successfully reduced infant mortality in the Delta, but we will also improve communities' ability to address many other issues that affect the quality of life for its residents.

[The prepared statement of Ms. Williams follows:]

DELTA FUTURES
MS Healthy Start Initiative



Report Submitted to:

Sub-Committee on Human Resources and Intergovernmental Relations

Congressman Christopher Shays
Chairperson

DELTA FUTURES
A HEALTHY START INITIATIVE

BACKGROUND

The Delta Futures Healthy Start Initiative seeks to ameliorate the tragic problem of high infant mortality rates in eight counties in the Mississippi Delta. Funded in 1994 as one of the seven special projects added to the Healthy Start Initiative, the project area's infant mortality rate of 15.5% infant deaths per 1,000 live births, a three year average from 1988-1990, was well above the state and national averages. Charts depicting the service area and relevant infant mortality and teen pregnancy statistics are enclosed in Attachment A. These charts provide a reflection of the complex range of sociodemographic data and history of the area.

The area encompasses 5,109 square miles in rural northwest Mississippi. Counties in the service area include Bolivar, Holmes, Humphreys, Leflore, Quitman, Sunflower, Tallahatchie, and Washington. Portions of all of the counties in the service area are included in an Empowerment Zone or Enterprise Community. According to the 1990 U.S. Census, the total population for these eight counties was 239,456. Of this number, 150,204 were African American, and 89,252 were White. Also according to the 1990 U.S. Census, the percentage of persons, 25 years and older who have at least a high school education averaged 50.7%, which is below the statewide average of 64.3%.

A variety of state and community-based service programs are attempting to address some aspect of the infant mortality problem. However, the major needs for this area include the need for: better coordination and collaboration of federal, state, and local services; greater expansion of proven intervention measures; greater penetration of existing programs and services down to the community/grassroots level; a more concerted preventive attack on the "gateway" problem of teen pregnancy; greater and more effective community education and information initiatives to prevent negative outcomes; and greater increase in medical access to health and prenatal care, especially among teens and other young parents.

Through the project's grantee, the Mississippi Primary Health Care Association (MPHCA), Delta Futures' efforts have focused on two primary goals:

1. The expansion of community based groups to provide input and guidance in policy development and program planning that will facilitate better communication and collaboration among existing agencies and organizations

2. The reduction of the infant mortality rate in the rural project area by 20% over the project's three year implementation period.

The project also seeks to impact the infant mortality rates through the reduction of teen pregnancy. Since the project's inception, the infant mortality rate has dropped to 10.6 for 1995, a decline of 30%. Data, however, is inconclusive as to what impact Delta Futures might have had on this decline. Unfortunately, while this reduction is a significant accomplishment, the rate of teen births in the project area has increased during the same time period; in 1995, 30.8% of births in the project area occurred among teens. Thus, Delta Futures still has much work to do. Delta Futures received funds for operation in Year 01 and Year 02 in the amount of $982,200. Year 03 funds received are $650,000.

ORGANIZATIONAL STRUCTURE

Delta Futures' parent organization, MPHCA, is the statewide trade association that represents a readily accessible network of Federally Qualified Health Centers (FQHCs) with which to work. Four of these FQHCs are located, in whole or in part, within the Delta Futures project area. Delta Futures strives to maximize community based/grassroots input into program planning and implementation. This is facilitated through the project's organizational structure.

The Project Area Council (PAC) serves as the organization's primary governing body. The PAC's membership is comprised of representatives from six local county consortiums, the Public Health Districts Health Officers from District I and III, a representative from the Mississippi Division of Medicaid, a representative from the local Mississippi Department of Human Services, a March of Dimes representative, a Youth representative from the project area, a Consumer representative from the project area, a representative from a Community Health Center in the project area, a representative from the Second Congressional District Office, and a representative from the University of Mississippi Medical Center. The PAC serves as the primary mechanism through which community based input is received. It also provides oversight and advice with regards to program planning and service provision. The PAC is a community based, consumer driven body with the majority of its membership comprised of consumers from the project area. Organizational charts are located in Attachment B

The PAC Executive Committee acts on behalf of the PAC to carry out administrative, personnel, budgetary, and financial responsibilities. The Executive Committee is responsible for the development of policy and programmatic recommendations for consideration and adoption by the full PAC; serves as a liaison for communicating with local, state, and federal agencies, foundations and other organizations; hears and makes recommendations to the PAC concerning grievances and other policy and administrative issues involving the local consortiums; and provides oversight to ensure program quality and fiscal integrity. It is comprised of seven members: the PAC Chairperson, two local consortium representatives, one District Health Officer, the Grantee Executive Director, a Consumer at Large representative to the PAC, and a representative from the March of Dimes.

Local County Consortiums (CC) serve as the "grassroots voice" to the project. Their primary functions include encouraging local citizen input and support of Delta Futures project activities

and efforts; providing resources that facilitate input and participation at the local level; participating in decisions regarding shifts in project direction and allocation/management of project resources; and sharing responsibility for data collection, monitoring and evaluation of project activity. Membership is comprised of representatives from a variety of community groups and organizations that include: consumers, local schools, health care providers, local government, teens, parents, local businesses, law enforcement, clergy, and media representatives. According to the Delta Futures bylaws, the CC Chairperson must be considered a consumer and not a provider of health care services and the Chairperson serves as the local consortium's representative to the PAC.

In regards to the project's management, the project maintains nine staff positions and three offices in the project area. The Central Administrative Office is located in Greenville, Mississippi, with in-kind office space provided by Mississippi Department of Public Health District III. The Project Director, Senior Secretary, Contract Compliance Officer, Health Educator, one Project Coordinator, and Community Relations Coordinator all function from this location. Two field offices are located in the project area. The Field Office located in Marks, Mississippi utilizes in-kind office space provided by the Mississippi Department of Public Health District I. The field office located in Lexington, Mississippi utilizes in-kind office space provided by the Dr. Arenia C. Mallory Community Health Center. Each office is manned by a Project Coordinator and Secretary. These offices help to facilitate the visibility of Delta Futures staff at the local level. A brief description of each staff position is located in Attachment B.

IMPLEMENTATION STRATEGIES

Consortium building and development has been at the heart of Delta Futures implementation strategy. The project is built around the principle of community input and support as essential to the effective implementation of service delivery systems. Consortium building is a complex and intensive process that requires collaboration and cooperation from all segments of the community. The purpose behind consortium development for Delta Futures was to secure a mechanism through which community input could be received regarding service delivery strategies and needs in the local community. The community's perception of what the problems really are is critical to this process and does not always mesh with program management's thinking.

This process is further complicated by issues that are related to community development in rural areas. Training and infrastructure building was a necessary component in bringing all segments of the community together and equipping them with the skills and knowledge necessary to effectively participate in program planning and development. Conflict arose as a natural part of this process. Community participant's lack of understanding of how the process works and inexperience in dealing with programs of this size and scope sometimes led to misunderstandings. We also discovered that participants in this process did not always come to the table with the purpose of working towards infant mortality reduction. The availability of dollars to community based organizations for service provision sparked controversy as to who should receive/administer those funds and what purpose/activity those funds should support. The project

staff and Division of Healthy Start recognized a need for training in conflict resolution and the procurement of mediation services. These services were essential in alleviating and resolving the issues that arose. When possible compromise was struck with opposing parties and issues and their concerns were incorporated into service provision strategies.

Delta Futures has and remains vigilant to the principle of listening to the community's concerns and responding appropriately to the issues that surface, with the PAC's input and involvement. A Request for Proposals (RFP) process was developed to solicit proposals for service delivery strategies from the local community. Tremendous effort was put into developing an RFP tool that would not be difficult for small community based organizations to complete and submit for funding. Training was also conducted with these community based organizations on proposal development and grant writing techniques. A system for review of the proposals was also developed to insure maximum input at the community level as to what strategies they thought would work. A two tiered system of review was implemented. CC's were given the responsibility of reviewing proposals received for service provision in their counties. An Independent Proposal Review Team (IPRT), made up of individuals with organizations whose mission was related to infant mortality reduction and from outside the Delta Futures project area, was also formed to review the proposals and provide technical expertise and comments on the viability of each proposal that was received. The recommendations from these two very different perspectives were then presented to the PAC who made awards based on the input that was received. RFP's were issued in Year 01 and Year 02 of the project's implementation, resulting in $840,408.62 being provided to local grassroots/community based organizations for the provision of a variety of services. As a result of our track record for identifying and administering the community based type efforts, we have submitted an application to the Mid Delta Empowerment Zone Alliance (MDEZA) to administer their infant mortality reduction funds using the system we have in place.

Delta Futures has also worked to enhance clinical services wherever possible. Many communities within the project area do not have access to perinatal care providers and must travel great distances in order to see a doctor. A two year effort was initiated with the Dr. Arenia C. Mallory Community Health Center to identify and secure a perinatal care provider to the Holmes County community. The Enhanced Recruitment component of this initiative provided funds to this Community Health Center that enabled them to develop recruitment strategies and materials and actively recruited perinatal providers for the area. Recruitment packages were sent to 27 medical schools and at least nine of the sites were visited by project personnel. By the end of the recruitment phase of this project, contracts had been offered to two physicians and three nurse practitioners.

The second phase of this initiative, Perinatal Access, utilized funds to actually secure the identified perinatal provider. By July 1, 1996, a contract was secured with a physician to provide perinatal services to that community. Since that time access to perinatal services has increased by 100% for the Health Center and 338, children ages 0-2 and 29 pregnant/post-partum women have received health care services. Additionally, the physician has provided a series of lectures to over

100 local high school students on pregnancy prevention issues. He is also working to become involved in the community by attending community meetings and forums that focus on health care issues.

Programmatic efforts have focused on strategies that seek to reduce risk and insure healthy outcomes for pregnant women. The Child Birth Doula Project is one example of our efforts in this area. This project focuses on providing pre and post-natal care to pregnant teens in three counties in the project area. Trained "Doulas" were assigned to work with pregnant teens enrolled in the project. Doulas and teens attended training on a variety of topics relative to prenatal health, labor and delivery, post-natal care, and personal development. Moreover, participating teens were accompanied by their Doulas during labor and delivery. Following delivery, Doulas continued to serve in a mentoring capacity, following up post-partum with the teen mothers and infants with the goal of enhancing parenting skills, particularly with regards to newborn care. According to records, for the two year period that this project has operated, a total of 376 pregnant teens have been served by this project. A sampling of 48 teen participant's project records indicates that only two miscarriages were reported along with 45 single deliveries (24 boys, 15 girls, 6 not reported) and one twin delivery (boys). Three deliveries were indicated as Caesarean. All delivery dates were within one month of anticipated dates of delivery, indicating that prematurity was not a problem. Birth weight data reveals an average birth weight of 6 lbs. 12.8 oz.; for the one twin delivery, average birth weight was 5 lbs. 13.5 oz.

Sixty adult Doula volunteers were provided over 80 hours of training. The curriculum, developed by the project, included detailed information on pregnancy, child development, and labor coaching techniques. Twenty five teen Doulas received the same training and were paired with a pregnant teen as a peer mentor. Academic enrichment was also provided to the pregnant teens enrolled in the program. A local university, Mississippi Valley State University, provided 10 academic enrichment sessions that enhanced study skills and worked to assist the pregnant teens in maintaining their academic responsibilities while pregnant. Newspaper articles highlighting the Doula project and personal interviews with project participants are located in Attachment C.

The Resource Moms project is another example of services aimed at reducing risk. The purpose of this project was to form a coalition, a support group of experienced mothers to work with pregnant teens, teen fathers and fathers to be in the Tallahatchie County area. Fifty one program participants attended 13 training sessions on a variety of topics selected by the participants. Supportive networks were also developed between the pregnant teens and the 18 adult Resource Moms who provide support and assistance to the participants.

The Teen Parent Support Project aims to provide day care services to teen parents in the Hollandale School District. The project participants are allowed the opportunity to complete high school diploma or GED requirements or to pursue educational opportunities beyond the high school level. Participants are also provided with life skills training opportunities designed to enhance participants' parenting skills, personal independence, and self esteem. A total of 18 teen parents and 18 children have been served by this project

Delta Futures has worked to reduce infant mortality by providing services that work to facilitate access to perinatal care services by providing transportation and child care services to those in need in the project area. Transportation services have provided over 791 trips to mothers and infants in the project area to and from perinatal care providers. This has been accomplished on two levels. A consortium of transportation providers in the Delta was formed to work together to provide transportation services. Individuals in need of transportation services were then able to call one number to access services to a variety of locations without having to coordinate transportation with a number of providers. Transportation services were also provided that coordinated with the perinatal providers to schedule and provide follow up transportation needs.

Child care services were provided to mothers and children in the Leflore County area. The Mother's Morning Out project offered drop-in day care services to women and children that enabled them to keep appointments with perinatal care providers. Services were offered free of charge to mothers with children who were seeking perinatal services. A total of 75 mothers were served by this effort.

Raising public awareness and educating communities on issues that impact infant mortality has been a critical component to project implementation. Various types of public awareness materials, posters, videos, television and radio PSA's, were developed and distributed throughout the project area. One project was even developed to address a specific community's concerns surrounding issues related to teen pregnancy. The Holistic Prevention Project was implemented to make citizens and policy makers in the Tallahatchie County area aware of various community and individual barriers to preventing teen pregnancy. The primary component of this project was the provision of intensive training sessions for local religious leaders and other interested citizens. A total of 57 adults and 72 teens participated in eight training sessions and five community resource activities, all aimed at heightening the community's ability to respond to the complex issues that impact teen pregnancy.

A significant amount of effort has been spent on implementing strategies that target adolescents. Several Delta Futures projects target female and male adolescents with information and activities that encourage healthy behaviors, self-esteem, and abstinence. The Parent Youth Partnership for Success is one example. The purpose of this project is to involve parents and youth in meaningful activities aimed at boosting self-esteem and diminishing sexual activity among teens, and to provide youth opportunities to participate in meaningful community projects. The project has enrolled 231 teens and 70 adults who participated in 48 workshops on a variety of subjects all aimed at reducing/preventing teen pregnancy.

The Male Responsibility Project works to provide for adult mentors to work with young men towards enhancing self-esteem and delaying youth participation in sexual activity. Participants attend a series of training sessions on subjects that include HIV prevention, preparing for adolescences and making responsible choices. The project has enrolled 118 teens and 84 mentors. Mentors receive training in eight different modules that include the types of mentoring relationships, enhancing self-confidence and self-awareness, and helping adolescents achieve

educational and career goals. The mentors are paired with a young male participant and together they participate in community service activities that include community beautification, visits to local nursing home facilities, and black history/awareness activities.

