



## Policy equity assessment of the national healthy start initiative

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### ABSTRACT

Infant mortality is one of the indicators of a country's health and well-being and an important determinant of development. Trends in the United States show a decline in Infant Mortality Rate but racial/ethnic, socioeconomic, and geographic disparities exist. The paper analyses the National Healthy Start Initiative, a program created to reduce infant mortality in the United States with a focus on African-American women and other minority groups, using the policy equity assessment method, and provides recommendations on program improvement.

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### Introduction

Infant mortality is one of the indicators of a country's health and well-being and an important determinant of development [1]. It reflects a society's commitment to ensuring access to health care, adequate nutrition, a psychological, social, and physical environment that is healthy, and the alleviation of the effects of poverty [2]. It is calculated as the rate of infant deaths in the first year of life per 1,000 live births. Trends in the United States show a decline in Infant Mortality Rate (IMR) over the past three decades but racial/ethnic, socioeconomic, and geographic disparities exist [3]. Between 2000 and 2011, the IMR fell from 6.89/1,000 live births to 6.05/1,000 live births, however, among African-Americans, in 2007, the IMR was 13.3/1,000 live births (2.4 times the IMR in non-Hispanic Whites) and 9.2/1,000 live births among American-Indians (1.6 times the IMR in non-Hispanic Whites) [4]. The decline in IMR is largely due to increases in the availability of life-saving neonatal care, increased access to primary care, and better nutrition, however, data shows that not all race/ethnic groups have benefited equally from these advances [2]. Among the developed countries, the United States lags in ranking on infant mortality, ranking 34th out of 44 countries, [5] and racial inequities in the IMR is one of the main

reasons for this lag [2].

Because the risk factors for IMR are multifactorial, there are many points of intervention for reducing IMR such as increasing access to pre-conceptual care, provision of quality prenatal care, breastfeeding support and immunization, and provision of safe housing and healthy neighborhoods [2]. The Healthy Start (HS) program was created in 1991 to reduce IMR in the United States by addressing factors that contribute to the high IMR, with a focus on African-American women and other minority groups [6]. The program started with 15 grantees and has expanded to 100 grantees in 37 states and Washington, DC to reduce differences in access to, and use of health services, improving the quality of the local health care system, empower women and their families, and increasing consumer and community participation in health care decisions [7].

Policy equity assessment is a unique, three-stage approach to analyzing social policies and programs for effectiveness in improving equity, integrating policy assessment approaches with rigorous equity-focused research methods. It provides policymakers with comprehensive information on a policy's impact on racial/ethnic inequities, effectiveness among

racial/ethnic subgroups, and identification of data gaps in answering equity-related implementation questions [8]. The first stage, logic, examines the program's history, goals, and design, with attention to whether the program's original conception and subsequent evolution address inequities explicitly; the second stage, capacity, consider the program's ability to deliver services to all eligible participants who could potentially benefit from it; the third stage, research evidence, reviews empirical evidence on program impacts in light of the logic and capacity findings to conclude the program's effectiveness in improving outcomes and reducing inequities both within the program and at the population level [8]. The policy equity assessment has been used to evaluate the Family and Medical Leave Act Section 8 housing program and Head Start Initiative [8,9].

The paper analyses the HS program using the policy equity assessment method and provides recommendations for improvement.

### **Policy equity assessment of the health start program**

**Logic:** The logic stage of the policy equity assessment requires a detailed examination of the policy's historical context-the legislation and the changes over time; the acknowledgment of racial/ethnic inequities (whether explicit or implicit) and the targeting of the services to address racial/ethnic inequities.

The HS program was one of 18 proposals by the interagency Task Force created by President George H. W. Bush to reduce infant mortality. It was launched in 1991 to reduce infant mortality by 50% in 5 years. The program started with 15 sites with IMR 1.5 -2.5 times the national average and were funded to be innovative, community-driven projects and targeted women, infants, and their families [10]. In 2000, HS was authorized by Congress as part of the Children's Health Act and in 2002, the scope evolved to focus on preconception health, child development from birth through age 2 years, maternal depression screening, the involvement of fathers, and consumer participation. It was transformed in 2014 to apply lessons from emerging research, past evaluation findings, and to act on national recommendations from the Report of the Secretary's Advisory Committee on Infant Mortality (SACIM) [11]. From 2019 however, the US Department and Health Services have announced that the HS program will now serve infants and

families for the first 18 months after birth because it will allow the program to focus resources on its key purposes and associated milestones while ensuring support for children through critical milestones. The change was also said to reflect feedback from current recipients in the field to increase program capacity to serve more pregnant women within the project period and promote healthy pregnancy outcomes [12].

