

## THE NATIONAL BLACK WOMENS HEALTH PROJECT, 1983 - 1995: A MOVEMENT OF INCLUSIVE HEALTH CARE FOR GIRLS AND WOMEN

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# THE NATIONAL BLACK WOMEN'S HEALTH PROJECT, 1983 - 1995: A MOVEMENT OF INCLUSIVE HEALTH CARE FOR GIRLS AND WOMEN

## A Thesis

Presented to the Faculty of the Graduate School of Cornell University

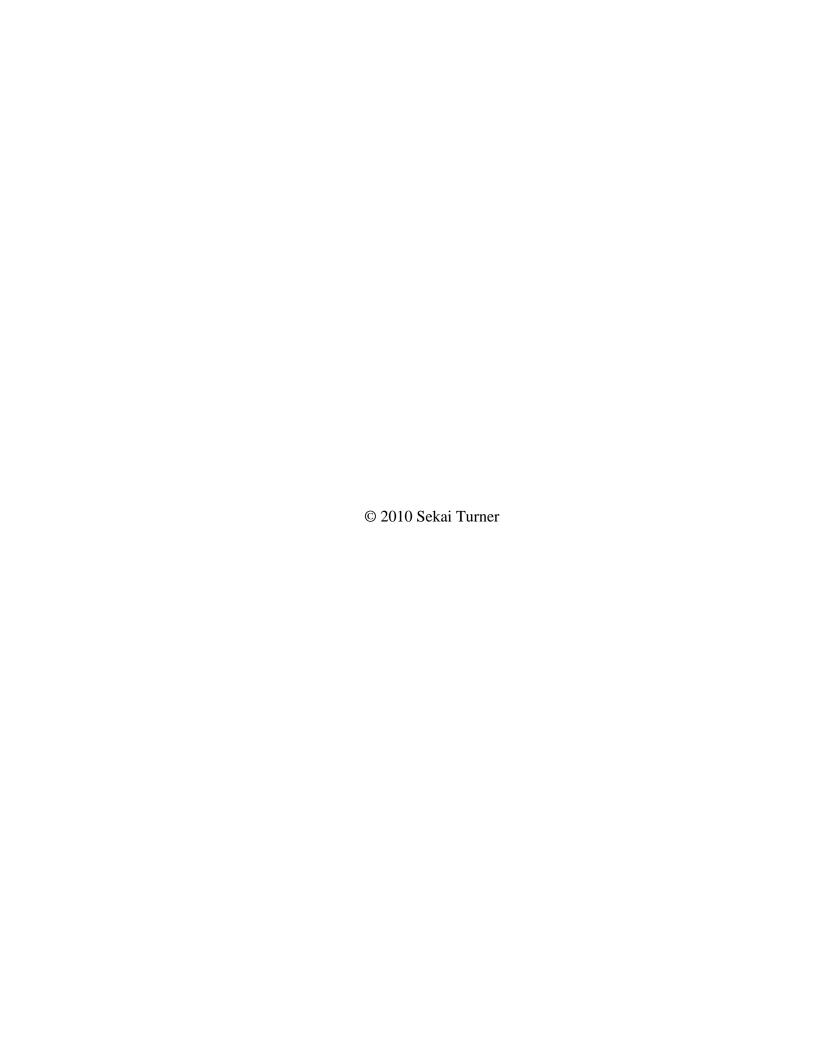
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by

Sekai Turner

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#### **ABSTRACT**

This thesis critically analyzes the National Black Women's Health Project (NBWHP) in its mission to raise awareness about health issues among African-American women in the United States and develop health promotion interventions to be used by adolescents and adult women in the U.S., Africa South America and the Caribbean.

Data in this thesis pertain to roughly 12 years (1983-1995) of NBWHP'S development as a national grassroots organization committed to responding to the health needs of multigenerational and socio-economically diverse females of African descent in the United States population and abroad. Particular attention is given to the organization's development under the leadership of founding President Byllye Avery.