The Pregnancy Prevention Project focused on implementing a human sexuality education curriculum in the Quitman County School District in an effort to reduce the number of first time and recurring teen pregnancies. The project also featured career development opportunities and educational and clinical services to pregnant/parenting children and adolescents served by the school district. The project has served a total of 159 teens. Pre and post-tests administered to the project participants indicates a fairly substantial knowledge gain following the educational interventions that were employed.

During the project's past two years, it has served a total of 2,837 individuals and 399 pregnant women to date. These numbers do not reflect the individuals who have been impacted by Public Education/ Public Information efforts. Year 03 brings many new and exciting challenges for Delta Futures. The project will continue to explore opportunities for collaboration and partnering with existing organizations to enhance service delivery. We are very optimistic about the opportunity to partner with the Mississippi Department of Public Health District III to provide Perinatal High Risk Case Management services to pregnant women in the service area. Delta Futures hopes to partner with this organization to use an existing model for perinatal case management and enhance the model with Outreach Workers who will work with the professional case management team to provide direct services to pregnant women and their families. It is our hope that as Mississippi moves toward Managed Care, this model will be attractive and marketable to Managed Care Organizations. Efforts will also focus on transitioning to other funding sources. We will work to secure resource development services that will explore other funding opportunities, both public and private, that will help to sustain this project. And finally, efforts will continue on strengthening and improving our data collection protocols with service providers.

CONCLUSION

The Division of Healthy Start has been very helpful to Delta Futures with implementation of this initiative. Through site visits and technical assistance during critical periods of implementation the Division has demonstrated a commitment to fostering successful achievement of project goals. It should be noted that while expansion of effective infant mortality prevention initiatives to new communities is important, it is equally important to assist currently funded Healthy Start projects to sustain and continue effective services as well. Healthy Start should balance use of available funding for both maintenance of service levels for current projects and seeding of new projects. It would be ironic, indeed, if the original projects which demonstrated the effectiveness of infant mortality prevention services were to be significantly cut while new projects are funded. In today's current climate of extraordinary federal and state budget constraints, many existing projects may be unable to locate alternative funding to sustain valuable prevention services such as pre and post natal care, home visiting, and case management.

Delta Futures is a unique Healthy Start Initiative in as much as it is only one of three rural projects. Our experience has been that expectations and/or objectives are often times too ambitious for rural communities. Many systems and organizations that are readily available in urban areas do not exist in rural communities. Much of Delta Futures efforts have focused on building infrastructure and strengthening communities' capacity to meet the challenges of dealing with these complex issues. Because of these challenges our progress has sometimes appeared slow and/or fraught with conflict. We are strengthened, however, by the ever increasing commitment, enthusiasm, and willingness of the communities we serve to reduce infant mortality. As a result of Delta Futures efforts, we believe that not only will we successfully reduce infant mortality in the Delta; we will also improve communities ability to address many other issues that effect the quality of life for its residents.

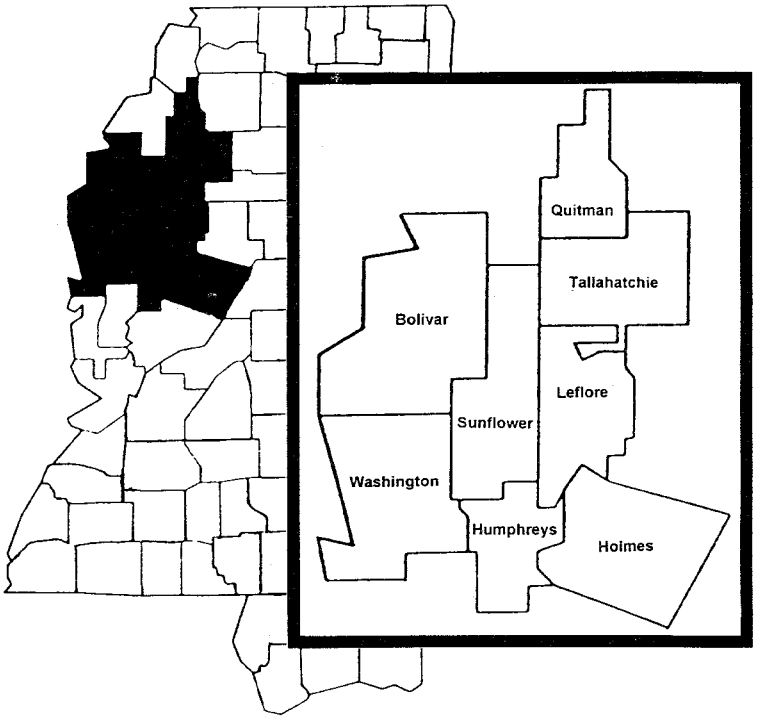
ATTACHMENT
A

DELTA FUTURES PROJECT AREA
AND
RELATED STATISTICS

DELTA FUTURES

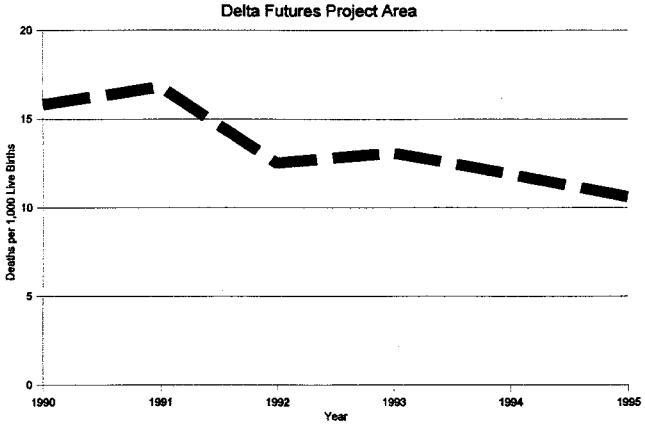
MS Healthy Start Initiative

Project Area



Infant Mortalilty Rates 1990-1995

Delta Futures Project Area



Year	Live Births	Infant Deaths*	Rate**
1995	4140	44	10.6
1994	4262	51	11.9
1993	4415	58	13.1
1992	4528	57	12.5
1991	4683	79	16.8
1990	4736	75	15.8

* Infant deaths are those infants who die under one year of age.
** Deaths per 1,000 live births.

Source: Mississippi State Department of Health, Bureau of Vital Statistics

1993-1995 Total Births vs. Teen Births
Delta Futures Project Area

1995 Statistics

County	Bolivar	Holmes	Humphreys	Leflore	Quitman	Sunflower	Tallahatchie	Washington	Total
Total Births	681	372	189	694	189	548	241	1 ,226	4,140
Teen Births	219	122	43	221	57	177	69	367	1,275
Percentage	32%	33%	23%	32%	30%	32%	29%	30%	30.8%

1994 Statistics

County	Bolivar	Holmes	Humphreys	Leflore	Quitman	Sunflower	Tallahatchie	Washington	Total
Total Births	681	423	190	680	190	515	265	1,319	4,263
Teen Births	238	119	57	226	54	179	88	413	1,374
Percentage	35%	28%	30%	33%	28%	35%	33%	31%	32.2%

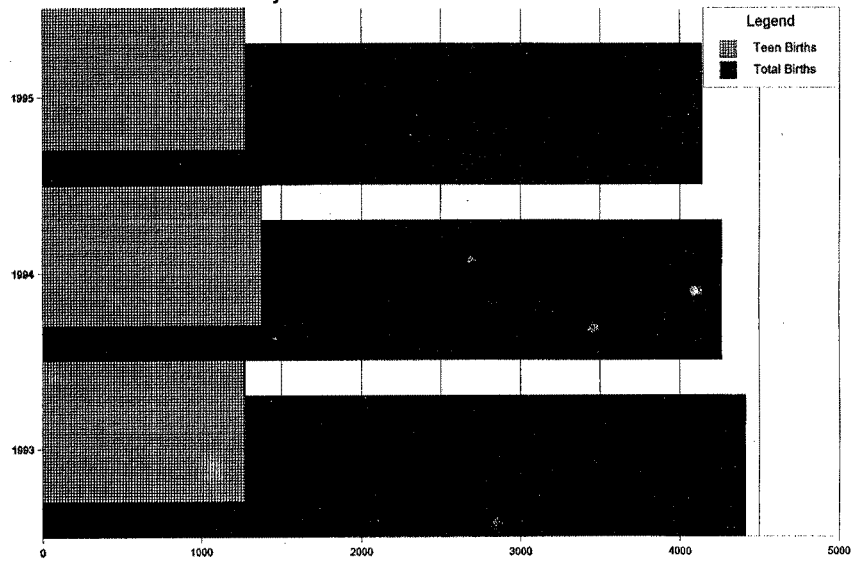
1993 Statistics

County	Bolivar	Holmes	Humphreys	Leflore	Quitman	Sunflower	Tallahatchie	Washington	Total
Total Births	745	410	210	689	204	600	263	1,294	4,415
Teen Births	224	110	54	219	55	179	57	375	1,273
Percentage	30%	27%	26%	32%	27%	30%	22%	29%	28.8%

Source: Mississippi State Department of Health, Public Health Statistics

Total Births vs. Teen Pregnancies

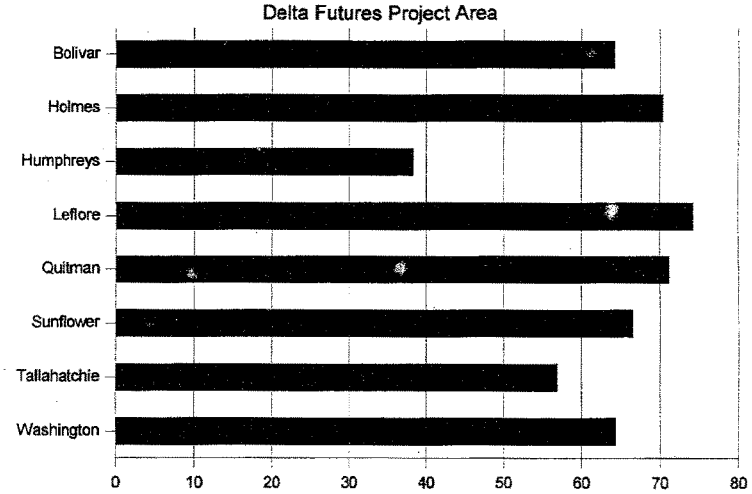
Delta Futures Project



Source: Mississippi State Department of Health

1995 Teen Pregnancy Rates

Delta Futures Project Area



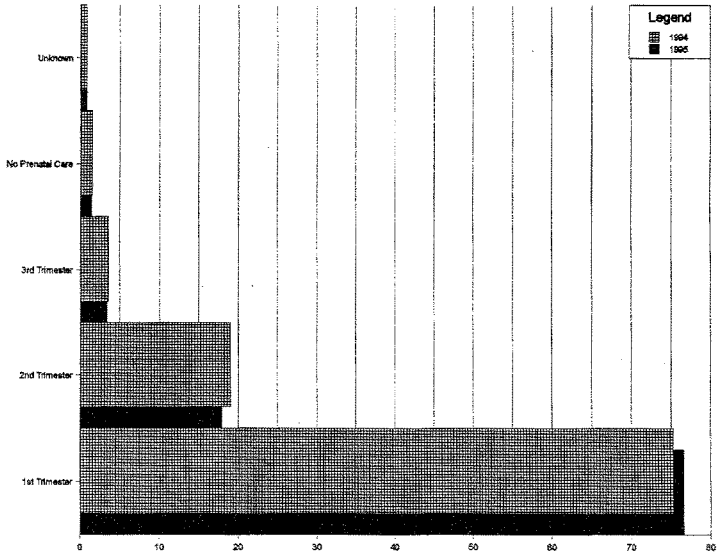
Bolivar	**64.19**
Holmes	**70.37**
Humphreys	**38.23**
Leflore	**74.19**
Quitman	**71.17**
Sunflower	**66.58**
Tallahatchie	**56.82**
Washington	**64.34**

$$\text{Teen Pregnancy Rate} = \frac{\text{\# Live Births, Fetal Deaths, Induced Terminations} \times 1000}{\text{\# of Women Ages 10-19}}$$

Source: Mississippi State Department of Health, Public Health Statistics

1994-1995 Prenatal Care Percentages

Mississippi Delta Futures Project Area



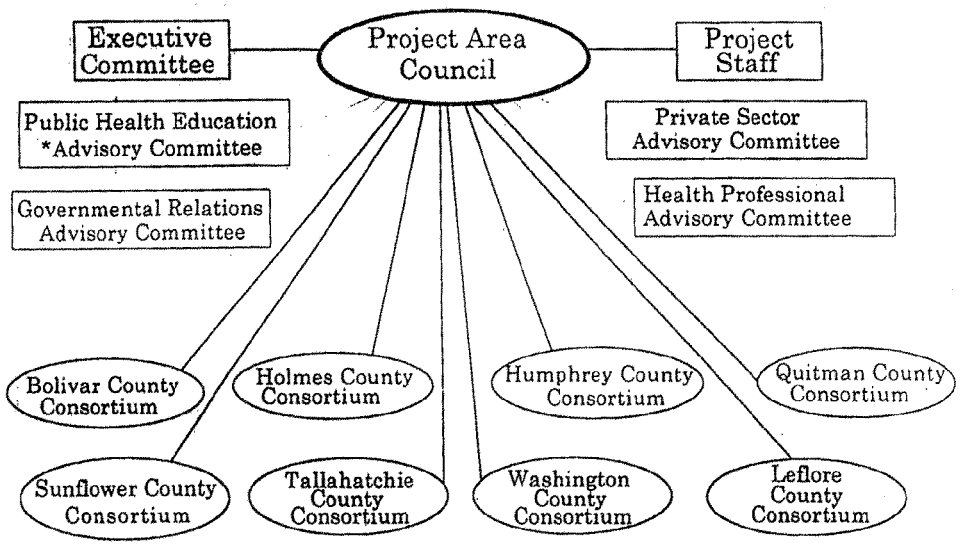
Prenatal Care	1994	1995
1st Trimester	75.2%	76.6%
2nd Trimester	19.0%	17.9%
3rd Trimester	3.5%	3.3%
No Prenatal Care	1.5%	1.4%
Unknown	.8%	.8%