The goal of the program ("for logic model see <http://www.healthystartepic.org/wp-content/uploads/2015/11/Scope-Logic-Model.pdf>") is to improve maternal and infant health and to reduce disparities in adverse perinatal outcomes in the United States through evidence-based practices, community collaboration, organizational performance monitoring, and quality improvement [11]. To achieve this goal, the HS program employs five community-based approaches to service delivery and facilitates access to comprehensive health and social services for high-risk pregnant women, infants, and their families in geographically, racially, ethnically, and linguistically diverse low-income communities with exceptionally high rates of infant mortality [11]. The five approaches include: (1) improve women's health; (2) promote quality service; (3) strengthen family resilience; (4) achieve collective impact; and (5) increase accountability through quality improvement, performance monitoring, and evaluation. Each HS grantee is required to address the five approaches, although they may engage in a diversity of activities within the five approaches [11].

Using an equity assessment to the logic of the HS program, racial equity was explicitly stated as part of the program design. The program at inception acknowledged racial disparities in the IMR between Non-Hispanic White and other racial minority groups [6]. HS grants are targeted to places with IMR at least 1.5 times the national average and services are designed to reduce the disparities in the IMR among racial/ethnic subgroups. HS also targets communities with disproportionately high rates of adverse perinatal outcomes such as low birth weight, preterm delivery, maternal morbidity, and mortality [12]. The SACIM report mentioned the social determinants of health as the major cause of racial disparities in IMR and made recommendations for policies and programs to be created to address these factors. Some of these factors include poverty, unemployment, unequal treatment,

institutionalized racism, minority status stress, income inequities, applying a life course approach in explaining the impact of these risk factors, especially as it applied to disparities in adverse pregnancy outcomes among African-American women [2]002E The HS program specifically targets these social determinants of health.

HS funding has no cost matching and sets aside funding for programs on the US/Mexico border. Eligibility for funding explicitly states criteria for target population as those with identified disparities in IMR, and other adverse perinatal outcomes. Eligibility also takes into consideration those with low income.

**Capacity:** The capacity stage of the policy equity assessment focuses on policy targeting and access, specifically, the proportion of the eligible population that was served and the differences by race/ethnicity; the policy resources including current level of funding, funding available for expansion and resources allocated specifically to target subgroups within the eligible population; and policy implementation, such as administrative processes that serve as facilitators and barriers and the fidelity of programs to the set objectives of the program.

Healthy Start Program gives grants to domestic public or private entities including domestic faith-based and community-based organizations, tribes, and tribal organizations [12]. Projects operate in urban, rural, tribal and border communities and grantees specifically aim to address racial/ethnic disparities in the health of mothers and babies in under-resourced communities that face many challenges, including high poverty, inadequate access to care, and environmental risks [2]. As of 2015, there were 101 grantees nationwide (with 1 grantee specifically providing services to native Alaskans) providing services for 24,628 pregnant women [13]. Of these, 61.2% are African-American, 24.2% are Whites, and 4.4% belong to more than one race. Women aged 24 -34 years constituted the majority, 46.6%, with women aged 20 -23 years constituting 27.8% and those aged 18 -19 years constituting 10.8%. In the same year, the program provided male support services to 6,984 men, 41.2% of which were African-American, 8.9% were White, and 4.5% were those with more than one race. Males 18 years and older constituted the majority, 54.7% [13].

From 2008 to 2015, the total number of pregnant women served reduced from 35,667 to 24, 628 [13]. The program has continued to serve more minority populations than White populations in the period with close to 80% of the population served consisting of minority groups [13].

The total number of eligible participants for the HS programs nationwide is not available, therefore it is impossible to determine the unmet need of at-risk populations who are not receiving these services.

The funding for the five-year demonstration period of the 15 HS project areas was \$345.5 million, with an additional \$96 million appropriated by Congress for the sixth year. Subsequent budget appropriations funded additional project areas, as well as the 15 original project areas, although at reduced levels. In 2000, \$90 million was allocated in funding for 94 HS programs, in 2008, the number of funds allocated to the HS program nationwide was \$100 million [6]., it was \$101 million in 2015, and in 2018, the annual budget for the HS program was \$128 million [14]. The funding for HS in the Fiscal Year 2014 -2018 is divided into 3 levels: Level 1-community-based HS; Level 2-Enhanced Services HS; and Level 3-Leadership and Mentoring HS. The ceiling amount for each of these levels are Level 1-\$562,500 for the first nine months and \$750,000 per year for the remaining four years; Level 2-\$900,000 for the first nine months and \$1,200,000 per year for the remaining four years; Level 3-\$1,500,000 for the first nine months and \$2,000,000 per year for the remaining four years. Level 1 grants are expected to serve no less than 500 participants per year; Level 2, at least 800 participants per year; and Level 3, at least 1,000 participants [12]. There are no funds allocated for the expansion of the HS programs. Funds for three grants were set aside for Level 1 funding for grantees planning to target communities in the US/Mexico border. [12].

