Advisory Committee on Infant Mortality

RECOMMENDATIONS ON THE FUTURE OF THE HEALTHY START INITIATIVE

Final Report to
Secretary of the U.S. Department of Health and Human Services

December, 2001

The views expressed in this document are solely those of the Advisory Committee on Infant Mortality and do not necessarily represent the views of the Health Resources and Services Administration nor the United States Government.

ACIM

Advisory Committee on Infant Mortality

Antoinette Parisi Eaton, M.D.
Chairperson

Peter C. van Dyck, M.D., M.P.H.
Executive Secretary

Kerry P. Nesseler, R.N., M.S.
Principal Staff

December 2001

Dear Colleague:

The Advisory Committee on Infant Mortality (ACIM) advises the Secretary on Department programs for reducing infant mortality and improving the health status of pregnant women and infants. The Committee, representing a partnership among the public and private sectors, provides guidance and focuses attention on the policies and resources required to address the health and social problems contributing to infant mortality. As part of Secretary Louis W. Sullivan's original charter of ACIM on May 28, 1991, the Committee has had oversight responsibility for the Federal Healthy Start program.

We are pleased to present the Committee's final report on the first 10 years of the Healthy Start program. This report, entitled "Recommendations on the Future of the Healthy Start Initiative," represents the deliberations of an ACIM subcommittee of experts. In meeting their charge, subcommittee members reviewed the program, including the results of the national Healthy Start evaluation released in 2001, the current literature, and recommendations from State and local communities struggling to reduce infant mortality.

ACIM believes there is still an urgent need for the Nation to continue to improve the health of infants and children in all communities and to use state-of-the-art knowledge of the Healthy Start Demonstrations of the past decade. In particular, we recommend the following programmatic directions for Healthy Start, which are discussed in more detail in the report:

1. Broaden the focus of the program to reduction of maternal and infant mortality and morbidity with special attention on reduction of racial disparities to meet Healthy People 2010.

2. Guide the program to provide a framework for community initiatives that are supported by evidence-based interventions and focus greater attention on integration of services, which impact on women and families in high-risk communities.

3. Assure that local Healthy Start grants are closely aligned with the State Title V MCH Block Grant programs because of their complementary goals and enhance those partnerships, as well as private sector partnerships since all are needed to improve health at the community level.

4. Demonstrate accountability by participating in the State/Federal Performance Measurement System and enhancing key State and national data systems to monitor progress.

We feel strongly that this final report's recommendations will enhance efforts to reduce the disparities contributing to America's troubling infant mortality rate, which now ranks 27th among industrial nations.

Sincerely,

Antoinette Parisi Eaton

Antoinette Parisi Eaton, M.D.
Chairperson
ACIM

Telephone 301/443-2170 Parklawn Building, Room 18-05, 5600 Fishers Lane, Rockville, MD 20857 Fax 301/443-1797

ADVISORY COMMITTEE ON INFANT MORTALITY (ACIM) 2001

ADVISORY COMMITTEE MEMBERS

Antoinette Parisi Eaton, M.D.
Chairperson, ACIM
Professor of Pediatrics, Emerita
Ohio State University
Columbus, Ohio

Larry Roger Anderson, M.D.
Family Practice Physician
Sumner County Family Care Center, P.A.
Wellington, Kansas

Polly Arango
Past Executive Director
Family Voices
Algodones, New Mexico

Bruce B. Bragg, M.P.H.
Director
Ingham County Health Department
Lansing, Michigan

James W. Collins, Jr., M.D., M.P.H.
Associate Professor
Northwestern University Medical School
Chicago, Illinois

Mary Lou de Leon Siantz, Ph.D., R.N., * F.A.A.N.
Professor, Associate Dean
Georgetown University
Washington, D.C.

Nancy L. Fisher, R.N., M.D., M.P.H.
Medical Director
Regence BlueShield
Seattle, Washington

Fredric C. Frigoletto, Jr., M.D.
Professor of OB/GYN
Harvard Medical School
Boston, Massachusetts

David E. Gagnon
President
National Perinatal Information Center
Providence, Rhode Island

Elizabeth H. Hadley, M.P.H., J.D.
Consultant
Chevy Chase, Maryland

Robert E. Hannemann, M.D.
Visiting Professor of Biomedical and Chemical Engineering
Purdue University
West Lafayette, Indiana

Agnes Hinton, R.D., M.S., Dr.P.H. *
Associate Professor
Center for Community Health
Hattiesburg, Mississippi

Bette Rusk Keltner, Ph.D.
Dean, School of Nursing and Health Studies
Georgetown University
Washington, D.C.