Source: Mississippi State Department of Health, Bureau of Vital Statistics

ATTACHMENT
B

ORGANIZATIONAL STRUCTURE

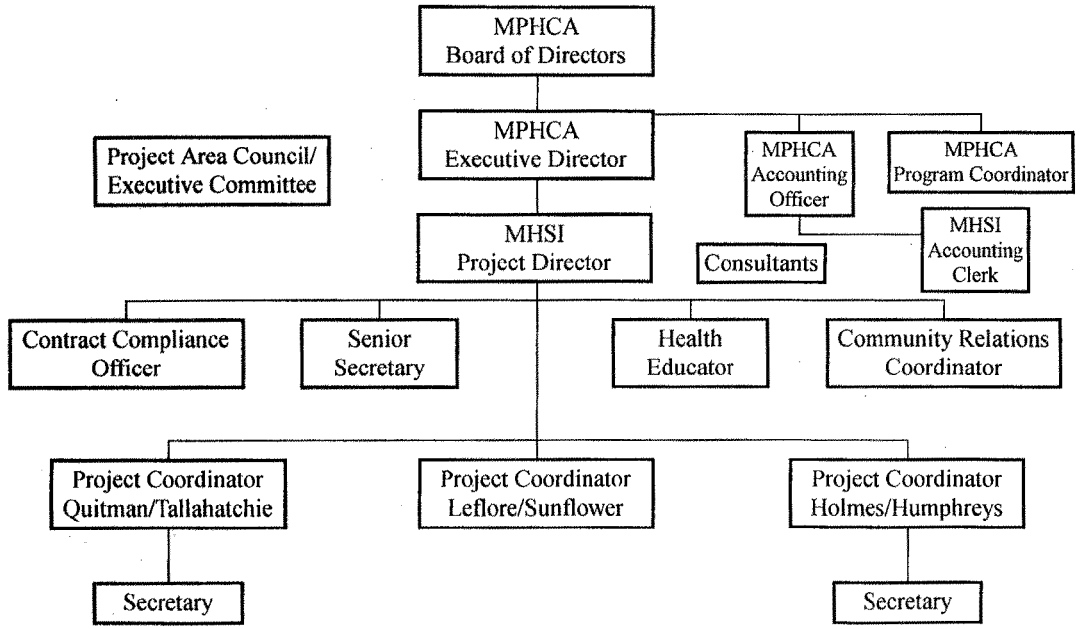
Mississippi Healtny Start Initiative
Management Organization



*Other committees may be added based on need

DELTA FUTURES: Mississippi Healthy Start Initiative

Project Staffing Plan



Delta Futures: Mississippi Healthy Start Initiative

Staff Positions

PROJECT DIRECTOR

The Project Director supervises the work of all MHSI staff as well as any contract personnel. The Director is responsible for the overall planning, development and implementation of policies and procedures governing the operation of the Delta Futures Project. The Director has the responsibility to ensure that all goals, objectives and associated tasks are carried out successfully. The Director provides project supervision necessary to support the development, maintenance and activities of the local County Consortiums and the Project Area Council.

CONTRACT COMPLIANCE OFFICER

The Contract Compliance Officer provides assistance to contract personnel with pre-award activities and post-award administration of contracts for the Delta Futures Project. The Officer provides technical assistance to contractors as needed. The Officer assists in monitoring contractor performance throughout the contract period, including financial and progress reports, to ensure that the contract objectives are being accomplished within the financial parameters.

HEALTH EDUCATOR

The Health Educator provides community health education and serves as the health information coordinator for the Delta Futures Project. The Educator designs and conducts health education trainings throughout the project area. The Educator participates and assists in data collection and analysis activities for the Delta Futures Project. The Educator maintains an up-to-date resource file of video materials which enhance Delta Futures activities.

COMMUNITY RELATIONS COORDINATOR

The Community Relations Coordinator serves as the principal coordinator of public awareness and community relations activities. The Coordinator sustains the Delta Futures public information efforts throughout the project area by working with media outlets. The Coordinator develops print materials, gathers existing resources and assists contractors with technical assistance when needed. The Coordinator works with the Project Area Council and County Consortiums to identify informational needs.

PROJECT COORDINATOR

The Project Coordinator is responsible for developing County Consortiums and obtaining commitment and participation by all affected parties in the Delta Futures Project. The Coordinator supervises the day-to-day activities of the County Consortiums and participates in meetings and public gatherings to inform people about Delta Futures. The Coordinator monitors contractors to ensure policies and procedures are being carried out.

SENIOR SECRETARY

The Senior Secretary provides assistance to the Project Director in accomplishing the goals and objectives of the Delta Futures Project. The Senior Secretary prepares minutes for the Project Area Council meetings and maintains the files for the Delta Futures Project. The Senior Secretary collects and obtains approvals for personnel records. The Senior Secretary processes all incoming mail, prepares purchase orders and orders office supplies.

SECRETARY

The Secretary provides administrative support to the Project Coordinator in implementing the directives of the County Consortium and the Project Director. The Secretary maintains files and composes materials for reports, meetings and conferences. The Secretary types correspondence for reports, minutes and similar documents from printed copy making independent decisions regarding format and arrangement.

ATTACHMENT
C

CHILD BIRTH DOULA PROJECT
NEWSPAPER ARTICLES

The Clarion-Ledger

Mississippi edition ■ Jackson, Mississippi

Monday ■ May 22, 1995 ■ 35¢

Young moms get Healthy Start

■ The federally funded program hopes to break cycle of children having children.

By Butch John
Clarion-Ledger Staff Writer

GREENVILLE — Jennifer Murry's first client, for lack of a better term, was a 12-year-old expecting her second child.

Murry, a former prison guard from Greenwood, skipped the judgment. The kid was a mother about to have another baby. Lecturing her on the benefits of chastity or abstinence hardly seemed appropriate.

As a trained doula, best described as a combination midwife and counselor, Murry took another route. Two children before you're a teenager, she told the girl — let's take a look at avoiding No. 3.

"She's been introduced to contraceptives and safe sex. I can't say she has stopped having sex, but she has been introduced to contraceptives and realizes their importance," Murry said.

Murry, a former teenage mother, is project coordinator for the Mississippi Action for Progress' Childbirth Doula Program — one of three programs funded by Mississippi Healthy Start Initiative Delta Futures.

The federally funded Delta Futures serves eight Delta counties and is one of 22 Healthy Start initiatives across the United States. The program began in 1990 during President Bush's administration, but the state was not included until last year when it received a $997,762 grant.

Mississippi's program is directly designed to bite into teen pregnancy and the myriad social and economic problems caused by children having children, state project director Melanie Williams said.

The U.S. Department of Health and Human Services said the cost of an average childbirth, about $2,900, escalates to about $21,000 for the care of a low birth-weight baby — a frequent complication in teen pregnancy.

More than 25 percent of the births in each selected county are to teens, state Department of Health statistics show. Teenagers were responsible for more than a fifth of Mississippi's live births the last five years. In 1993, the figures show, 7,156 children were born to unwed mothers 19-and-under.

"When you look at the statistics, it's frightening. It's almost like a Third-World country," said Williams, whose hands-on experience covers more than a decade. "It gets back to awareness. Some people are not aware of the problem. We hope to educate people and force a change in attitudes."

Mississippi's Healthy Start program funds three current projects, including doula training in Leflore, Humphreys and Holmes counties, and is looking to add a couple in the next few months, Williams said.

In addition to the doula program:

■ Sunflower and Humphreys counties are working on a project that will pair mentors with adolescent boys, the goal being to promote male responsibility in the birthing process.

■ In Lexington, the Arenia C. Mallory Community Health Center runs a parent-youth training session to discuss topics including decision making, conflict resolution, alcohol and drug abuse, pregnancy and self motivation.

Each project was developed and submitted by local agencies to deal with local needs in the eight-county area, Williams said.

"Each community is unique and brings with it a unique way of approaching things," she said. "We feel very strongly about this being a grass-roots effort, starting from the community up. They give us the problem, then a new and different idea and a way to solve it."

The local approach flies in the face of typical government: policy where officials come in, identify a problem and attempt to fix it without any real investment in the community, said District 3 Health Officer Dr. Alfio Rausa.

District offices in two regions are assisting where able, Rausa said, but in a complementary rather than dictatorial fashion.

"Sometimes in government, we get blinders on," Rausa said. "The state says, 'You have to do this, you have to do that,' because that's the law and the rules we work under. This way, they get to drive the train.

"We offer the training and technical staff to provide them help to solve the problem. We're taking a step back in order to take a leap forward within the limits we have to work."

Local initiative strengthens local commitment, even after the grants and the government funding begins to dwindle, Rausa said.

The biggest problem was selling the communities, Williams said.

"There are lots of people frustrated or overwhelmed, and then we come in and say we have another program to help them alleviate the problem," Williams said. "We say, 'Come to our meeting,' and they tell us they're already going to 15 or 20 meetings and ask, 'What are you going to do for us?'"

Ideally, Williams said community involvement would fuel community spirit that is often lacking in social-improvement programs.

"We're beginning to see people see that although the problem is not in their household, neighborhood, group or area of the community, what happens across town permeates all aspects of the community," Williams said.

In baser terms, she added, "Teen pregnancy is a drain on the economy. If you're in the car business, it kind of makes it hard to sell your cars if we have a lousy economy."

State Department of Human Services Executive Director Don Taylor backed Williams' assertion: About 80 percent of babies born to unwed teens wind up living in poverty, as opposed to about 8 percent born to dual-parent households.

Murry started her first group of 22 girls, 10th- and 11th-graders, on April 29. The training period will be 10 weeks, and Bostman said she will be on hand to help as necessary.

"The potential of the doula program is breaking down the cycle of children having children," said Stewart, who was instrumental in drawing up the Healthy Start proposal for the Delta doulas.

TEEN PREGNANCY/LOW BIRTH WEIGHT

Healthy Start: *Delta Futuras* program is designed to combat teen pregnancy, premature and low birth-weight babies in eight Delta counties. The figures are from 1993. Low birth weight is defined as a child weighing less than 5.5 pounds. Very low is defined as below 3.3 pounds.

County	Teen births	Premature	Low Weight	Very Low
Bolivar	30.1%	17.2%	10.3%	1.9%
Holmes	26.8%	19.3%	12.2%	2.2%
Humphreys	25.7%	11.9%	11.0%	1.0%
Leflore	31.8%	19.4%	11.5%	1.2%
Quitman	27.0%	18.6%	13.2%	3.4%
Sunflower	29.8%	20.0%	10.8%	2.0%
Tallahatchie	33.1%	21.7%	12.3%	1.4%
Washington	30.4%	18.6%	11.3%	2.2%
Statewide	21.5%	15.7%	10.1%	N/A

GENERATIONS

DELTA DEMOCRAT TIMES

Program tackling infant mortality

■ Group takes grassroots approach

By LEIGH DAMMANY
Delta Democrat Times

The people who work to reach the goals of Delta Futures have a daunting task in front of them.

The Healthy Start program initiative which opened its doors in Washington County on Dec. 1, 1994, has as its goal reducing the infant mortality rate by tackling all that goes along with it.

Melanie Williams, director of the program, said the Greenville-based group takes a grassroots approach to addressing the problems of teen pregnancy, low birthweight babies and poor coordination of resources and services.

Its goal is to increase at least 90 percent the proportion of all pregnant women who receive prenatal care in the first three months of pregnancy and to reduce low birthweight rates by at least 25 percent.

Eight counties are served by Delta Futures: Bolivar, Holmes, Humphreys, Leflore, Quitman, Sunflower, Tallahatchie and Washington.

Williams said the group works closely with the counties in several areas: first there is a major public awareness campaign; second, health educators work with parents on the importance of perinatal care and how to get it; and third, Delta Futures helps counties find out where the gaps are in their own services.

"One of our programs is the doula program," said Williams. "We find women who have experience with childbirth and who might want to become a nurse, and pair them with a young girl who needs support and encouragement."

She said that many myths are still passed down through generations about prenatal care and the care of newborns that may not be medically sound. Young girls who listen to this advice, plus live in fear of giving birth, are not adequately prepared for the task of motherhood.

The doula program helps to reduce the number of adolescent and young adult mothers experiencing multiple pregnancies, ensures that young mothers continue their education and improves birth outcomes by helping them know what to expect.

There is also a successful male responsibility and mentoring program in Humphreys County, an ongoing educational outreach program in Holmes County stressing sex education, family planning, AIDS and disease prevention.

"We hope to fund four more programs in the future. We've requested projects to increase transportation for women and children to doctors' offices," Williams said.

With so many rural areas in the Delta, some people still don't see a doctor because they have no way to get there, even if they're within walking distance.

The group is also trying to help recruit perinatal health care providers into the rural areas still underserved.

Williams said that the program was pitched for funding in 1991, when Healthy Start was funded, but it was turned down and had to rely on March of Dimes money until it was approved for federal funding recently.

There are two years left of funding, then Delta Futures will try and find other avenues. She said they're optimistic.

"President Clinton announced that $50 million will be set aside for special projects, but we're still trying to find other avenues of funding," she said.

The Delta is an area which needs a program like this, she said.

The region's infant mortality rate was 17.1 deaths per 1,000 live births during the last five-year count; low birthweight babies averaged 11.7 percent of all births and the average percentage of premature babies was 19.9 percent.

"We're excited about this opportunity. We have an enormous task, but if we're successful in lowering it by any percent, then we'll have accomplished something," she said.

For the Delta Democrat Times

An effective teaching tool: Jennifer Murry, childbirth doula coordinator for Leflore County, demonstrates to a class of young mothers-to-be the effects of smoking on an unborn child by using a specially designed teaching tool.

Mr. SNOWBARGER. Thank you very much, Ms. Williams.

I apologize to the panel. We have been called to the floor for a vote, so we will take a recess. Until we get back, we would ask those that want to continue on the panel here, and, Mr. Towns, if we can get back as quickly as possible so we do not inconvenience these panelists any more than necessary. We will stand in recess.

[Recess.]

Mr. SNOWBARGER. OK, we are ready to begin again. Mr. Towns.

Mr. TOWNS. Thank you, Mr. Chairman. I want to thank all of the panel members for coming here today to present your testimony. I would also like to introduce Dr. Barbara Hatcher, who is the project director for the District of Columbia Healthy Start Program. Dr. Hatcher, Representative Eleanor Holmes Norton has asked me to commend you, on her behalf, for your excellent service.