The materials used in this thesis present leading national health issues and percentages for asthma, overweight and obesity, cancer, and HIV/Aids incidences in U.S. children, adolescents and young adults by sex, race/ethnicity and socioeconomic status (based on available data). Selected interventions are reviewed based on evidence-based research underscoring the importance of family health awareness and linking mother-daughter relations to adolescent health outcomes.

Health challenges, documented by researchers of female adolescent and adult health, suggest that strong positive interactions with mothers play an effective role in empowering girls to avoid risks associated with poor health outcomes. Other studies of adolescent girls reveal they may be assets in efforts to "break the silence" around health issues in their families and achieve better health outcomes among members.

## **BIOGRAPHICAL SKETCH**

Sekai Turner received her BA degree in psychology from Spelman College in Atlanta, Georgia, graduating with honors. She completed her master's and doctoral degrees in Human Development at the University of Maryland in College Park. She also holds a master's degree in Social Work from the University of Pittsburgh. She served as assistant professor and project director of a multi-year, youth health promotion campaign at the University of Pittsburgh. In 2006, she served for one year as a visiting assistant professor at St. George's University in Grenada, West Indies where she established the Global Youth School Health Survey Project funded by the Pan American Health Organization, a health promotion collaboration with the government of Grenada. Her research interests include child and adolescent health, family and school-based health promotion with emphasis on intergenerational communication, nutrition, physical activity, and preparing girls to be leaders in the area of health promotion and policy development.

To my grandparents Willie and Alfreida Turner, Rainey and Fanny Pinkney and my parents Janice F. Turner and James E. Turner believers in justice, equality and their granddaughter/daughter's right to define herself free from internalized oppression.

To my friend Jill Hector Bledsoe who brought her own special truth about the meaning of sisterhood to Spelman College. She left us too soon.

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Having grown up in Ithaca, I have been privileged to have enjoyed a long and warm relationship with many of the senior faculty and staff at the Africana Studies & Research Center. In 2008, after receiving notice of my acceptance to the Africana Studies graduate program, I looked forward to my return to Ithaca with excitement and anticipation. While I had the prior experience of attending Cornell for one year as a visiting undergraduate student, I could not predict what my experience would be like years later.

Some, not all, aspects of the Africana Center were consistent with what I remembered from an earlier time, however, the support from individuals who contributed to advancing the department's founding mission was significant and gratifying. My interactions with these wonderful people in the department and other campus units comprise the best part of my experience at Africana and Cornell.

I am deeply appreciative of the opportunity to further my education at the Africana Center. I must thank two of my most cherished and longtime mentors Professors

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In the university context, libraries have always been among my favorite places to meet new people, explore new ideas, and simply escape. Through my many hours in the campus libraries, I was fortunate to amass a solid collection of materials not just from these institutions but those in other states. Looking back, I am certain I would not have been able to locate many of them if it weren't for the kindness and

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Once my thesis committee was formed, a friend congratulated me for securing two members from what she liked to refer to as Africana's "dream team". She meant the unique collection of faculty members who were widely known for their consistent and extraordinary efforts to provide the rest of us with a rich and supportive learning

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Although writing can be quite a lonely business, I am grateful for family and friends who let me know that the work I was doing was valuable and worthwhile. I thank all of them for their good wishes and for being there with me throughout the full journey.

From the start, it was not possible to enter many campus units, attend academic events or even take a meal at one of the dining hall facilities without someone calling me out and sharing their happy association with either one or both of my parents. These acknowledgements were very enjoyable. Based on many shared perspectives, one of the many reasons why my parents are so well respected is their consistent commitment to standing up against injustice and in support of others, especially those placed in difficult circumstances. I appreciate the fact that these values were part of my socialization and also consistent with the rich legacy of Africana Studies at Cornell.

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## CHAPTER 1

#### INTRODUCTION

The main thrust of this thesis is to critically analyze the National Black Women's Health Project (NBWHP) in its mission to promote better health among women of African descent and their families. Formerly, the Black Women's Health Project, the National Black Women's Health Project was founded in 1984 as a women's health collective and became the first of its kind to focus exclusively on improving the health conditions of African-American women in the United States. NBWHP became a model community-centered, health advocacy institution with numerous affiliate groups throughout the United States and is noted for its technical assistance to women's groups similarly operating to alleviate poor health in Africa, the Caribbean and South America.