Darlene A. Lawrence, M.D. *
Family Practice Physician
IMANI Health Care
Washington, D.C.

Tracy A. Lieu, M.D., M.P.H.
Associate Professor
Harvard Pilgrim Health Care & Harvard Medical School
Boston, Massachusetts

Charles S. Mahan, M.D. *
Dean, College of Public Health
University of South Florida
Tampa, Florida

Marsha McCabe, M.S. *
Senior Manager
Raytheon Company
Lexington, Massachusetts

Elizabeth R. McAnarney, M.D.
Professor and Chair
Children's Hospital at Strong
Rochester, New York

Linda A. Randolph, M.D., M.P.H. *
Research Professor and Chair
Georgetown University
Arlington, Virginia

Ann Miller Redmond, Ph.D.
Director of Pastoral Care
Cook Children's Medical Center
Fort Worth, Texas

E. Albert Reece, M.D.
The Abraham Roth Professor and Chairman
Temple University School of Medicine
Philadelphia, Pennsylvania

Carolina Reyes, M.D.
Assistant Professor
UCLA School of Medicine
Los Angeles, California

Diane Rowland, Sc.D.
Executive Vice President
The Kaiser Family Foundation
Washington, D.C.

Jesus J. Rubio, Ph.D. *
Administrator
Associated Catholic Charities
Houston, Texas

Betty K. Tu, M.D., M.B.A.
Clinical Associate Professor
Keck School of Medicine, USC - LAC
Anaheim, California

Kathleen Filip Waleko, Ph.D., M.B.A.
Vice President, Patient Care Services
Magee-Women's Hospital of the University of Pittsburgh
Pittsburgh, Pennsylvania

Deborah Klein Walker, Ed.D. **
Associate Commissioner
Massachusetts Department of Public Health
Boston, Massachusetts

Kenneth D. Wells, M.D. *
President
Wellcorp
Houston, Texas

****Chair, Subcommittee on Healthy Start**

***** Member, Subcommittee on Healthy Start**

ACKNOWLEDGEMENTS

The members of the Advisory Committee on Infant Mortality wish to acknowledge the efforts of many other people who contributed to the preparation of this report. The Advisory Committee appreciates the ongoing contributions and commitment of Julius Richmond, M.D., Former Assistant Secretary for Health and Surgeon General, U.S. Public Health Services, U.S. Department of Health and Human Services; Maribeth Badura, M.S.N., R.N., Acting Director, Division of Perinatal Systems and Women's Health, Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA); Donna Hutten, M.S., R.N., Project Officer, Abstinence Education Program, Division of State and Community Health, MCHB, HRSA; Karen Thiel Raykovich, Ph.D., Senior Fellow, Office of Planning and Evaluation, HRSA; Milt Kotelchuck, Ph.D., M.P.H., Professor, Department of Maternal and Child Health, Boston University School of Public Health; and Amy Fine, M.P.H., B.S.N., Health Policy, Program Consultant.

Advisory Committee on Infant Mortality
Recommendations on the Future of the Healthy Start Initiative
December 2001

Introduction

As we enter the 21st century, the infant mortality rate (IMR) continues to be an important indicator of success in improving the lives for children and their families in the United States. Even though the overall rate for infant mortality has consistently declined from 12.6 in 1980 and 9.2 in 1990 to the lowest ever rate (7.2 per 1000 live births in 1998) in the United States, low birthweight has slightly increased from 7.0 in 1990 to 7.6 in 1998. Of special concern related to both outcomes are the persistent racial disparities in rates for blacks, whites and hispanics that have remained as the overall rates decreased for IMR and increased for low birthweight. For example, the IMR among black infants is over twice that of white infants (2.4 ratio) and rates for hispanics fall between those for whites and blacks. Furthermore, there is a large variation in both black and white rates by state; in 1997, black IMRs ranged from 8.8 to 19.2 and white IMRs from 4.3 to 9.1. Although there has been some improvement in infant mortality rates during the past decade of relative peace and strong economic prosperity, the United States is still far behind all other industrialized western nations in this primary indicator of well-being for children. Finally, the increasing numbers of low birthweight infants born with a variety of associated developmental and other conditions pose special challenges to families and the communities in which they live.

The Advisory Committee on Infant Mortality (ACIM) feels there is still an urgent need for a continued response as a nation to improve the condition of

infants and children in all communities across the nation. Since there are many social, political and economic strategies needed to improve both infant mortality and low birthweight, ACIM recommends that there be a renewed commitment to efforts in improving these outcomes, using the most current state-of-the-art knowledge including the results of the Healthy Start Demonstrations of the past decade.