Ms. HATCHER. Thank you very much. Good morning, Mr. Vice Chairman and other honorable members of the subcommittee. I am Dr. Barbara J. Hatcher, project director for the District of Columbia Healthy Start project. I am here today with Carol Coleman, a resource mother in our project.

I am pleased to have this opportunity to share what we have learned in the District of Columbia. There are many lessons learned from our experience with Healthy Start. I would like to take just a few minutes to summarize three major lessons learned from this demonstration effort.

From a practical standpoint, we have learned about dealing with communities and people in communities. We know the importance of taking the services to the community and getting community "buy-in." For example, we have hired and trained community residents and provided them with some marketable skills.

This was not an easy or simple task. It is important to note that some of our staff from Wards 7 and 8 are ex-offenders, former substance abusers, and former welfare recipients. We also have a cadre of community residents also working on this problem. We have learned what it takes to prepare those who have never worked or have not worked in a long time.

Besides new skill development, we know we must help individuals improve their self-esteem, self-worth, and life skills. The hiring and training of community residents is a small but important economic and community development effort. It is important to the individual and the total community.

Because of efforts like Healthy Start, Wards 7 and 8 are beginning to change. Given our practical and hands-on experience, we can assist new communities to design appropriate training programs. This not only has applicability for Healthy Start but for new welfare reform efforts at the State level.

We have learned about working in communities and addressing the infant mortality problem holistically. We have clearly learned that Medicare alone cannot reduce infant mortality. We are helping to redefine health care to be an inclusive concept viewed within the community context and on a continuum.

Health care in depressed and low-income communities means more than prenatal care. It includes what health professionals call "enabling services," such as social case management, smoking cessation, substance abuse counseling and treatment, and an array of

preventive and educational services. We can guide new communities as they attempt to redesign their system of care.

While we must continue to validate our data scientifically, we have also learned more about the association of substance use with poor pregnancy outcomes. Our infant mortality review and case management data strongly suggest that substance use is a marker for poor pregnancy outcome. We believe that data such as this from Healthy Start can help researchers pose and examine new research questions.

However, the lack of scientific rigor does not diminish what we have to share with others. We can help new communities learn efficient and effective techniques for finding substance abusers, screening for substance use, working with families affected by substance use, and designing a system of care for those very complex cases.

I would like to take a few minutes to address sustainability. We are trying to sustain our efforts but must compete with public safety, public works and welfare funding in the District. As the total dollars decrease in the District and we change to a system of managed care, sustainability is not assured and will, of course, be more difficult. Infant mortality is on the District's health policy agenda, and we hope to be able to influence funding decisions.

In closing, these are only a few of the lessons we have learned. We hope this is helpful and thank you for the opportunity. I will be open for questions.

[The prepared statement of Ms. Hatcher follows:]

The Healthy Start Program: Implementation Lessons and Impact on Infant Mortality

Testimony of Barbara J. Hatcher, Ph.D., R.N.,
Director, District of Columbia Healthy Start Project

before the

Congress of the United States
House of Representatives
Committee on Government reform and Oversight
Subcommittee on Human Resources and
Intergovernmental Relations

Christopher Shays, Connecticut, Chairman

March 13, 1997

THE HEALTHY START PROGRAM: IMPLEMENTATION LESSONS AND IMPACT ON INFANT MORTALITY

My name is Barbara J. Hatcher. I am Acting Chief of the Office of Maternal and Child Health(OMCH) in the District of Columbia Department of Health. I have been Acting Chief of OMCH since December 1, 1994. I also serve as the Project Director of the District of Columbia Healthy Start Project and have been involved with Healthy Start since its inception in 1991. My office is at 800 Ninth Street, Southwest on the third floor. I have lived in the District of Columbia for the better part of twenty-nine years.

I am a Registered Nurse. I hold a Bachelor of Science degree from the University of Connecticut, Storrs, CT(1967), a Masters of Public Health degree from the University of North Carolina, Chapel Hill, N.C.(1970), and a Doctorate of Philosophy from George Mason University(1994). Besides this training, I took coursework in public administration at the University of Southern California-Washington Public Affairs Center. I also completed a certificate program at Children's Hospital National Medical Center that prepared me as a Pediatric Nurse Practitioner(PNP)(~1974). I was among the first four PNPs in this city and one of the first two African-Americans. From 1986 to 1996, I served as Chairperson of the District of Columbia Board of Nursing.

The Healthy Start Program: Testimony of Dr. Barbara J. Hatcher

Since its inception, I have been a co-investigator with the National Institutes of Health- District of Columbia Initiative to Reduce Infant Mortality. This is a collaborative research project to study the epidemiology of infant mortality in our city. Specifically, I helped to design the Barriers, Motivators, and Facilitators of Prenatal Care Utilization research protocol. Now, I conduct some qualitative research of this protocol. Since December 1994, I have also served as the Department of Health's Site Principal Investigator for this research initiative.

I recently completed a two-year W.K. Kellogg Community Partnership Leadership Fellowship Program. As a Kellogg fellow I have had the opportunity to visit and compare an array of community-based health programs nationally and internationally. These visits have given me insight into what works from a world perspective. I have also completed an array of military leadership courses, served in Saudi Arabia and hold the rank of Lieutenant Colonel in the U.S. Army Reserves on inactive ready reserve status.

I have extensive experience in maternal and child health, public health, and have, primarily, worked with low-income African American populations. I worked as a visiting nurse(i.e., community health nurse), directed a teen pregnancy program, provided primary care to teenagers and their babies, and co-

directed an improved pregnancy outcome project.

As Acting Office Chief, I serve as the District's Title V(Maternal and Child Health/ Children With Special Health Care Needs) Director and I am responsible for state-based issues related to maternal and child health. Title V, the Maternal and Child Health Block Grant (Title V of the Social Security Act), provides States with funding to build and maintain a system of care for women, infants and children, and children with special health care needs. The Title V program is a federal/state partnership, with states using the block grant funds to meet the unique needs of their community. In the District of Columbia, OMCH is the state agency responsible for the administration of the block grant.

Giving Every Child A Healthy Start

The media regularly portray the District of Columbia as a failed city with little hope for the future. Daily, headlines feature stories about our budget crisis, poor management, drugs, and crimes. The media rarely describe the heart and soul of the District where citizens have come together to rebuild their communities. This spirit of civic responsibility and engagement characterizes the citizens and agencies in our Healthy Start project area.

Cities, like the District of Columbia, have a long history of persistently high

infant mortality despite several innovative health, social service, and economic interventions. The baby of an African American woman is still twice as likely to die in the first year of life and be born with low birth weight when compared to the babies of Caucasian women. The Healthy Start Project grant, then, provided the citizens of the District of Columbia with a unique opportunity to address the issue of infant mortality from a community-based perspective and to find ways to give every child a healthy start.

Citizens wholeheartedly embraced this opportunity and helped us to design and set up a successful and effective infant mortality reduction effort. There is evidence of the community' cooperative and collaborative efforts: a slow but consistent decline in infant mortality, the significant reduction in very low birth weight babies (babies weighing 3 ½ pounds or less), and the apparent change in high risk behaviors, such as drinking, smoking, and using drugs, among pregnant women. Any success is the community's and they are proud and committed.

Program Focus

The District of Columbia Healthy Start Project targets a 11.6 square mile area composed of two adjoining areas: Wards 7 and 8. Compared to other wards,

Wards 7 & 8 have the highest percentage of:

- persons under 18 years of age(26% Ward 7 and 33% Ward 8)
- household poverty(18% Ward 7 and 26% Ward 8)
- adults with less than a high school education(36% Ward 7 and 39% Ward 8)
- residents in public housing(21% Ward 7 and 24% Ward 8)
- unemployment(9.6% Ward 7 and 15.6% Ward 8).

These Wards also have the lowest: median household incomes($25,500 in Ward 7 and $21,300 in Ward 8) and intact families. The 145,145 residents of this area are primarily African American(97% in Ward 7 and 91% Ward 8). Females of childbearing age(10 to 44 years)make up 31% (44,637) of the population and are 94.9% African American; 3.9% white; and 1.1% of Hispanic descent.

The District of Columbia Health Start Project initiated many systemic change efforts in these two extremely depressed wards of the city with a concentration of low-income African-American households and a disproportionate share on income-linked problems such as HIV/AIDS, increased use of drugs, violence, and poor housing. The six key change efforts include:

- (1) integrating perinatal care

- (2) providing intensive case management and care coordination
- (3) linking outreach/casefinding services to nontraditional service sites
- (4) designing an integrated system of care for pregnant and parenting women including a computerized tracking and case management system
- (5) facilitating ongoing community activation and participation
- (6) hiring and training over 200 community residents as lay outreach workers, drivers, secretaries, health educators, peer counselors and volunteers

Implementation Strategies

Our community-based approaches to fighting infant mortality are:

- Providing case management and outreach programs that target pregnant and parenting women.
- Providing door-to-door transportation to and from prenatal and well child care appointments to reduce access barriers.
- Training and employing neighborhood residents as Resource Mothers and Male Outreach Workers to identify and counsel mothers and fathers.
- Training and employing neighborhood residents as secretaries, drivers, and health educators.

- Establishing a school-based adolescent wellness center that includes a teen peer educator program.
- Providing home visiting using public health nurses and lay outreach workers
- Linking women and families to enabling services such as drug abuse counseling/treatment, smoking cessation programs, nutritional counseling/WIC
- Linking women and families to individual development services such as parenting education, housing assistance, job skills training/referral
- Putting in place a computerized local area network
- Increasing the availability of WIC and in-home nutrition counseling
- Putting in place a multifaceted public information and education campaign
- Setting up a high risk perinatal unit at the public hospital
- Providing bedside family planning counseling
- Increasing the availability of smoking cessation programs
- Providing "curbside" service using the Maternity Outreach Mobile(MOM) clinical unit.

- Using volunteers as "Sister Friends," "Telephone Friends" and mentors
- Beginning an incentive program, "Points for Healthy Babies"
- Incorporating and sustaining a community-based consortium

Accomplishments

By Fiscal Year 1996 (October 1,1995 - September 30, 1996), the Project achieved 21 of its 27 ongoing objectives. Among the achieved targets are: reductions in the incidence of sexually transmitted diseases, self-reported alcohol, tobacco, and other drug (ATOD) use, confirmed prenatal exposure of babies to ATOD, the actual number of infant deaths, births to teens, anemia, and women with no prenatal care. Further, the Project increased nutrition, family planning, school-based health, and substance abuse treatment capacity. The District of Columbia Healthy Start Project increased the number of women who achieved the recommended weight gain during pregnancy and decreased rates of anemia, STDs, and smoking, drinking, and "drugging" among pregnant women. The key achievements are:

- The Project-area infant mortality rate declined almost 17% from the 1994 rate of 24.2/1,000 to the 1995 rate of 20.2

- The actual number of infant deaths declined by 20 in 1995 (58, 1995; 78, 1994).
- The Project-area average infant mortality declined 12% from 24.9/1,000 (1988-1990) to 21.9/1,000 (1993 - 1995).
- Low birthweight (weight 5½ pounds or less) among infants known to the Project declined 48% from 43.9% (FY93) to 22.7% (FY96).
- Very low birthweight declined 72% from 20% (FY 1993) to 5.8% (FY 1996).
- Proportion of women who receive no prenatal care declined 13% from 9.1% (1990) to 7.8% (1995).
- Self-reported alcohol use among pregnant women known to DCHS declined almost 63% from 8.1% (FY 1993) to 3.0% (FY 1996).
- Exposure to alcohol declined 72% among babies known to the Project from 14.2% (FY 1993) to 4.0% (FY 1996).
- Self-reported smoking among pregnant women known to the Project declined almost 54% from 8.1% (FY 1993) to 3.8% (FY 1996). The FY 1996 proportion is below the District's Year 2000 Goal of 8.0%.
- Confirmed prenatal exposure to tobacco among babies known to DCHS declined over 70% from 11.9% (FY 1994) to 3.5% (FY 1996).

- Self-reported drug use among pregnant women known to DCHS declined almost 71% from 21.6% (FY 1994) to 6.4% (FY 1996).
- Exposure to drugs declined almost 68% among babies known to the Project from 40.7% (FY 1993) to 13.2% (FY 1996).
- Confirmed sexually transmitted diseases (STDs) among pregnant women known to the Project declined over 56% from 7.5% (FY 1994) to 3.3% (FY 1996).
- Exposure to STDs declined 67% among babies known to the Project from 10.4% (FY 1994) to 3.4% (FY 1996).

Further, the preliminary analysis of the data set suggests that women receiving Healthy Start's case management services have better pregnancy outcomes. The data includes the District's 1994 linked birth/infant death records and the Project's case management information. average birth weight was higher and the infant deaths were fewer. The preliminary analysis also suggests that the Healthy Start women were at higher psychosocial risk than other ward 7 & 8 mothers not receiving Healthy Start services directly. Most encouraging is the continued decline in smoking, drinking and using drugs because substance use is a significant marker for perinatal mortality and morbidity (See Attachment A & B: Graphs of Perinatal Substance Use and Transportation). Women who use

substances also utilize prenatal care poorly and are at higher risk of low birth weight and prematurity.

Successful Models

There are several models I believe have been successful and can be replicated in other urban communities: case management/care coordination; public information/public education; and outreach/client recruitment and incentive.

Case Management/Care Coordination

As previously stated, our preliminary data strongly suggests that a case management/care coordination model that includes intensive in-home assessment and support to pregnant women helps to improve birth outcomes and reduce the number of infant deaths. Other urban areas can easily replicate our program.

Materials developed during the Project include a Resource Mother training curriculum, Male Outreach Worker Training Curriculum, Home Visiting guide, Peer Educator Training curriculum, case management policies and procedures. Also, we have learned a lot about the recruitment and retention of residents particularly those previously receiving AFDC.

Public Information/Public Education

The Project has put into place a multifaceted and lowcost program. Besides

brochures, newsletters, tipsheets and other print media, the District of Columbia's made creative use of public service advertising and event sponsorship. The Project received the 1994 Bronze and Silver Awards for Excellence in public health communications from the National Public Information Coalition for our newsletter and radio PSA.

Some lessons we learned that other communities can use as they replicate this model are as follows:

- The use of public service advertising space on public transportation is an economical approach to "getting the word out." The Project funded the entire campaign from conception to start-up, for a cost of approximately $7,000. The costs include the materials students needed to design posters, poster production and printing, and installation fees. City officials', residents', students', parents' reactions, to this lowcost, easily replicated campaign, have been positive. More important, a follow-up focus group with pregnant and postpartum after the first two waves of bus and subway posters, suggest that the messages reached the intended target population.
- Sponsorship of Radio station events results in "media buy" discounts, high visibility, and name recognition. Our sponsorship of several large annual events

supported by local radio stations help us get $3-$4 of air time for every dollar we invest. These radio announcements also help us to "get the word out."