A qualitative study of selected grantees from the 2004 National Survey of Healthy Start Programs[6]. highlighted several challenges to program implementation: the inability to reach mothers with daytime jobs; undocumented participants who fear deportation; language barriers; and budget constraints which prohibit the provision of tangible goods to retain program participants, as most programs use incentives such as the distribution of items or provision of transportation to retain the enrolled participants. Aside from the constraints of patient engagement and retainment, other challenges to adequate capacity reported were: a lack of adequate staffing which leads to an increase in patient load for the case managers; inadequate funding to meet direct patient needs after assessments; participant distrust; limited mental health access; and mobile or hard to reach populations. These challenges affected the core components of the program including participant engagement, case management, health education, and the provision of direct care to pregnant women. Certain

subpopulations, such as Latinas, homeless people, and drug-addicted pregnant women were described as hard to reach and posed as barriers to effective patient engagement as well as racial, class, and gender-based discrimination.

From the study, community partnership was identified as one of the key ingredients to success and so far, it has demonstrated active community partnerships via town hall meetings, involvement in evaluations, and development of public awareness materials. The HS program has always emphasized the need for cultural competency for staff and providers and to a large extent, grantees have followed this requirement, conducting staff training, providing bilingual staff, and establishing a relationship with the community and faith-based organizations that work with their target populations. Also, grantees reported reduced no-shows, and client retention although these reports were anecdotal [6]. Another study highlighted characteristics of successful HS programs: 1) Strong program organization and administration leading to better program implementation and improved outcomes. 2) Programs that focused on service coordination, with close links to the existing clinical care system. 3) Community involvement through the employment of community residents [15].

## Research

The research stage of the Policy Equity Assessment identifies, summarizes, and assesses research evidence to determine policy outcomes and whether the policy reduces racial/ethnic inequities in outcomes.

Reduction in IMR and racial disparities in IMR between Whites and other minority groups are the major outcomes of HS. Since its inception in 1991, the IMR in the USA has reduced from 9.1/1,000 live births in 1991 to 5.7/1,000 live births in 2017 [16]. Since 2010 however, the IMR in the US has been relatively stable [16]. In 1990, the IMR for Whites was 7.6/1,000 live births compared to 18.0/1,000 live births for African-American women, while in 2015, the IMR for Whites was 4.9/1,000 live births compared to 11.4/1,000 live births for African-Americans [17]. It is clear that while there has been a decrease in the overall IMR, there has been no change in the racial disparities in IMR. In 1990, IMR was 2.4 times higher in African-Americans compared to Whites, and in 2015, IMR was 2.3 times higher in African-Americans compared to Whites. For all racial/ethnic groups, the IMR trend has been downwards, however. Racial disparities also exist in the low-birth-weight rate: African-Americans are about 3 times higher than the rate for Whites and Hispanics [18].

The HS program also tracks the changes in health behaviors of the participants as short-term outcomes which are used as performance measures by the Maternal and Child Health Bureau (MCHB) to evaluate the effectiveness of the HS program. There are 41 secondary outcome measures developed, 23 of which are frequently reported by HS grantees to provide a national snapshot of program effectiveness. These include: percentage of very low birth weight live births; the percentage of live singleton births weighing under 2500 grams; Neonatal-, Postneonatal- and Perinatal-mortality rates; the percent of pregnant participants of MCHB supported programs who have a prenatal care visit in the first trimester of pregnancy; the percentage of completed referrals among women in MCHB-funded programs; the percentage of women participating in MCHB-funded programs who smoked in the last three months of pregnancy; the degree to which grantees have facilitated access to medical homes for participants, etc. Analysis of the MCHB data shows that between 2012 and 2016 (the years for which data are available for these measures), the proportion of pregnant participants who smoked in the last three months of pregnancy increased from 11.8% to 13.1%, the percentage of very low birth weight live births increased from 1.7% to 2.0%, and the percentage of live singleton births weighing less than 2500 grams reduced from 10.2% to 9.7% [19]. These data show that the HS program is not meeting the set goals and objectives for most of the performance measures.