ACIM's Healthy Start Subcommittee of the Advisory Committee on Infant Mortality met during several ACIM meetings (October, 1998; April, 1999; September, 1999; and February, 2000) as well as separately in January 2000 to discuss findings from the Healthy Start national and local evaluations and to make recommendations to ACIM for the future of the Healthy Start program after the demonstration phase is ended in Spring 2001. The Healthy Start Subcommittee's analysis and recommendations for the future of the Healthy Start program were endorsed by ACIM at the February 2000 meeting. This document will summarize ACIM's conclusions about the nine-year demonstration phase of Healthy Start that was initiated in 1992, as well as articulate recommendations for program, policy and evaluation strategies for the next phase of a Healthy Start initiative.

Learnings from Healthy Start Demonstration Phase

After a careful review of all program documents and evaluation findings on the Healthy Start program, the Secretary's Advisory Committee on Infant Mortality (ACIM) concludes that the goal of a 50% reduction in infant mortality in five years in Healthy Start demonstration communities was unrealistic for the reasons discussed below. The Committee recommends that future evaluation efforts include a broader range of outcomes during pregnancy and after birth, and that evaluation not focus exclusively on the reduction of infant mortality, low and very low birthweight, preterm birth and adequacy of prenatal care. Because of the time it takes to fully implement interventions as well as the nature of the interventions in the Healthy Start communities, ACIM would not expect the national evaluation to show decreases in infant mortality and low birthweight early in implementation development; instead of a reduction in these birth outcomes, ACIM would have expected to find differences in process measures (e.g., increased referrals, increase in women entering prenatal care in the first trimester, etc.), individual "risk" behaviors (e.g., decrease in smoking during pregnancy, decrease in alcohol and other drug use during pregnancy, decrease in domestic violence, decrease in nutritional deficiencies, etc.) and system indicators (e.g., restructuring and linkages among community service providers, changes in staffing to match community profiles, policy changes re: eligibility or content of services, changes in community feedback loop, etc.) most of which were not included in the national evaluation.

The national evaluation included a postpartum survey of both Healthy Start clients and women who resided in the project areas but did not enroll in the Healthy

Start program. Findings from the survey will help understand the differences between the women who enrolled and did not enroll in the project and the services provided to each group. In addition, the outcome analyses between each local site and their two comparison sites, which were usually composites of non-contiguous census tracks matched to the project area on race/ethnicity and infant mortality trends, will provide some insights on the overall impact of the Healthy Start intervention on the rates of infant mortality and low birthweight compared to a similar area of the same state without the intervention. Finally, the results of the national evaluation will not be as robust as originally planned since the original assumption for the evaluation design relied on the early implementation of local management information systems in all sites that did not occur.

Because of the problems with the original design and execution of the Healthy Start evaluation, it is difficult to know the true impact of the various individual interventions (e.g., coalitions, case management, infant mortality reviews, public information campaigns, management information systems, etc.) implemented in Healthy Start sites. Even if the local site evaluations possibly show impacts on short-term outcomes and specific program components, it is highly unlikely that the national evaluation will document an impact on overall birth outcomes as the interventions are currently structured. This may be true because the community-based Healthy Start interventions are inherently limited in their focus and can not change systemic structures such as insurance coverage, hospital practices, unemployment, poverty and violence in the community. It is unrealistic to expect that community coalitions and case management, which account for a large portion of the dollars spent in program

sites, can impact on infant mortality rates in a community without simultaneous changes in other common barriers (e.g., financing of care, access to and entry into prenatal care, cultural competency of care, assurance of quality standards of care, access to substance abuse treatment, access to WIC and family planning, etc.). In summary, Healthy Start interventions implemented in the demonstration phase could not be expected to impact on infant mortality rates unless other systemic changes which remove barriers to care had been made at the same time.

Future Directions for Healthy Start

ACIM strongly recommends that the investment and commitment to the reduction of infant mortality and low birthweight needs to continue with a systemic planned approach to improvement during the next decade. There should be a renewed effort, building from the lessons learned from the demonstration phase of the Healthy Start program during the past decade, to improve infant outcomes and reduce racial disparities in these outcomes across the country. In order to succeed during the next decade in addressing these issues, ACIM believes that all programmatic and evaluation decisions about the future of Healthy Start should be made in the context of other health and human services policies at the local, state and federal levels. In order to reduce infant mortality a systemic assessment of the barriers to reducing poor infant outcomes must be made in the preconception, prenatal, perinatal, postneonatal, and interconception periods. In order to succeed in the future adequate capacity to support efforts in all these periods must be addressed. The barriers which must be assessed in each community in the context of the local and state systems include the financing of medical and related health services, the availability of and linkages among services for high-risk women and their families (e.g., existence of and linkages among services regarding substance abuse, domestic violence, early intervention, family planning, nutrition, etc.), the availability of culturally competent health care providers and materials, the assurance that quality standards of care regarding referrals and regionalization are in place, the availability of information and educational campaigns, and community ownership and participation.