Outreach/Client Recruitment and Incentive

The Project's efforts have helped to increase access to care and decrease barriers. Our incentive program, seeded by Healthy Start, is essentially a volunteer effort of the Delta Sigma Theta Sorority. Incentive program participants are more likely to attend prenatal care regularly, improved pregnancy outcomes, and subsequently enroll and keep their babies in a well-child care program. "Points for Healthy Babies" can be replicated by other civic groups and a "how-to" manual is available.

Casefinding and recruitment at "nontraditional" sites(i.e., welfare offices, crisis centers, community centers) is effective. The project can share lessons learned about identifying and negotiating for sites. Also, the Project can help others learn to use geomapping to better target services. An extension of casefinding, "curbside" services help to reach the "hard-to-reach" women who do are not linked with health care facilities.

Healthy Start National Evaluation

The evaluation conducted by MATHEMATICA will provide some valuable data. However, much of its work, the quantitative data will not be available until after the Project ends. Our community felt it was important to have an ongoing assessment of our progress and success. Thus, the District's Healthy Start Project uses a local evaluator to assess the program's progress and relies heavily on this information to provide as a barometer of change. The local evaluator is currently conducting an extensive evaluation of our case management component.

To some extent, the National evaluation is a work in progress. Each Project has its unique approach to reducing infant mortality. Thus, it has been difficult, at times to work with the Minimum Data Set and collect the required data. At times, the National evaluator misses subtle nuances. I am sure It is difficult working with 22 diverse and individually designed initiative.

Although, I wish the emphasis on quality assurance came earlier in the Project, our involvement with Healthy Start forced the Project to improve our data quality assurance capacity. The Project assesses ongoing quality regularly and has procedures in place to ensure corrective action. This improved capacity has future positive implications for the District's Office of Maternal and Child Health.

The Project and Consortium found one component of the national evaluation very useful: the community focus groups. The focus groups, conducted by RIVA Marketing Research, Inc., gave us some indication of citizens' perceptions and satisfaction with the program. For example, based on information from the community focus groups, we reassessed outreach worker assignments and intensified the role of the male outreach worker as a member of the case management team.

Healthy Start Program Management

For the most part, I found Maternal Child Health Bureau staff helpful. The Healthy Project, however, was actually a cooperative agreement not a grant. There are very strict fiscal and program reporting requirements and external monitoring. Although extremely time consuming, the District's involvement with this program forced us to put an internal fiscal monitoring system in place that will have many long-term advantages. Our involvement with Healthy Start also prepares us to participate in the proposed performance partnership to meet GPRA requirements.

Summary

In summary, District is beginning to turn the corner on infant mortality. The conclusions are optimistic: improved pregnancy outcomes are apparent. The

District's involvement with Healthy Start has been a privilege and a fascinating learning experience.

COMMISSION OF PUBLIC HEALTH
OFFICE OF MATERNAL AND CHILD HEALTH
1995-96 ESTIMATED GRANT AWARDS*

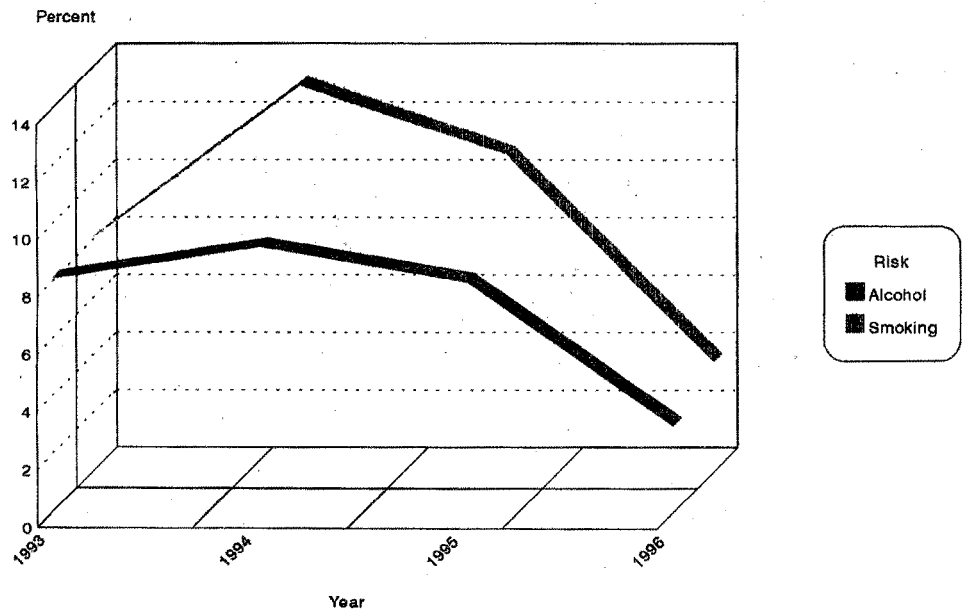
GRANTS	GRANTOR	AWARD	PERIOD OF AWARD
D.C. Healthy Start (DCHS)	DHHS/HRSA/MCHB	$6,076,008	10/01/95 - 09/30/96
Synergy/High Risk Youth	CDC - (DASH)	$157,497	03/01/96 - 09/30/96
Comprehensive HIV Intervention & Prevention Services (CHIPS) for Families (formerly D.C. Pediatric AIDS Health Care Demonstration Project	DHHS/HRSA	$608,397	08/01/95 - 07/31/96
NIH Community-Based Perinatal Research (NIH)	NICHD/NIH	$689,399	09/01/95 - 08/31/96
State System Development Initiative (SSDI)	DHHS/HRSA/MCHB	$100,000	10/01/95 - 09/30/96
Pregnancy Risk Assessment Monitoring System (PRAMS)	CDC	$37,132	09/27/95 - 09/26/96
Pregnancy Nutrition Surveillance System (PNSS)	CDC	$34,860	08/16/95 - 08/15/96
Title V Block Grant	DHHS/HRSA/MCHB	$7,033,000	10/01/95 - 09/30/96
Healthy Communities-Family Preservation Services	DHHS/HRSA/BHRD	$20,000	10/01/95 - 09/30/96
TOTAL ESTIMATED AWARDS		**$14,756,293**	

APPENDIX A

District of Columbia Healthy Start Project

Trend of Smoking and Alcohol Abuse Among Women Known to Healthy Start

1993 Through 1996



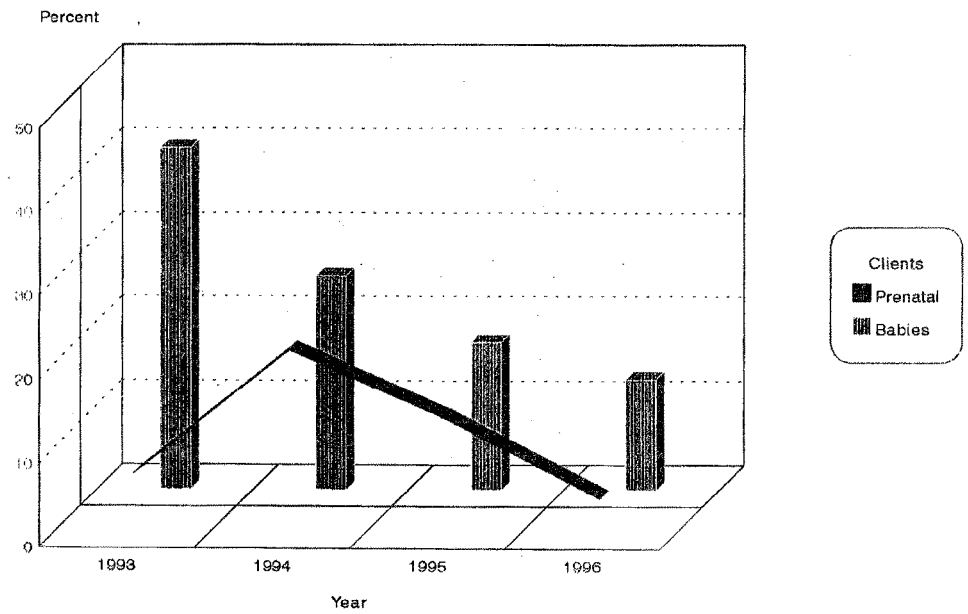
Source: DC Healthy Start

APPENDIX B

District of Columbia Healthy Start Project

Drug Abusing Women and Babies Exposed to Drugs Known to Healthy Start

1993 Through 1996



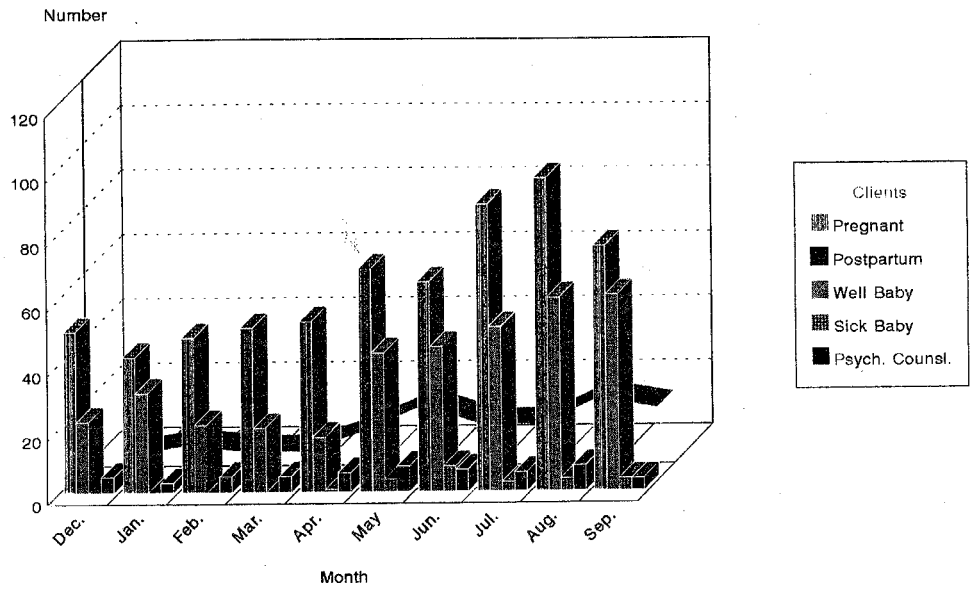
Source: DCMOMS Data, 1993-1996

APPENDIX C

D.C. Healthy Start Project

Transportation Services Provided By Type Of Clients

December 1, 1995 Through September 30, 1996



D.C Baby Hotline Monthly Report

55% were Pregnant, 31.6% well babies, 6.4% Postpartum, 5.0% psychiatric pts., and 2.0 % sick babies.

Mr. SNOWBARGER. Thank you, Dr. Hatcher.

OK. I am going to call on Juan Molina Crespo, please.

Mr. CRESPO. Good morning, Mr. Chairman, members of the committee. My name is Juan Molina Crespo, and I am the project director of the Greater Cleveland Healthy Family/Healthy Start Project, which is the Healthy Start Initiative in Cleveland, OH. On behalf of Michael R. White, mayor of the city of Cleveland, I would like to thank this committee for the opportunity to provide testimony regarding our project.

Mr. Chairman, with your permission, sir, I did bring a poster that I would like to put on the easel.

Cleveland is 1 of the 15 original Healthy Start sites. Healthy Start services have been available in 15 designated neighborhoods in the city of Cleveland since October 1992, and since that time we have seen steady progress. We have seen a dramatic drop in infant deaths among the women who actively participate in the Healthy Start Project, from a high of 20.2 deaths per 1,000 births in 1993 to 11.3 per 1,000 births in 1995.

In calendar year 1996 alone, 1,852 pregnant women were enrolled in the Cleveland project. Each one of those women then received the help and support they needed to ensure a healthy birth. The rate of infant deaths for the population of women who live in the project neighborhoods but who did not enroll in the project rose from 21.5 in 1993 to 25.7 deaths per 1,000 in 1995.

We know that when we are able to find and enroll pregnant women, outreach, indeed, works to reduce infant mortality. Overall stats show that in 1990, the infant death rate in the Project area was 22.4 deaths per every 1,000 live births. In 1995, that number was reduced to 20.8.

The impact of the program can also be seen in the decrease in low birth weights among infants born in the Project area. Low birth weight is defined as an infant who is born weighing less than 2,500 grams. Low birth weight is often a precursor of severe health problems for the baby, which can often lead to death.

In 1990, the rate of babies born at this weight in the Project area was 148 for every 1,000 live births. In 1995, in the Project area, we have seen that rate drop to 121.3 for every 1,000 live births. In order to reduce infant mortality and address the problems leading to infant death, it is imperative for a woman to enter prenatal care early in her pregnancy and to continue that care on a prescribed schedule up to delivery.

In 1991, the percentage of women living in the Project area who delivered without having any prenatal care at all was 8.9 percent. By 1995, that figure had been reduced to 3.8 percent. In 1990, 48 percent of women living in the project area who delivered received an adequate level of prenatal care; that figure was raised to 50.2 by 1995.

Our Project in Cleveland was carefully designed to achieve these types of results, and began with a focus on four goals, sir. The first, of course, was the reduction of infant mortality in the city of Cleveland by 50 percent within 5 years.

Second, the Project was to create support for a system-wide collaboration and integration among the social and medical systems in the community.

Next, the Project sought to empower the community through entry-level job opportunities, as well as volunteer leadership development.

Finally, the Project was meant to test and refine new strategies for addressing infant mortality, and identify those which work and develop ways to sustain them and their effects.

The Healthy Start Initiative funding launched the creation of a community-wide consortium to systemically address the problem of infant deaths. Now well-established after 5 years, the Healthy Start Consortium is made up of community residents, project participants, medical and social service providers, nonprofit agencies, community-based organizations, clergy, and educators.

The Consortium has provided an unprecedented opportunity for citizens and the public and private sectors to work collaboratively to solve a major public health problem.

Healthy Start Initiative funding in Cleveland has also allowed for the creation of a research team devoted solely to investigating the causes of infant death in the city of Cleveland. The results of this research have revealed that the leading cause of death in our community is prematurity, followed by Sudden Infant Death Syndrome, birth defects, and infections, such as sexually transmitted diseases.