Centered around the concept of self-help, NBWHP cultivated a tremendous network of women from different backgrounds and welcomed the contributions of *progressive Black men*<sup>1</sup> who embodied the national project's commitment to promoting the health and survival of Black Women. Through this network, African-American men were regarded as valued partners in NBWHP's efforts to launch and promote health clinics, professional conferences, printed materials, health education interventions and activities, community outreach activities, inter-organizational collaborations, global health outreach initiatives and public health policy initiatives.

Historical records show that women of African descent have stood strongly for effective change against disparities in health outcomes and conditions that have jeopardized women, their families and communities (Smith, 1995). During the early 20<sup>th</sup> century, women members of social and community organizations were well aware

<sup>&</sup>lt;sup>1</sup>The concept of *progressive Black men* is found in Gloria T. Hull, Patricia Bell-Schott and Barbara Smith, A Black Feminist Statement – The Combahee River Collective, *All the Women are White, All the Blacks are Men, But Some of Us Are Brave (Feminist Press, 1982).* 

of social and economic inequalities in the U.S. and the role they placed in exacerbating health problems and limiting access to quality health services. Efforts to challenge social injustice; advocate for better community health services; found independent health care facilities; address physical along with personal and social health concerns; and promote health education and preventive health practices were all strategies for improving health outcomes within African-American communities that were embraced by NBWHP beginning in the early 1980s.

In this thesis, I argue that through its work to increase national awareness about women's health concerns and champion the elimination of factors and conditions that place women at risk of poor health NBWHP has created a legacy of health activism that holds particularly significance in the current climate of health reform. Further, the significance of NBWHP should be understood in terms of its assertion that better health among African Americans requires moving away from content created outside of African descendant communities in favor of culturally informed strategies and initiatives that are specific to the social, developmental and ecological realities of women's experiences.

#### Issues in the Women's Health Movement

The rich legacy of African-American women's efforts to promote good health and eliminate factors that contribute to poor health conditions within African-American and neighborhoods have been documented (Smith, 1995). Critical concerns about gender and racial discrimination, child health disparities, poor living conditions, hazardous work place conditions and environmental racism that trigger and reproduce poor health were at the center of many of the health promotion projects undertaken by women from widely different social and economic backgrounds.

While middle income involved in the women's health movement are frequently mentioned for the contributions they have made in the area of women's health, Smith

(1995) underscores that it was predominantly Black lay women with limited resources who took on the challenging public health work in rural and urban communities throughout the North and South. These were extraordinary, every day women, many without formal medical education, who mobilized within their communities to assist those whose needs had been too long neglected. In the introduction to *Sick and Tired of Being Sick and Tired*, Smith writes:

"Despite the increasing involvement of white, and some black, health professionals and government officials in health and welfare work after 1930, much of the history of black health work is the history of lay workers. Laywomen played a key role because segregation severely limited the number of black medical experts; they made health programs available to a larger proportion of their communities than doctors and nurses could ever hope to reach" (1995, p. 2).

Smith further explains how chapter members and affiliates of the National Association of Colored Women, the organization of African-American club women, made significant contributions to African-American communities historically denied access to caring and committed health professionals and well resourced health facilities. Numerous projects focused on health education campaigns, medical services, and advocating for better access to quality public programs and resources.

Wide ranging projects and campaigns revealed the club women's dedicated commitment to alleviating the harmful effects of hazardous health conditions and ensuring the survival of their people. The negative realities of racism and poverty in urban areas spurred the establishment of hospitals that would extend treatment services to African Americans, especially women and children. These facilities also provided rare learning opportunities for African-American physicians and nurses who had been excluded from White medical institutions. African-American club women working in small, remote areas of the rural South brought health education and medical services to homes, schools and churches. In other locations, public health

workers founded community health centers offering unparalleled treatment services; led community-wide health campaigns; advocated for the extension of city services to African-American neighborhoods and the elimination of local environmental health hazards (Smith, 1995).