There are published data however on the effectiveness of HS programs by HS project areas. A study in Tampa, Florida found that the HS project contributed to a significant reduction in adverse fetal birth outcomes in families with absent fathers. The majority of the participants of the HS program were black, high school graduates, and less than 35 years old. The effect was retained even after the control sample were matched, demonstrating the effectiveness of the HS program [20]. Among the same population, beneficial effects of the HS program in reducing the risk of adverse birth outcomes in mothers exposed to high levels of air pollutants, and in obese pregnant women have also been reported [21,22]. Another study also reported a reduction in HIV/AIDS risk among women who participated in the program, especially black women participants [23]. The HS initiative in Louisville, Kentucky recorded no infant deaths among participants from 2002 - 2005 and reported a 54% reduction in smoking rates among HS participants [24]. In Sedgwick County, Kansas, HS participants, majority African-American, and Hispanic women were 80% less likely to have a preterm birth

and 70% less likely to have low-birth-weight infants [25]. Among American-Indians in Michigan, there was no difference in low-birth-weight rate, preterm birth, and inadequate care between HS participants and non-participants. However, stratified analysis revealed a lower low-birth rate among HS participants who reside in Medically Underserved Areas [26]. The study suggests HS may be most effective in areas with limited access to care through its focus on community engagement and case management [26,27]. A study done in Kalamazoo, Michigan, found a reduction in the rate of adverse perinatal outcomes in African-American women who participated in HS program but not in their White counterparts showing that HS might address factors responsible for adverse perinatal outcomes in this sub-population [28].

A national evaluation of HS program in 2010 found that only 27% of the programs had a statistically significant effect on lowering rates of preterm delivery and only 20% saw reductions in low birth weight and very low birth weight in participants compared to non-participants [29]. Also, analysis of data from 2001 -2005 found that regardless of enrollment in HS, women who delivered babies after the HS program began were 85% less likely to deliver preterm babies than women giving birth before the program began and they concluded that the community activities of the HS program might have promoted increased attention to health issues among these women with a consequent positive effect on birth outcomes [29]. Another national evaluation study, analyzing data from the 2010 national project director survey data, found that implementation of all core components of the HS program was associated with lower IMR and low-birth-weight rates [27]. These evaluation studies have helped to inform the HS program fidelity and the importance of the HS program components for achieving program goals [27,30].

Since the transformation of the program in 2014, only one implementation evaluation [30]. has been done. Ninety-five grantees serving 341 distinct HS sites and providing service to 44,219 women, including pregnant, preconceptional, and interconceptional women were surveyed in 2016. The majority of the grantees were located in urban areas, with only 20 located in the rural areas and 5 HS sites along the US-Mexico border. Rural areas are usually where there a lot of low income and minority women who have poor access to health care such as abortion and contraceptive access, and prenatal care including screening for depression [31]. However, the distribution of the HS program does not concentrate these services to those areas.

The evaluation found that most HS grantees provided comprehensive needs/risk assessment for their participants, and these include screening for risk factors such as diabetes, hypertension, depression, substance abuse, domestic violence, nutrition, physical activity, and smoking. Only a few HS programs provided direct services related to risky health behaviors and treatment for medical conditions. For example, 40% of HS grantees provided direct services for smoking cessation, 16% provided direct services related to substance abuse, while about 80% provided referral services for these conditions. Direct services for chronic conditions were provided by about 20% of the HS programs surveyed while 75% provided referral services for these conditions. Only 40% provided universal screening for perinatal depression and 13% offered screening of children for socioeconomic risk factors. There was a geographical variation in the implementation fidelity: HS program in rural areas provided more referral services for risky health behaviors (such as smoking cessation, nutrition, physical activity) and treatment of chronic medical conditions (such as diabetes and hypertension) compared to those in urban areas. Also, nearly all HS sites in rural areas offered universal screening for women and children compared to urban area HS sites. However, none of the HS sites met the benchmark performance goal for perinatal depression screening, which required that 100% of all women served to be screened for perinatal depression. Many HS programs provide case management for participants and to engage the community to actively participate in the program: 70% assign single case managers to participants, 13 -15% assign a team of case managers and 30% decide on a case-by-case basis whether to use a single case manager or a team. HS sites also provided linkage services to primary care providers for participants; nearly all HS programs had established protocol to link new participants to primary care; about 77% of HS programs provided linkage to medical services (chronic disease management, dental care, emergency services, routine care, specialist referrals) while 47% provided linkage services to mental/behavioral health services. The evaluation reveals several gaps in the implementation of HS: there was a relatively low rate of referral to community sources for supportive services such as employment, child care, and transportation; heterogeneity in the organization and operation of each HS sites which makes each site differ somewhat from the priorities set at the national level. [30].