Taken together, these factors account for two-thirds of the infant deaths in Cleveland. Armed with this information, the Consortium began to focus its energies on the prevention of these specific problems. The focal points of the Consortium's educational programs were narrowed to the signs and symptoms of preterm labor, the prevention of sexually transmitted diseases, and appropriate sleep positioning for newborns to prevent SIDS.

These programs have been aimed at the general public through a public information campaign. Outreach workers have also received extensive training on these issues in order to educate project participants one on one.

As the demonstration phase of the Healthy Start Initiative draws to a close, we are in a position to analyze the public health lessons learned. In Cleveland, our success rests largely on the consortium structure, which has allowed a high level of communication amongst providers and community to better address the needs.

Also, we have learned that the causes of infant death in our community may most often be traced to high-risk situations in which a pregnant woman may find herself. You may remember that in December 1994, there was a discovery of pulmonary hemosiderosis that was found in Cleveland, and members of the CDC dispatched a team to be able to do the appropriate investigation of hemosiderosis.

The team that was dispatched by CDC from Atlanta was met by our outreach workers. They were allowed into the homes where the cases had been found, so we see that the outreach team which has been developed in Cleveland has gone beyond the Healthy Start box, and it has ramifications for other public health initiatives in the city of Cleveland.

With these lessons in mind, the Greater Cleveland Healthy Family/Healthy Start Consortium's vision for the future is the provision of supportive services to the highest risk women in the community:

those who struggle with chemical dependency, those who reside in homeless shelters, domestic violence shelters, those who are incarcerated, as well as the teens and the women who have fallen through the cracks of the health care safety net in our communities.

Therefore, I would respectfully urge this committee to recommend the continued funding of the Healthy Start Initiative at the community level. Channeling this money through any other agencies, either State or Federal, would dilute the effects of the program and halt the real progress being made to reduce infant deaths.

In Cleveland, we believe the people most qualified to combat the issues of infant mortality are the people who face those problems on a daily basis. Thank you.

[The prepared statement of Mr. Crespo follows:]

Testimony of

Juan Molina Crespo
Greater Cleveland Healthy Start Project Director
Cleveland Department of Public Health
Cleveland, Ohio

Before the House Subcommittee
on
Human Resources
and
Intergovernmental Relations
on
Government Reform and Oversight

March 13, 1997

My name is Juan Molina Crespo and I am the Project Director of the Greater Cleveland Healthy Family/Healthy Start Project, the Healthy Start Initiative in Cleveland, Ohio. On behalf of Michael R. White, Mayor of the City of Cleveland, I'd like to thank this committee for the opportunity to provide this testimony regarding the Cleveland Healthy Start Project.

Cleveland is one of the fifteen original Healthy Start sites. Healthy Start services have been available in fifteen designated neighborhoods in the City of Cleveland since October 1992 and since that time we have seen steady progress. We have seen a dramatic drop in infant deaths among the women who actively participate in the Healthy Start Project from a high of 20.2 deaths per 1,000 births in 1993 to 11.3 per 1,000 births in 1995 (Figure 1). In calendar year 1996 alone, 1,852 pregnant women were enrolled in the Cleveland Project. Each one of those women then received the help and support they needed to ensure a healthy birth. The rate of infant deaths for the population of women who live in the Project neighborhoods, but who did not enroll in the Project rose from 21.5 in 1993 to 25.7 deaths per 1,000 births in 1995. We know that when we are able to find and enroll pregnant women outreach does work to reduce infant mortality.

Overall statistics show that in 1990, the infant death rate in the Project Area was 22.4 deaths per every 1,000 live births. In 1995 that number was reduced to 20.8 per 1,000 births in the neighborhoods in which we operate (Figure 2).

The impact of the program can also be seen in the decrease in low birth weights among infants born in the Project Area. Low birth weight is defined as an infant who is born weighing less that 2,500 grams. Low birth weight is often a precursor of severe health problems for the baby which can often lead to death. In 1990, the rate of babies being born at this weight in the Project area was 148 for every 1,000 live births. In 1995 in the Project Area we have seen that rate drop to 121.3 for every 1,000 live births (Figure 3).

In order to reduce infant mortality and address the problems leading to infant death, it is imperative for a woman to enter prenatal care early in her pregnancy and to continue that care on a prescribed schedule up to delivery. In 1991 the percentage of women living in the Project Area who delivered without having had any prenatal care at all was 8.9%; by 1995 that figure had been reduced to 3.8% (Figure 4). In 1990 48% of women living in the Project Area who delivered had

received an adequate level of prenatal care; that figure was raised to 50.2% by 1995.

The Project was carefully designed to achieve these type of results, and began with a focus on four goals. The first was the reduction of infant mortality in the City of Cleveland by 50% within five years. Secondly, the Project was to create support for systemwide collaboration and integration among the social and medical systems in the community, to ultimately make them more responsive to clients' needs. Next, the Project sought to empower the community through entry level job opportunities as well as volunteer leadership development. Finally the Project was meant to test and refine new strategies for addressing infant mortality, identify those which work and develop ways to sustain those strategies and their effects.

The Healthy Start Initiative funding launched the creation of a community wide Consortium to systematically address the problem of infant death. Now well established after five years, the Healthy Family/Healthy Start Consortium is made up of community residents, project participants, medical and social service providers, nonprofit agencies, community based organizations, clergy, and educators. The Consortium has provided an unprecedented opportunity for

citizens and the public and private sectors to work collaboratively to solve a major public health problem.

The Consortium has used outreach and case finding as its primary intervention model. In this model, community residents were hired to canvass their neighborhoods, finding women who are pregnant, or who are parents to children under the age of one. Outreach Workers enroll women into the Healthy Start program; once enrolled, women are encouraged and supported to take care of themselves and their babies. Outreach Workers help a woman find a doctor and get to appointments both during her pregnancy and during the baby's first year of life. Outreach Workers also assist mothers with other obstacles to properly caring for themselves and their children, such as securing food, housing, education or job assistance. Outreach staff in Cleveland also work in the public school system to encourage teens to practice abstinence and to provide resources to those teens who are pregnant or parenting.

Healthy Start Initiative funding in Cleveland also allowed for the creation of a research team devoted solely to investigating the causes of infant death in the City of Cleveland. Results of this research have revealed that the leading cause of

infant death in our community is prematurity, followed by Sudden Infant Death Syndrome, birth defects and infections such as sexually transmitted diseases. Taken together, these factors account for two thirds of infant deaths in Cleveland.

Armed with this new information, the Consortium began to focus its energies on the prevention of these specific problems. The focal points of the Consortium's educational programs were narrowed to the signs and symptoms of preterm labor, the prevention of sexually transmitted diseases and appropriate sleep positioning for newborns to prevent Sudden Infant Death Syndrome. These programs have been aimed at the general public, through a public information campaign. Outreach Workers have also received extensive training on these issues in order to be able to educate Project participants one-on-one.

During the latter half of the Project's fifth year (Federal Fiscal Year 1996) the Greater Cleveland Healthy Family/Healthy Start Consortium began to plan and strategize the best way to function in what was believed would be a situation of greatly reduced funding in FFY '97, while at the same time maintaining those efforts which were effective in reducing infant mortality. Administrative positions were slashed by forty percent and funds were directed toward maximizing

outreach services. All outreach functions were transferred to a community based organization which has a strong potential for sustaining the program beyond federal funding. In a similar fashion, responsibility for outreach to adolescents was placed with the city's school system where the Project may easily be absorbed into its large structure. Basing our adolescent programming within the Cleveland public schools has heightened the Project's visibility among teens, making it much easier to engage them in the program.

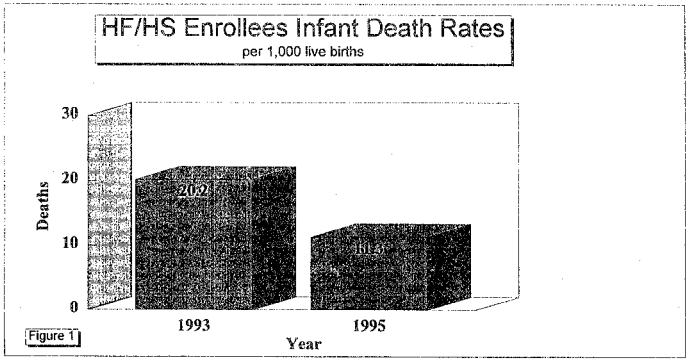
As the demonstration phase of the Healthy Start Initiative draws to a close we are in a position to analyze the public health lessons learned. In Cleveland, our success rests largely on the Consortium structure which has allowed a high level of communication among providers and community to better address health care delivery needs. Also we have learned that the causes of infant death in our community may most often be traced high risk situations in which a pregnant woman may find herself.

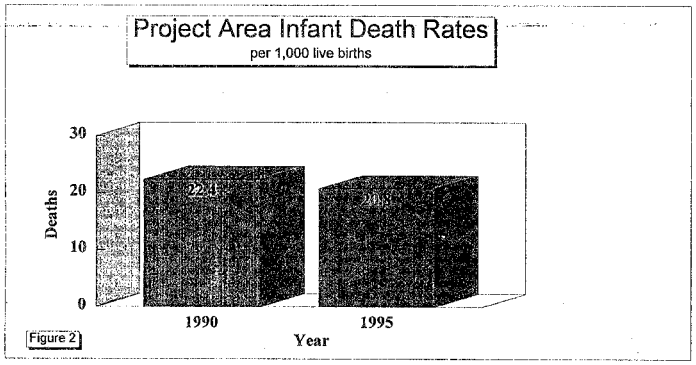
With these lessons in mind, the Greater Cleveland Healthy Family/Healthy Start Consortium's vision for the future is the provision of supportive services to the highest risk women in our community: those who struggle with chemical

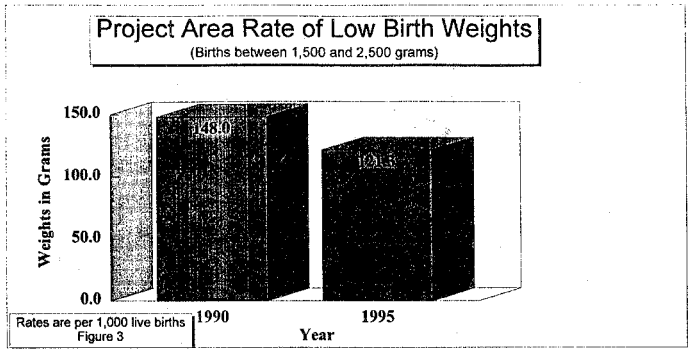
dependency, those who reside in homeless or domestic violence shelters, or who are incarcerated, as well as teens and women who have fallen through the cracks of the health care safety net in our community. Our efforts to date would be seriously jeopardized if funding is cut, or redirected through state programs.

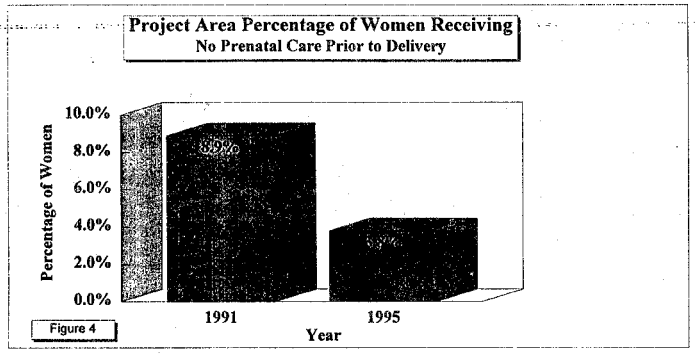
Therefore, I would respectfully urge this committee to recommend the continued funding of the Healthy Start Initiative at the community level. Channeling this money through any other agencies, either state or federal would dilute the effects of the program and halt the real progress being made to reduce infant deaths. In Cleveland, we believe the people most qualified to combat the causes of infant mortality are the people who face those problems daily.

Greater Cleveland Healthy Family/Healthy Start, Cleveland Department of Public Health
Cleveland Ohio






Project Area Rate of Low Birth Weights
(Births between 1,500 and 2,500 grams)
150.0
100.0
50.0
0.0
Weights in Grams
1990
1995
Year
Rates are per 1,000 live births
Figure 3


Project Area Percentage of Women Receiving
No Prenatal Care Prior to Delivery
10.0%
8.0%
6.0%
4.0%
2.0%
0.0%
Percentage of Women
1991
1995
Year
Figure 4

Mr. TOWNS [presiding]. Thank you very much. At this point, I would turn to a gentleman from Cleveland who knows a lot about Cleveland. In fact, he was the mayor of Cleveland.

Mr. KUCINICH. Thank you very much, Mr. Chairman, members of the committee. I certainly want to welcome our visitors from Cleveland and let Mr. Crespo know that I appreciate the work that you are doing in our city on this program.

In my view, Healthy Start presents possibilities for saving the next generation and for saving succeeding generations. It is a part of our responsibility as lawmakers and as policymakers to be sure that our policies are going to enable babies to grow, to blossom in a healthy way, and I know this is what this program is about.

And I have a few questions, if I may, with permission of the Chair, to ask relative to the program in Cleveland, so that perhaps you can help us understand precisely where those benefits are and enable us to develop policies that will be consistent with the needs of the people of not only our community, but others who are affected by this program.

With respect to the data that has been provided to the committee, one document cited Profiles, Attachment No. 1. It says that Cleveland has seen a reduction of infant mortality among women enrolled in Healthy Start from 22.4 out of 1,000 births in 1991 to 16.33. And in another document, which is the Health and Human Services Fiscal Year 1998 Justification, Attachment 3, it says there has been a reduction in infant mortality from 22.4 to 13.5 per thousand. Still, in another document provided by the city of Cleveland, as well as cited in your testimony, it says that infant mortality among women enrolled in the program is now at 11.3 deaths per 1,000 births.

Could you help to establish what is the correct infant mortality rate per 1,000 births for women enrolled in the Healthy Start Program today?

Mr. CRESPO. Thank you, Congressman, yes. The data that you referred to earlier is earlier data. The most current data that we have, as of January 1997, for the women enrolled living in the project area and enrolled in our Healthy Family/Health Start Program is 11.3 deaths per every 1,000.

Mr. KUCINICH. So, then, it would be fair to say, then, that over the course of the program the infant mortality rate has actually been cut in half, from 22.4?

Mr. CRESPO. That is correct, for the women enrolled in the project——

Mr. KUCINICH. Right. I understand that——

Mr. CRESPO [continuing]. The infant mortality rate has been reduced by approximately 50 percent.