Primary emphasis on the role of professional African-American men in the movement to improve the health of African-Americans tends to dominate the discourse among African-American health intellectuals which tends to result in relatively little attention directed at the contributions of African-American laywomen (Smith,1995). Not only was the health work of these women critical for raising awareness about the need for better health care in their communities, it also gave community members reasons to work together to protect their institutions and people. Referring to the establishment of Chicago's Provident Hospital and Nurses' Training School, Smith confirms the significant role played by local laywomen: "While Daniel Williams led the efforts to establish Provident, black women presided over most of the community organizing and fund-raising work, tasks that were essential to the survival of all voluntary institutions" (Smith, 1995, p. 22).

By the late 1960s, White women were nationally recognized as lead agents of the women's health movement having incorporated activist strategies born out of the civil rights and freedom movements into their protest agendas. They spoke out in favor of women's reproductive rights and against issues they considered to be harmful to women such as paternalism and sexism in the treatment of women within the health care service and delivery industries (Morgen, 2002). Throughout the U.S., these women led marches, held public rallies, established health collectives, and raised funds all towards the aims of achieving better health services for women and having a say in national public policy matters linked to women's health.

One of the leading organizations active in the women's health movement was the

Boston Women's Health Collective (BWHC) created in 1969 with a small group of middle class White women who first met at a conference in Boston. The BWHC comments on the importance of that initial gathering in the preface of the collective's signature publication, *Our Bodies Ourselves*: "For many of us it was the very first time we got together with other women to talk and think about our lives and what we could do about them. Before the conference was over some of us decided to keep on meeting as a group to continue the discussion, and so we did" (BWHC, 1973, p. 1). After the initial meeting, planned follow up discussions helped participants realize the extent of their common concerns and motivated their development of a series of resource materials describing many aspects of women's health.

To assess leading health related issues confronting women on a national level, BWHC (1973) talked to White women they knew in their families and neighborhoods. Some of the issues were inadequate knowledge about their bodies and appropriate care methods; dissatisfaction in relationships with male partners; frustration with male health professionals and the male-centered health care industry; and internalized sexism. BWHC staff considered that one approach to resolving these problems was bringing women together to work on research papers on little known health topics that could be introduced in education courses with other women. The research papers covered a myriad of health topics relevant to women and were subsequently published in the organization's text, *Our Bodies Ourselves*, which has been printed approximately eight times between 1973 and 2008.

In other women's collectives, members sought solutions to problems they perceived were also negatively influencing women's lives. For the Federation of Feminist Women's Health Centers, Morgen (2002) explains that self-help gynecological examinations and menstrual extractions were introduced as alternatives to the standard medical exams typically implemented by male physicians. Federation women visited

clinics to both perform these procedures and teach women to perform them on their own. Morgen (2002) states that self-help gynecological examinations and menstrual extractions were controversial throughout the movement as Federation members performed them without appropriate medical licenses. Such violations not only polarized group members but caused some observers to question how such alternative care strategies were actually helping the cause of women, especially those with limited resources and medical care options.

The National Women's Health Network (NWHN), the policy unit of the women's health movement, used research evidence to prepare briefings about controversial drugs typically prescribed to women in effort to promote awareness of the potential risks to their health (Null and Seaman, 1999; Morgen, 2002). Charging sexism in the health profession and industry, NWHN criticized male physicians, drug companies and government health departments for failing to inform women of risks associated with various medical treatments and prescription drugs, and for neglecting to share information about existing treatment alternatives. Among NWHN's other efforts to improve health care for women, members developed an information clearinghouse containing different materials about women's health, monitored national health policy initiatives and advocated for the increased participation of women in decision making around health policy legislation.

Before abortions were legal in the U.S., Jane, a group of White middle class women, offered abortion information, counseling, and referred women seeking abortions to physicians willing to perform abortions at affordable costs. Eventually some members of Jane, operating without medical credentials, learned how to perform abortion procedures and began to treat clients themselves. This controversial action, perceived as a literal manifestation of self-help in the White women's health movement, has been largely silenced in the discourse on women's health (Morgen,

2002).