Since the demonstration phase of Healthy Start addressed only a subset of these

issues, future program funding, evaluations and expectations must be made in light of Healthy Start's partnership with other federal, state and local funding streams. The federal funding streams of importance to the impact of Healthy Start are the Maternal and Child Health Title V Block Grants, the Child Health Insurance Program (CHIP), Title XIX (Medicaid), Community Health Centers (Section 330), Early Head Start, Part C of IDEA (e.g., early intervention), Immunization Grants, Substance Abuse Block Grants, Welfare Grants and the Ryan White Program. These federal funding streams, together with state and local financing, determine the context of the Healthy Start experience in a local community.

Program Recommendations: The focus of Healthy Start in the future should be on the reduction of maternal and infant mortality and morbidity. Within this focus special attention for all efforts should be on the reduction of racial disparities in order to meet the Healthy People 2010 goals outlined for the nation. In order to meet these broad goals, programs and policies should be designed which enhance the health and well-being of all women of reproductive age, women during pregnancy, as well as the mother, child and family during birth and the early childhood period. ACIM recommends that more programmatic emphasis should be placed on supporting women's health as well as children's health. More attention and integration of the services which impact on women and families in high-risk communities (e.g., substance abuse, violence, environmental exposure to tobacco and other toxins, etc.) is needed in the next phase of Healthy Start grants.

The national guidance to programs should provide a framework for community initiatives, which are supported by scientific evidence on "what works" for individuals,

families and communities. This guidance should also provide a clear framework for all communities in which flexibility for local solutions to local issues can be shaped. One requirement for the community projects should continue to be community participation and "ownership" through such activities as the development of coalitions and networks focused on the reduction of maternal and infant mortality and morbidity. Community efforts are important since they enhance "ownership," provide "authenticity" by anchoring programs in the values and culture of the community, empower communities to "own" their problems as well as solutions to them, provide a mechanism for communication with all levels of government and other public and private entities, and help to build community cohesion and governance to facilitate on going systems change. It is important to delineate between integrated service delivery and integrated systems at the local and state level; although both are desirable outcomes, it is assumed that the achievement of integrated state and local systems will assure integrated service delivery at the local level. Both service delivery and systems changes at the local level should be tracked over time and linked to the desired outcomes for mothers, children and their families. The developmental cycle for building healthy communities which support healthy children and families needs to be addressed in both programmatic and evaluation initiatives for the next phase of Healthy Start.

Because the goals of the local Healthy Start interventions are similar to those of the MCH Block Grant which exist in every state, local Healthy Start grants should be closely aligned with the state Title V program. **Future guidance for local communities and state projects should be carefully crafted to enhance local-state as well as private sector partnerships since strong action at both levels is ultimately**

needed to improve health and well-being for women and children at the community level.

Local grantees should develop interventions and strategies, which build community capacity, sustain community leaders, foster community empowerment, enhance linkages to high quality clinical services and are consistent with their state maternal and child health system. Moreover, potential grantees should be encouraged to use Healthy Start funding to leverage other resources at the state and local level (e.g., Medicaid and CHIP dollars, hospital and managed care community benefits initiatives, provider practices, purchaser and insurance policies, etc.) in order to ensure program sustainability beyond the funding period. The development and implementation of healthy communities will improve state outcomes and potentially enhance state systems as well as much as those in the local community. Finally, states should be encouraged to partner with local community sites to provide additional technical assistance and support to local sites. In addition to the provision of enhanced technical assistance and support to local grantees, states--in partnership with the federal Maternal and Child Health Bureau--can improve outcomes for all infants and their families in the state through the adoption and implementation of systemic policies and programs known to be associated with improvements in infant mortality and low birthweight.

In addition, states should be given grants for focused work to expand statewide capability for data collection and analyses (e.g., provide funding for ongoing surveys such as PRAMS, conduct localized fetal and infant mortality reviews, etc.), provide technical assistance to local Healthy Start sites, enhance media and public relations

campaigns, coordinate with Medicaid and other purchasers in the state to assure coverage for quality care, coordinate with medical and other health providers to assure clinical guidelines are updated and disseminated and facilitate discussions and negotiations with other state entities (e.g., WIC, family planning, substance abuse, violence prevention and intervention, etc.). Additional money to states focused on these activities is needed to enhance ongoing state efforts currently supported by the Title V block grant since many states do not have enough resources to fully address all the barriers currently in place in local communities and states. New dollars are especially needed by states to support and enhance a broad range of data initiatives and women's health activities.