Mr. KUCINICH. Mr. Chairman and members of the committee, this is, I think, a striking testimony to the effectiveness of a program when you can actually cut infant mortality rates by one half. There are certain challenges, which, as you know, are out there to the whole idea of Healthy Start, and some people would say that the decrease in infant mortality rate could not be directly attributed to Healthy Start. But even though let's suppose for the sake of discussion that the decreases in the IMR cannot be directly attributed to Healthy Start, aren't there intangible benefits which

are not measurable by the statistics which accrue to the community?

Mr. CRESPO. I think that in terms of the spillover effect that we have that this project has been able to provide to the community is one of dignity to a population where historically we have not been able to do that. When we speak about empowering the community and bringing them to the table to develop the strategies and help us administer a project that is going to save the babies in our community, I think that is something that is very valid and certainly is something that speaks to the future generations, like you indicated earlier.

So there are a lot of things. In terms of the job training, the skills development, our outreach workers, for the most cases, this was their first real job. I mean, they were one step away themselves from being a participant in this project. We have been able to not only bring them on as indigenous outreach workers, those folks that are recognized by the community as a leader in that community and to train them, but also in many cases they have moved on to other jobs.

A good example of that, sir, is the recent flurry of HMO activities all over this country. We have had our outreach worker army raided, to some degree, by HMOs because they know that the members that they are trying to reach are, for the most part, the same participants that our outreach workers have access to.

So we have developed a mechanism that is now being used by at least three HMOs in Cleveland to be able to access those difficult members. And as we all know, if we continue to get them in prenatal care early, that means higher profit margins for the HMOs.

Mr. KUCINICH. Mr. Chairman, is there time for a couple of more questions?

Mr. SNOWBARGER [presiding]. Well, let's see. Make them short. Go ahead.

Mr. KUCINICH. OK. According to Lolita McDavid, who I know you are familiar with at Cleveland Rainbow Babies and Children's hospital, says that for every $1 spent on prenatal care, we save $3 in later cost for babies that are born too soon or too small. And through this program, have you done any studies which estimate how many dollars have been saved by getting women, particularly high-risk women into early prenatal care?

Mr. CRESPO. Sir, I have not done that study, but let me try to respond this way. I have taken a walk through the intensive care, perinatal unit at Metro Health Hospital, and every baby—those million-dollar babies that are lying there—and some of them never get a chance to go home—we feel that those are our babies, and if we can continue to reduce the number of babies, the number of million-dollar babies that are in that intensive care unit, then we think that all the dollars that are spent with respect to Healthy Start are dollars well spent.

Mr. KUCINICH. Thank you, Mr. Chairman. I want to thank you. I just would like to conclude by saying this, that Cleveland has this wonderful facility at Metropolitan General Hospital, where we care for babies that are born prematurely for a number of reasons, and this is what he is talking about. There are babies that effectively

require $1 million in care because they have not received—their mothers perhaps have not received the kind of care which this program can provide.

So I view life as a seamless web, and these newborn children are certainly part of that, in the essence of it, and so I am strongly in favor of this program, and I hope that we will get support from members of the committee and the Congress to continue. Thank you very much.

Mr. SNOWBARGER. Thank you. I do not know how many of you were in the room before Chairman Shays left, but he left us with a question that probably you can answer better than those on the first panel. It was his understanding, as this Healthy Start Program was put into place initially, that there were really two hopes for these programs. One is that they would be very much controlled locally, and the second is that they would be at some point in time where they would be self-financed and self-sustaining.

I believe that Dr. Hatcher addressed that, to some extent, in her testimony, but could the others of you respond to the sustainability question, please?

Mr. COYLE. Yes. I would like to. We, in Baltimore, never understood that.

Mr. SNOWBARGER. Well, it is important for us to know that.

Mr. COYLE. We understood that that was supposed to be the strategy. We did not understand how that would ever work. The reverse would be true for us. We would think that the strategy would be if you took 15 sites and did this kind of intensive intervention, looking for real models that work, that you would then continue a few of the best sites and let the rest of the sites go—that is what our view of what a demonstration project ought to be—so that those sites that have done this would continue and be able to put that kind of information and technical assistance and research out to the rest of the country.

We are working very aggressively to find dollars to sustain our program, and we hope to do that, but if anybody knows the foundation situation these days and the whole other cutbacks in State government, as well as the Federal level, where one would think that you could sustain a program at $7 or $8 million is hard to understand.

We are committed to sustaining our program, but I must say we never understood the model to start with.

Mr. GUYER. Can I just make a quick response?

Mr. SNOWBARGER. Yes.

Mr. GUYER. I think sustainability is a really tough issue for these programs. In part it is because I think the level of investment that it takes to have the good outcomes is much higher than any of us ever anticipated it would be. This is not the level of investment that providing early prenatal care takes. It is a level of investment that accounts for all of the social issues related to these poor outcomes as well.

To the extent that there are savings to these programs, those savings probably accrue to Medicaid, and you did not have anyone from HCFA here today in your earlier panel. You might want to think about using savings that accrue to the Medicaid program to, in fact, sustain these preventive efforts at the community level.

Ms. WILLIAMS. Mr. Vice Chairman, I neglected in my opening remarks to introduce our executive director, Mr. Robert Pugh, who is the executive director for the Mississippi Primary Health Care Association, which is my organization's grantee, and I believe he would like to address your question.

Mr. SNOWBARGER. Mr. Pugh.

Mr. PUGH. Thank you, Mr. Vice Chairman and other members of the committee. Since I have not had the opportunity to say "good morning," I will now say good morning or early afternoon and will say that I am very delighted to have the opportunity to be here today and to address you.

The issue of sustainability is one in which the Delta Futures Project in Mississippi is currently developing a strategy around. As Ms. Williams indicated during her testimony, we are one of the seven supplemental projects that were funded; therefore, we are just in our 3d year of Healthy Start.

The issue of sustainability was not very clear at the beginning; however, the division of Healthy Start has worked very diligently with us to help begin the process of looking at sustainability. I can tell you that that issue is a very difficult one for a rural area and a very economically depressed area like the Mississippi Delta.

Unfortunately, the Medicaid managed care picture in Mississippi has not moved along as far as it has in some other States. We do not have operating HMOs. We had hoped that we would be able to develop a practical sustainability approach through working with HMOs that would be developing in Mississippi around Medicaid managed care. Unfortunately, this has not happened.

Currently, however, we are working with our State health department to look at ways in which we can identify a sustaining and recurring source of revenue through providing case management services to the Medicaid-eligible population through our Medicaid Division, and we are very, very excited about the possibility of getting that program under way during this 0–3 year to continue not all of the efforts we are doing under our Healthy Start Project, but some of the areas around case management that are very important to us.

So it is going to be very difficult to undertake any real sustainability for a program like we have in Mississippi in the near future in the short run, but we are hopeful that some success can be reached and can be started.

Mr. SNOWBARGER. Mr. Crespo, do you care to respond?

Mr. CRESPO. Yes, if I may. Thank you. We looked at components that we had nurtured, if you would, for the first active 4 years of the project and saw where we were getting the most bang for our buck, if you would pardon the pun.

We found that clearly outreach was something that needed to be sustained. How we did that, we moved our outreach team in terms of the management of that team from two, very good, sort of traditional medical providers to an organization that is called the Neighborhood Centers Association, which is an umbrella organization of 22 settlement houses in the community. So now the outreach is being managed by them.

They have been able to successfully enter into two contracts with HMOs to deliver the outreach services that I spoke of earlier. With

respect to the school teams, we also had outreach workers called "specialized outreach workers" that work solely in the middle and high schools.

That was given also to the public school system because, again, the cultures of the organizations where it was really meant to manage could not really understand, I mean, the needs of the kids effectively. So we gave the administration of that over to the school system. We are expecting that they will be able to sustain components of that within their own structure.

When we talked about the component of the high-risk teen, we have a high-risk team that goes into the Justice Center for Incarcerated Women in Cleveland. We have worked out a memorandum of understanding with the Cuyahoga County Justice Center so that they can again absorb those kinds of models that we know are effective and working.

Last, I just want to bring up the issue of consortium. As you know, the Consortium is sort of the whole infrastructure that has to be maintained, and how do you do that? Well, consortia activity, the community activity with the settlement houses that are doing the outreach really validate those kinds of efforts. Those are the kinds of things that bring together community leadership.

Clearly, everyone that comes to the table is not concerned about infant mortality, but the problems that come to the table are directed and are involved and do have a causal effect on the babies that are dying in our community. So everyone comes with some solution, although in their mind they may not know that the solution that they are providing is, indeed, a solution to help combat infant mortality.

So those are the ways that we are attempting to sustain the successful components that we have seen in Cleveland.

Mr. SNOWBARGER. Is it fair to say that you are sustaining your program be delegating your outsourcing?

Mr. CRESPO. I think it is fair to say that in Cleveland we need to look at existing structures and prove to them that we have a model, show them that we have a model that has had some results, and we would like for them to help us sustain those, yes.

Mr. SNOWBARGER. Just a real quick yes/no answer on this, because I heard it a couple of places. Do you feel like you are properly advised concerning the expectations on sustainability? I have one yes, one no, obviously. You really kind of mention——

Mr. COYLE. I do not want to be misunderstood. What I was saying is the Federal Government 2 or 3 years ago started asking each of the sites to get ready for sustainability, so there is no question that the Federal Government gave the signal. In my mind, they did what they were supposed to do. What I was saying to you is that it would seem to me if you develop models that work, if you took a model in cancer or AIDS and it was working, you would not come to the point where, OK, it is working; now we are going to put it out of business.

I said I had trouble with the idea of how to do that. Let me just make one important point here. Baltimore is committed to raising significant dollars for sustainability, but what is going to happen in Baltimore is if we do this, because people believe in the infrastructure that we have, we are going to move away from infant

mortality because if you are dealing with managed care organizations or foundations or others, a lot of them want you to do something, but it is not infant mortality driven.

So I have explained to the feds earlier that, yeah, we can raise a lot of sustainability money, but it is not going to help necessarily reducing infant mortality and low birth weight because the dollars that we will get will not be targeted for that. So there is a real dilemma here.

Mr. SNOWBARGER. Dr. Hatcher.

Ms. HATCHER. Yes. I would just like to add and supplement what has been said. I think the Federal Government was very clear with us regarding the sustainability, but what has happened to us, there is a changing with health care reform, welfare reform, and all these changing systems, it is just very hard to begin to look at sustainability. I mean, to actually do it, not to look at it. You can look at it, you can plan, but you have a lot of people competing for a shrinking pot.

Mr. SNOWBARGER. Does anybody else care to respond? I apologize.

Mr. CRESPO. Mr. Chair, with my experience, I think that the direction that we received from Washington in terms of sustainability has been fairly clear.

Mr. SNOWBARGER. Thank you. Mr. Towns.

Mr. TOWNS. Thank you very much, Mr. Chairman. Mr. Chairman, we have been joined by one of our senior, senior, senior Members in Congress, and I am referring to his service. [Laughter.]

An outstanding and highly respected Member, Congressman Lou Stokes from Cleveland. At this time, Mr. Chairman, I would like to yield to him.

Mr. STOKES. Thank you very much, Mr. Towns and Mr. Chairman. It is a pleasure to be here, even if I have to withstand these attacks on me. [Laughter.]

But I want to say for me it is a special pleasure to be here, first, because this committee has been so instrumental in terms of the promulgation of this particular legislation. I have had occasion to come here before the subcommittee and testify, and I really commend you for the interest and concern that you have taken in this whole matter. I am pleased to see these outstanding panelists who are here this morning and want to extend a special welcome to Mr. Juan Crespo, who is our Healthy Start Program director in Cleveland.

The Healthy Start Program is very important to me. As you know, former Secretary of the Department of Health and Human Services, Dr. Louis Sullivan was one of the initiators of this legislation. We included it at the time we put forth the Disadvantaged Minority Health Improvement Act, which I sponsored in the House and Sen. Kennedy sponsored in the Senate, historic legislation which Healthy Start became a part of.

I serve on the Appropriations Subcommittee on Labor, Health, and Human Services, and Education, Mr. Chairman, where last year we put up an extensive fight to try and save this program. At that time, it was felt that we had reached the 5-year mark and perhaps we should move on and do other things.

And we had some pretty tough fights over on our committee trying to get it funded because we realized that we could show on graphs the kind of progress that has been made in 15 cities around the country, major cities. We were able to show what was happening in infant mortality prior to the initiation of this legislation and how the graph would show in a very vivid way how we had made some inroads on this whole infant mortality problem.

So, I am hoping that we can get this program reauthorized and funded, and let us continue making the progress that has been made.

I have a statement which I will submit for the record, and I appreciate the opportunity to be here with you, Mr. Chairman and Mr. Towns.

[The prepared statement of Hon. Louis Stokes follows:]

Testimony of

The

Honorable Louis Stokes

(D-OH)

House Subcommittee on Human Resources and Intergovernmental Relations
Committee on Government Reform and Oversight

Oversight Hearing on the Healthy Start Program

March 13, 1997

Thank you, Mr. Chairman and members of the Subcommittee on Human Resources and Intergovernmental Relations. I am very pleased to be here today to share with you my strong support for the Healthy Start Program. I also want to take the opportunity to thank my good friend Mr. Towns for his efforts over the years to support this very important program.

In addition, I am pleased that Mr. Juan Malino Crespo the Program Director of the Cleveland Healthy Family/Healthy Start Project, which is the Healthy Start initiative in my Congressional District of Cleveland, Ohio, had the opportunity to testify before your Subcommittee earlier today. Under Mr. Crespo's leadership and direction, the Cleveland Healthy Start Project has made significant contributions to the reduction of infant mortality in the Cleveland community.

As a member of the Labor, Health and Human Services, and Education Appropriations Subcommittee, I have worked with my colleagues to provide consistent funding for the Healthy Start Program. As a health advocate, I have a strong commitment to this pro-life and quality of life initiative.

In 1995, the United States experienced a reported declined in infant mortality from 8.4 deaths per 1,000 live births (reported in 1993) to less than 7.5 deaths per 1,000 live births. Unfortunately, the shocking disparity between the infant death rate for the general population and for poor and minority communities is still a serious concern. The mortality rate for African American infants remains 2 and one-half times greater than that for White infants. There is no

excuse for this dire public health problem. There are entirely too many resources and too much technology for us as a society to allow this situation to continue.