As the movement's cadre of health practitioners and other advocates increased in large cities and small towns carrying out women's health services, they promoted female empowerment through the establishment of "feminist clinics." These clinics, founded by women, hired female health providers and urged the active and informed participation of women in matters of their health while also critiquing male health professionals, the health care industry and drug companies for their faulty treatment of women's concerns. The empowerment approach used by these clinics to address women's health issues was not significantly different from the activities emanating out of other women's collectives. Serious efforts were directed towards providing health education, offering health treatment alternatives, and a pressing for the right of women to decide their own reproductive matters.

Health practices at various clinics across the country differed depending on the values and decision making orientations of clinic staff. The growing concern about the excessive use of prescription drugs to treat feminine health conditions by hospital physicians led to reductions in drug treatments and the expansion of preventive health measures at clinics run by the Berkeley Women's Health Collective in California. Affordable abortion and other gynecological care services provided by both professional and lay health workers were part of the experience at Concord Feminist Health Center in New Hampshire. In addition to menstrual extractions performed at the health centers run by The Federation of Feminist Women's Health Centers, natural home remedies were used to identify and treat a number of frequently occurring conditions.

What was not given much attention in these health collectives at the time, was the way the health needs of African-American girls and women had been shut out of the collective public discourse. The predominantly White staff members at the clinics,

while aware of the terrible burden of racism, sexism and class discrimination impacting the lives of many African-American women, did little to transform this knowledge into practices that would extend needed health services to these women where they lived. Furthermore, problems achieving consensus in decision making contributed to the under representation of African-American women among the staffs at these White run clinics (Morgen, 2002).

Working in small towns and large cities throughout the U.S. to alleviate the health burdens of women while their own needs were neglected by the movement, African-American women reached the conclusion that autonomous spaces were needed to address the unique health concerns of African-American women and their families living amidst difficult social and economic circumstances.

In their introduction to *All the Women are White, all the Blacks are men, But Some* of Us are Brave, Gloria Hull and Barbara Smith assert: "Only through exploring the experience of supposedly "ordinary" Black women whose "unexceptional" actions enabled us and the race to survive, will we be able to begin to develop an overview and an analytical framework for understanding the lives of Afro-American women" (Hull, Scott and Smith, 1982, p. xxii). From a political standpoint and writing from what the authors identify as a "Black feminist analysis", they rejected the separatist ideology of white women and their reluctance to confront racial oppression among themselves and in the spaces they shared with other African-American women. To all concerned, the type of progress that would indicate major improvements in the health and well being of African-American women necessitated research, health education, accessible treatment services and policy initiatives tailored to address their specific developmental and socio-cultural priorities.

The National Black Women's Health Project (NBWHP) was the first national organization founded in 1984 to respond to these critical issues. Based initially in

Atlanta, NBWHP organized women from communities throughout the U.S. and established health education interventions, community clinics around its core value of self-help. Not limited to the health concerns of Black women in the U.S. the national project extended its reach to women and their local groups in Africa, the Caribbean and Central America in its mission "to develop ways of motivating and empowering Black women to take charge of their health, their families, and their lives" (Avery, 2002, p. 573). A major achievement of the national organization was the way its leaders used knowledge of aspects of the developmental, social and cultural realities of girls and women to inform health education and prevention programs and processes. For over 20 years, their unique approaches set the stage for the successful development and operation of project chapters, community-based health facilities, self-help groups in major cities and small towns throughout the U.S.

NBWHP's innovative health programs have been modeled by researchers who stressed the importance of cultural competence in designing preventive health programs for African-American women, men and children. Federal institutions have units for addressing gender and racial disparities and publications that feature information and details about the unique health needs of African-American women and girls. On March 11, 2009, President Obama signed an executive order that created the White House Council on Women and Girls to be led by a senior advisor and friend, Valerie Jarrett. Based on the President's commitment to improve women's lives and eliminate all forms of gender inequality, the Council is expected to focus on challenges impacting women's lives and monitor federal policies for their relevance to female issues. While the Council is supported by many units in the federal government, it has been met with mixed responses especially from women's advocates. Clearly, it is too soon to tell what its contributions will be during President Barak Obama's administrative tenure and beyond.