It is noteworthy to note that there are several limitations the implementation evaluation of the HS program such as lack of data on service utilization of HS services

by participants, the variability in services offered by different HS sites, survey instruments and methods with possible response bias, limited information about the risk profile and social determinants of health of the participants [30]. These limitations affect the inferences that can be drawn about program effectiveness

## Recommendations

### Logic

The HS program targets at-risk populations and provides a wide range of services to reduce adverse pregnancy outcomes and racial disparities. The logic of the program was explicitly designed to eliminate health inequities. It is possible that the activities designed to achieve this goal are not based on theoretical models of behavioral change. Programs designed based on theory tend to be more successful compared to those that are not [32]. Designing a program using theories of behavioral change helps inform the methods and activities that form the core components of the intervention, and increase the likelihood of success [32-34].

Also, the HS program did not take into account the impact of socioeconomic status, changes in clinical care, and quality of clinical care in its program design [29]. Income inequalities and institutionalized racism are the most important cause of health inequities in the US,[35-37]. and these should be the primary focus of any intervention aimed at reducing health inequities. Using Perinatal Periods of Risk Analysis, Kothari and colleagues demonstrated that regardless of socioeconomic status, African-American women have excess adverse pregnancy outcomes including fetal death compared to Whites. Therefore, it is important to tailor health promotion and preventive approaches towards this patient sub-population [38].

### Capacity

Funds for the HS program have increased since its inception and the number of grantees and HS program sites has also increased. However, the majority of HS sites are located in urban areas and not in rural areas where there are more underserved women. The MCHB should make additional requirements that HS programs be located in rural areas as conditions for funding or by making more funds available to programs sited in rural areas while cutting funding for urban HS programs.

It is also important for data to be collected on the number of people eligible to participate in the HS program in each HS site so that the percentage of those eligible to participate and who are currently enrolled can be

computed. Such data can inform the expansion of the program.

### Research

The HS program has well-defined performance measures with data available to inform evaluation, the most important of which is IMR, including racial disparity data. The HS program also tracks the changes in the health behaviors of the participants as short-term outcomes. However, changes in behaviors do not always translate into positive health outcomes if other social, economic, and political factors are not addressed. Therefore, the evaluation of the impact of the HS program should focus on the primary outcome measures of maternal and infant health. Also, HS sites should receive support in the accurate collection and reporting of data, in form of online support, and the standardization of performance measures being reported will help to provide adequate data for future evaluation [27,30].

### Conclusion

This paper examined the National Healthy Start Initiative using the policy equity assessment tool that evaluates the logic, capacity, and research of the program. The Healthy Start program's logic includes an explicit goal of reducing racial disparity in Infant Mortality Rate and other adverse pregnancy outcomes in the US and targets women and children up to the age of 2 years in areas with Infant Mortality Rate at least 1.5 times the national average. Analysis of capacity of the Healthy Start Initiative reveals that the Healthy Start Initiative continues to serve majority minority populations in urban, rural, and border areas of the US. While rural areas are more likely to have a concentration of risk factors for high infant mortality and adverse perinatal outcomes, there are fewer HS sites in rural areas compared to urban areas. Several challenges have been noted to the successful implementation of the Healthy Start program, chief of which are inadequate funding and staffing. Keys to successful programs include community engagement, effective service coordination and linkage to existing clinical services, and strong program organization. Despite a downward trend in the Infant Mortality Rate in the US over the past couple of decades, racial disparities persist. At the inception of the Healthy Start Initiative, Infant Mortality Rate among African-Americans was 2.4 times that of Whites, and this has persisted still. There is evidence of the positive impact of the Healthy Start program in reducing maternal risky health behaviours and low-birth-weight rates, especially among minority groups. A perinatal period of risk analysis identifies

unique risk factors among African-American women regardless of socioeconomic status that may explain the persistent adverse perinatal outcomes among this sub-population that can form the focus of a tailored intervention among this group. There is a need for accurate data to aid future evaluation of the program to determine the effectiveness of the Healthy Start Initiative and to determine the adequate dosage of intervention and association of program components to the short-term and long-term outcomes.

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