The brainchild of former Secretary of the Department of Health and Human Services, Dr. Louis Sullivan, the Healthy Start Program was designed to specifically address the needs of communities with excessively high infant mortality rates of at least 150 percent above the national average. We are just beginning to learn the extent of Healthy Start's positive impact. It appears that comprehensive intervention in the population of at-risk pregnant women can positively effect the reduction of infant mortality.

Healthy Start has laid the groundwork for a powerful, working infrastructure including: functional consortia, integrated service delivery systems, operational infant mortality reviews, management information systems, and other mechanisms that feed data back into the community for decision making. Healthy Start exhibits a clear understanding that communities ravaged by infant mortality and low birth-weight problems are often overwhelmed by the consuming effects of poor health, social, and economic status. If we are going to save our children, at-risk pregnant women who live in these conditions must have access to aggressive, targeted, and comprehensive services.

I know that in my Congressional District, the Healthy Start Project is making a positive impact on the health outcomes and the overall well-being of Cleveland's pregnant women, infants, and their families. Thus, I am convinced that the Healthy Start Program is indispensable.

As a staunch supporter of this program, I am excited about the results we are beginning to see. I eagerly await the completion of the Health Resources and Services Administration's (HRSA) 5-year, cross-site, independent evaluation of the 15 original Healthy Start demonstration sites (conducted by Mathematica Policy Research) and look forward to the 1998 release of this national evaluation's findings. I urge strong fiscal support for the continuation and expansion of the Healthy Start Program. Now is the time to apply what we have learned from the Healthy Start demonstration communities to other at-risk communities across the country.

Again, I thank you for the opportunity to testify before the Subcommittee and I look forward to working with you to strengthen and maximize the successes of the Healthy Start Program.

Mr. SNOWBARGER. Thank you, Representative Stokes.

Mr. Towns, do you want to do some questioning?

Mr. TOWNS. Yes. Thank you very much, and let me just say, it is a pleasure to have you here with us, and we know, in terms of the work that you have done in the area of health period, and then, of course, in this particular issue as well, so we are delighted to have you here.

Let me just move, first of all, to Mr. Coyle and to Dr. Guyer. My staff had an opportunity to visit your program, and they came back all excited, and, of course, I must admit, they do not get excited too often. So evidently you must be doing something very special over there.

Let me go to the question, though, of why do you think it was important to include men as part of your Healthy Start Project.

Mr. COYLE. We had a project that preceded Healthy Start, and that is one of the reasons we were selected, because we had a head start, something called the Baltimore Project, that had been in place for 2 years before we started Healthy Start, and so we had 2 years of experience in this business at a much smaller level.

In the first year of Healthy Start, as we were getting to some of the huge, risk-taking behaviors that our women have in these poor communities, the realization came to us, which should have come earlier, that many of these risk-taking behaviors, particularly substance abuse, is directly related to the male partner.

So a lot of their behaviors are affected dramatically by the male partner they are with, either the father of the child or a significant other, and we began to believe that if you are going to change risk-taking behaviors which are at the heart of reducing infant mortality and low birth weight, you have got to bring the father into this. And so we created this very special men's program.

Joe Jones, who is somewhere in the audience, he runs this program. We have had great publicity on this, national publicity on this men's program, and what it focuses on is taking the highest risk men that you all know that are in your communities and insisting that they pay attention to their children.

And so the first focus, when we get these men, is that their first responsibility is to their children. Once that starts happening, then we deal with all the other social, economic, and health issues dealing with the men, most of which is around substance abuse, drug dealing, and those kinds of things. And we have had tremendous success with getting the men not only to take better care of their children, but also to really turn their lives around.

But the answer to your question is, we believe you cannot change the risk-taking behaviors of women if you do not deal with their male partner simultaneously.

Mr. TOWNS. Thank you very much. Mr. Chairman, what I would like to do is ask this question, let it go down the line, and that will be it for me, but I wanted to get a response from all of them on this issue.

I guess the best way to ask this would be, let's switch roles, and thinking in terms of what Congressman Stokes said in terms of the fights that we have had around here trying to maintain programs such as this that we know are doing a great job: what should I say

to my colleagues that do not support these programs in order to convince them to do so? Arm me. Give me some material.

I tell you what, so I do not miss anybody, why don't we start with you, Mr. Crespo, and then we will come right down the line?

Mr. CRESPO. Thank you, Congressman. I think probably the most relevant thing is that we have seen, in the projects represented here today among others, have seen that the process objectives are being met; that is to say that we know that if we enroll them early in their pregnancy, infant mortality, indeed, is going to be reduced in that community.

And the spillover effect of that factor alone would have very positive outcomes in terms of the overall makeup of that community in terms of substance abuse, in terms of school dropout rates, in terms of other activity that would lend itself to putting together the community that we need in order for babies to live in it.

So I think that the important thing, sir, is that we need to look at this project, and we need to get out of the Healthy Start box. Infant mortality reduction is much more encompassing, and every facet of society has an impact on it, so the dollars that are spent here are dollars that are well spent.

Ms. HATCHER. I think that just by reducing low birth rate and some of the problems that we know occur in our communities, that costs a lot of money. Not only do you have to spend the $200,000 for a low-birth-rate baby in the neonatal, intensive care unit; that child is more likely to have other kinds of developmental problems, so long term, we continue to pay for this.

So in Healthy Start we can reduce the number to have healthier children from the beginning, I think over the long term there is a significant reduction in cost. It may cost us $100 or $200—and that is probably low—I will say $2,000 per case-managed woman, a woman that we case managed, but if you do not have to spend $200,000 for that neonatal, intensive care unit, right there you already have some health-care-dollar savings.

I do not think we see it all in the short term; some of it is a much more long-term effect, and so it is very hard for us to give the kind of specific data that people may want, but I think we have to see this as a long-term effect. There are some short-term savings, but there is also the big long-term savings.

Mr. PUGH. Congressman Towns, in response to your question, we certainly recognize that there are a lot of competing interests and priorities in this Nation and across the various States and other communities. The idea of improving pregnancy outcome certainly can be looked at in a cost-benefit way, just as Dr. Hatcher has talked about some, but she also made another profound statement a little bit earlier, when she said it takes more than direct medical intervention to reduce infant mortality and low birth weight.

The fact of it is, you can judge a nation by how it cares for its children, and the fact of it is that nothing is more important to our future in this Nation than raising healthy children and giving every child that is coming into this country, coming to life, a healthy start.

And one of the ways that we have known that we have done that in Mississippi is by increasing community awareness and bringing the community together around this issue to develop strategies to

help them solve their own problems in their communities related to infant mortality, low birth weight, high rates of teenage pregnancy. And we think it is very important that resources be provided to do everything we can in this Nation to raise a healthy, future population for this Nation's sustainability, and I think that it is very important that this be given top priority, regardless of the other competing interests.

And I believe that the Congress can do much in helping to foster the idea that this is a Nation who cares about its children, that, indeed, this is a Nation that cares about its future.

Mr. TOWNS. Thank you, Mr. Pugh. Ms. Williams. Oh, you want to be identified with his statement. Dr. Guyer.

Mr. GUYER. I will just make a brief comment. It is unfortunate that the timing of the evaluation of this project is not exactly synchronous with the project itself. The experiment is still in the middle, and it would be a shame if what seem to be promising early results, in fact, are lost because the level of support is not sustained. A few years later we may find out that this was one of the most successful efforts ever launched by the Federal Government in this area.

So I would make that argument for sustaining the level of effort that currently exists.

Mr. TOWNS. Thank you very, very much. Thank all of you for your testimony and for your comments. You have been extremely helpful. I yield back to you, Mr. Chairman. I am sorry I went a little over.

Mr. SNOWBARGER. That is fine, Mr. Towns. Let me ask two final questions. One, Ms. Williams, specifically relates to the Delta Futures Program. In her testimony, Dr. Nora indicated that this project was one of the problem projects, maybe is the best way to put it, and I suppose by raising the topic I give you the opportunity to respond, but really what I was looking for is, are there things that you have gone through that we can learn how not to do things perhaps?

Ms. WILLIAMS. I would certainly hope so.

Mr. SNOWBARGER. Do you have any specifics that you can give us at this point?

Ms. WILLIAMS. I think a lot of the struggles that we have dealt with deal specifically with rural communities, inasmuch as we are not always on the same learning curve as urban areas might be, and we found that people often come—when you have moneys that are available, everyone is struggling for their share or their piece of the pie, and conflict is oftentimes just an inherent part of that process.

And we certainly learned a great deal about how to deal with and manage conflict and work with those communities and deal with that, and I think that we have been very successful in that area.

Mr. SNOWBARGER. One last question, however many of you want to answer this. I asked the last panel about coordination and cooperation between Federal programs. They were all very self-congratulatory and actually had held a conference together, so obviously they are coordinating their programs.

Do any of you care to respond to that? Do you find that all of these child-health-care programs are working in synch and in coordination, or are there problems there?

Mr. CRESPO. Mr. Chairman, I think there is a need for improvement on how that information gets to the community level. That is not to say, of course, that we are not made aware of certain conferences or funds that are available or initiatives that we may be able to add our experience to, but at the community level, those decisions are made here; and the way they are brought down sometimes, I think, needs refining. But, overall, I would say, yes, at least from Cleveland's perspective, that we are made aware of those.

Mr. SNOWBARGER. All right. Does anybody else care to respond? Dr. Hatcher.

Dr. HATCHER. Well, I think they are working together. In the District of Columbia not only do we have the Healthy Start Project; we have what is called the National Institutes of Health D.C. Initiative, and that initiative is a research project, but it is looking at this issue of infant mortality so we can have a better understanding of what is impacting infant mortality and what is unique about infant mortality here in the District of Columbia.

I think it is particularly important because we are primarily an African-American community. The disparity in infant mortality is in our community, and so it provides a unique opportunity for us to somewhat be a laboratory, even though we do not want to be studied to death, but a laboratory for what can really work. And those efforts from NIH are very community based also. We hope the next level of funding will be more intervention projects that will kind of support that some of the Healthy Start models were actually very, very effective, even though we believe our preliminary data says that.

Also, we are very fortunate to have from CDC an epidemiologist assigned to our office so she can help us look at our data and help me and other staff have a better understanding of data and to use that data to really evaluate and design other projects.

Mr. SNOWBARGER. Does anyone else care to respond? Dr. Guyer.

Mr. GUYER. I think Healthy Start has been a somewhat isolated program since its inception, and I think it would actually benefit if the Federal agencies all spend some time thinking about what have they learned from the Healthy Start experience and how the different kinds of initiatives from the different agencies could interact with each other at the community level.

I think it is hard for community-level people to access all of the different Federal initiatives. You hear that the District of Columbia has lots of them. I suspect Mississippi has few of them; so there is a real unevenness. And I think HCFA also needs to be brought into that because they have the money, and they are potentially the ones who will both fund the failures and benefit from the savings.

Mr. SNOWBARGER. Representative Stokes.

Mr. STOKES. Thank you, Mr. Chairman. Once again, let me thank both you, and your ranking member, Mr. Towns, for inviting me to participate in this hearing this morning.

I have two quick questions. As we seek to reauthorize the Healthy Start Program in its own right and having looked at this program now for a period of 5 years, in your professional judgment, are there certain provisions that we ought to put into this legislation to strengthen it? And I hope I am not covering something that you perhaps have already covered today.

Mr. CRESPO. Congressman, I think that as we look at expanding this project, the local initiatives, I think, have a lot of experience and a lot of wherewithal to help shape the future of how infant mortality reductions projects in this country ought to be run.

I would respectfully recommend, suggest that project directors be brought in on the discussion when it is about expanding a project or funding a project, developing new criteria for a project, so that the Federal Government, the Federal entity charged with it, can benefit from our experience. And I do not know that that has been the case. We need to be at the table in terms of offering some direction and some experience.

Mr. STOKES. Last, as directors, do you see any special challenges facing either Healthy Start Program participants or yourselves as directors of this program?

Mr. CRESPO. The special challenges, sir, when we—I would like to answer that by pointing to our young people, and by "young," I mean middle school because, for the most part, when we get them in high school, it is already too late. So we need to start the prevention and the abstinence messages, we need to start them earlier. We need to start them in middle school.

So one of the challenges, sir, is that if this project is not allowed to continue, we allow—because of it, the Cleveland Public School System is for the first time beginning to track incidents of sexual activity and pregnancy in these schools. That has not been available before.

So I would again—that is going to be a big challenge for that school system and for the Cleveland project to be able to maintain that kind of information and that kind of data.

Mr. SNOWBARGER. Thank you, Mr. Crespo. Does anyone else have any comment?

Mr. COYLE. Just two things.

Mr. SNOWBARGER. Sure.

Mr. COYLE. One is—Congressman Towns asked something about this before—Congressman Stokes—the whole title of paternal child health in some way needs to be relooked at and redefined. Unless we can bring, especially in major cities, the African-American male into this process in a real way, we are going to make very little progress. And as long as we look at this—and I understand all the history of maternal and child health, but we have excluded African-American males from the whole family process. The welfare system has done that. A whole range of things have done that.

Until they are active participants in whatever Healthy Start and whatever other similar projects happen in the United States, we are not going to make a lot of progress.

Also, I just wanted to say that we did not have the opportunity at the beginning, but several of our participants, clients in Healthy Start, who are the heart of the matter, took the time to come down here today to see what a hearing was like because they are inter-

ested in that. I would like for them to stand up so that you know that they came and they wanted to see what this is all about. And they are the people that make our program work.

[Applause.]

Mr. STOKES. Thank you very much. It is nice to see all of them attending a hearing of this sort. I am sure it is edifying for them and a comfort for them to listen to all of the experts testify on something that is so near and dear to them.

Mr. Chairman, I think you have been very generous——

Mr. SNOWBARGER. Dr. Hatcher, did you care to respond?

Ms. HATCHER. I will just briefly say that I think that we are going on the right track with trying to strengthen Healthy Start. If we use the lessons that all of us have learned with 22 projects and we cannot only tell the next projects, but their communities need to understand, this is, you know, kind of the background of infant mortality, so they do not have to start from the beginning. We can give them some information, and they can go from that point forward.

Mr. SNOWBARGER. Thank you. I, too, want to thank all the witnesses for their appearance. Mr. Crespo, it was pointed out to me that you are at the table, but perhaps the table is a little too small and the time too short to get into all the detail that we need to.

There being no further business before the committee, the subcommittee is adjourned. Thank you again.

[Whereupon, at 12:55 p.m., the subcommittee was adjourned.]

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