From the standpoint that insufficient progress was being made to protect the health and well being of many African-American girls and women, NBWHP focused its energies and resources on identifying causes and remedies. Cancer and heart disease continue to end lives too soon and disparities in HIV/AIDS have not been eliminated. Factors associated with poor health are detectable early in a person's life and in the absence of appropriate intervention can carry serious consequences as they develop. Being poor limits women's awareness of what to do to prevent growth of chronic conditions and access needed care. Concerned about these and other serious health issues, the NBWHP leadership marked its 20<sup>th</sup> year anniversary in 2003 by reiterating its commitment to making sure there is greater awareness about the health concerns of African-American girls and women (NBWHP, 2003). Future challenges included adding new national initiatives dedicated to strengthening health education, policy, research; and increasing women's participation in leadership.

Community organizations and projects aimed at addressing health disparities within the African-American community face a myriad of complex challenges. Despite national calls for the elimination of gender and racial disparities in health, the allocation of some government funding targeted for community-based projects, and concerted efforts by lead organizations to effect positive change, it is disturbing to find African Americans continuing to fare poorly on a range of health indicators, health care quality and access. These challenges have also been faced by organizations with long foundational histories and enduring commitments to improving human development outcomes such as the National Council for Negro Women, the National Black Child Development Institute and the Children's Defense Fund.

Reorganizing to achieve better outcomes may require re-envisioning intervention approaches and strategies; affirming programming that is culturally relevant and trusted; ensuring that health policy decisions do not ignore African-American women;

enhancing advocacy among women regarding their own health needs; using research to inform health policy; expanding social networks of African-American women and the institutions they support; and reaching out to all who are dedicated to the survival of African-American women to invite their active and committed participation (Avery, 2002).

Policy decision making in health is tough, personal and political. As essential mandates for guiding action, strong policies can help push past social and economic barriers linked to problems of poor health and difficulties accessing quality treatment. The achievement of national health insurance coverage is just one proposed part of a plan towards improving current health inequities impacting African Americans. However, the elimination of entrenched societal segregation and institutional discrimination which have greatly undermined the healthcare experiences of African Americans relative to Whites necessitates a determined, unified political response that so far has been difficult to achieve. It must be noted that some African-American community-based organizations, specifically churches, have been sought as partners by governmental and other national institutions in the development of health programs and disease prevention initiatives to improve health within their congregations. The level of public awareness about health challenges and the capacity within communities locally and nationally to push for positive change will effect policy decisions and plans to implement them.

Community-based health organizations committed to the betterment of health conditions among African Americans must strive to influence public policies while also addressing major developmental, social and cultural considerations. Certainly, communities may differ in terms of the complex and varied issues linked to health and well being. It is vitally important that there are health professionals and well informed community members who understand the value of specifically tailored and

supportive health promotion and disease prevention measures. The National Black Women's Health Project, a groundbreaking women's health collective, provides the model for linking these critical components.

## **Study Rationale**

In the 1982 publication *All the Women are White, all the Blacks are Men, But some of Us are Brave*, Gloria Hull and Barbara Smith discuss the significance of studying African-American women's experiences. Indeed, the study of African-American women's lives is an essential area of scholarship in Africana Studies. Perhaps, it is one of the most important areas as it is inextricably linked to knowledge about child and family development. While Hull and Smith acknowledge the intellectual traditions of African-American women which have resulted in important documents and materials about many aspects of African-American women's lives, they urge a particular focus on health, specifying issues such as sexual violence, mental and physical health (1982).

Since Hull and Smith's visionary publication, there has been important literature documenting Black women's health and their participation in activist campaigns by Black and White women. Summaries of women's health status relative to various illnesses and diseases tend to be inconsistent in their examination of key developmental, social and cultural context considerations that may be important to explaining female health experiences. Scholars of Black family and community life have informed my understanding of the influence of social, culture and environmental factors on lifestyle choices, gender differences in socialization practices and the value of cultural competence in the design and delivery of programs and services.