Finally, universal access to comprehensive insurance benefits for women during the preconception period, women during pregnancy and young children from birth is critical to the success of any Healthy Start initiative. The financing of care is a necessary but not sufficient for improved maternal and infant health outcomes. States and communities with universal coverage for comprehensive quality services for both citizens and non-citizens have better maternal and infant health outcomes.

A strong system's development approach is needed at the state level to support and nurture community activities and change. Healthy Start in the future can be a model for enhancing local-state partnerships for improving the health of women and children in high-risk communities. Although crafting a balance between the community and state is not always easy, strong systems at both at the state and community level are needed to optimize the health and well-being of the members of the community. In addition, both local and state entities need to partner more

successfully with private sector and academic organizations. Future Healthy Start funds should encourage the collaboration and institutionalization of partnerships among a variety of entities (e.g., academic institutions, private sector entities, government agencies, community-based organizations, schools, residents within the communities, policy-makers, elected officials, etc.) in designing and implementing strategies to improve outcomes for infants, their families and their communities.

Future funding for Healthy Start should be authorized as a separate section of Title V of the Social Security Act; Healthy Start should become a sustainable national program linked to the Title V program in each state. Healthy Start funding should provide moderately-sized grants to each state to sustain core strategies (e.g., localized data collection and analysis, public information and educational campaigns, maintain statewide coalitions, etc.) for reducing maternal and infant mortality and morbidity, with the large majority of money available for competitively-bid grants to local communities with the largest disparities in infant mortality and morbidity.

Evaluation Recommendation: Healthy Start grantees in the next phase should participate in the state and federal MCH Performance Measurement System in order to track progress and monitor overall child, family, community and system outcomes. The performance measures selected for local grantees should be consistent with those currently collected for the state maternal and child health block grant and for monitoring progress in meeting the Healthy People 2010 goals. A clear conceptual framework for outcomes and processes expected at the local, state and federal levels needs to be developed to guide evaluation and monitoring of grantees in the next phase of Healthy Start. This framework should include the determinants of

infant mortality and low birthweight to assure that Healthy Start sites include interventions that are likely to impact on the determinants. In addition, the framework should include a broad range of outcomes for reducing disparities in health for women before pregnancy, women during pregnancy and after birth, as well as children at birth and in the early years. Concepts may include those related to the processes and quality of care (e.g., prenatal care during the first trimester, well-baby check-ups, etc.), community involvement (e.g., citizen inclusion in consortia, etc.), impacts on family members and morbidity in the surviving infants and maternal health such be included in the assessment framework.

Carefully executed local evaluations should be encouraged and developed within an overarching national systemic plan for local and state evaluations; a cumulative knowledge base acquired through multiple local evaluations can complement a national evaluation with standardized measures and approaches in every site. **Healthy Start local and state grantees should be held accountable in the short term only for those processes and outcomes they can change.** The focus of evaluations at the local level should be more defined and targeted than those conducted in the demonstration phase; concentration should be placed on the reduction/elimination of systemic barriers that result in poor maternal and child outcomes and can be realistically addressed with interventions funded by Healthy Start. Ultimately, however, the impact of the state systems development initiatives combined with that of local interventions should be on health status improvements and increased quality of life for women, children and their families.

Monitoring and evaluation efforts at the federal, state and local level should be

facilitated in the future by major enhancements in key state and national data systems (e.g., vital birth and death systems, birth defects registries, PRAMS and other survey mechanisms, etc.) in order to assure timely reporting of valid and reliable data which can be used at the local, state and federal levels for accountability and evaluation purposes.

In addition, both the Health Resources and Services Administration (HRSA) and the Center for Disease Control and Prevention (CDC) within the Public Health Service of the Department of Health and Human Services have made major commitments to improving the data collection and analysis capability in local and state maternal and child health programs; these enhancements along with increased funding to states should improve the capacity for timely information reporting and data capacity at the state and local levels.

Finally, evaluations of the impact of systemic changes at the community, state and national level must be supported over long periods of time since improvements in infant mortality rates and other outcome measures are the result of sustained activities and policies over time rather than short term interventions. **In sum, we recommend that Healthy Start in the next decade consist of both local and state grants designed to reduce maternal and infant mortality and morbidity, including the racial disparities in outcomes, in high-risk communities across the country.**