As I reviewed numerous health institutions and recalled conversations about the seriousness of many diseases and illnesses impacting African-American women, it was apparent that while some experts point to progress in reducing disparities in

health, data indicate little progress has been made to reduce the disproportionate health burden carried by African-American women. There is lack of agreement when it comes to identifying an effective framework for understanding the health experiences of girls. Examinations of adult health seldom interrogate risk factors in prior developmental periods for their implications in later life. Despite the fact that Black families tend to rely heavily on individual members to help in times of health crises, many struggle to talk openly about issues related to the illness or disease. Since it appears that women and girls are more likely than males to assume heath care roles in their families, researchers must examine what makes health communication so difficult.

The role of African-American women in ongoing efforts to enhance the lives of girls and women is essential to Black family life and survival. In what specific ways has their work been by helped by male participation? Has there been enough collaboration among women and men around eliminating health disparities or not enough? What role have African-Americans played in influencing federal policy discussions pertaining to health? What needs to be done to bring them closer to the process? These are questions that preoccupied me as I developed my research.

The importance of taking the context in which a person is developing into account in understanding health has been emphasized in lifespan development research (Bee, 1998; Santrock 2006). A human developmental framework such as the one proposed by Bronfenbrenner (1977, 1986) is useful for explaining how individuals and the environment interact to influence change over different developmental periods. It recognizes that development is a process and that behaviors in an early part of one's life promote change and continuity and incorporate roles, relationships, socioeconomic and cultural influences.

#### **Justification**

This thesis examines the role of the National Black Women's Health Project in its mission to improve the overall health and well-being of girls and women. The NBWHP was founded in 1984 at a time when little attention was being directed by health professionals, policy makers and health activists to the escalating health problems confronting African-American girls, women, and their families. By stressing self-help, health education and advocacy, NBWHP sought to empower women to take an active role in minding their own health. Towards that end, the national project helped community groups set up chapter affiliates throughout the United States, sponsored numerous learning opportunities, and added their voices to policy debates at state and federal levels.

This thesis will explore the evolution of the National Black Women's Health Project as it opened a previously closed public discourse around the health needs of African-American females. This thesis will focus on NBWHP's work between 1983 and 1995 during which the organizational was led by its founder Byllye Avery. A health educator, reproductive health rights activist and women's health advocate, she was dedicated to ameliorating youth and adult health problems within the contexts of family, community and the larger society. In the absence of national attention, Byllye Avery's work to disrupt patterns of poor health outcomes in African-American communities revealed unprecedented health promoting actions. Black women's developmental health priorities, a self-help philosophy, and a special emphasis on family communication were consistent with Avery's agenda to bring innovative health promotion programs to communities of African descent.

African-Americans are struggling under a growing health crisis burden, widely reported in the media, impacting all who are part of their social networks, particularly those living in poor economic circumstances. African-Americans have a longstanding

and deep commitment to family and African-American women are lead agents when it comes to taking care of the health needs of their families and neighbors. Black family scholars agree that African Americans perceive family as an essential part of their life experiences. The family is the safe context from which members learn critical lessons about developing and surviving particularly in the midst of difficult situations influenced by racism, discrimination, and injustice (Sudarkasa, 2007).

Grandparents, aunts, uncles, nieces, nephews and significant others participate in the development and maintenance of family life as child care givers, health care providers and sources of financial support to those residing in their homes and as well as in other more distant locations--commonly in ways influenced by African traditional customs. As Sudarkasa (2007) has documented, extended family is rooted in a system of African values that stresses self-care, collective work and kinship support.

African-American women and men raising children in households have historically found extended family vitally important to their struggle to socialize their children and provide for their needs. Extended family helped inculcate children around expectations regarding appropriate behaviors, obtain affordable food, clothing and health care and offer counsel pertaining to challenging emotional concerns. Women's participation in these families was primary as children and adults constructed their understanding of different family types and along with relationships with kin and non-kin. It is in these families that girls and women became health promoters and passed on their knowledge to subsequent generations of females.

Studies of African women underscore the importance of their contributions to promoting in families and communities (Onyekweodiri, 1992; Turshen, 2000). As the primary providers of health education and care, they make sure their husbands and children consume nutritious food; maintain a clean household; and obtain safe

drinking water. African women travel great distances to have their children properly immunized and give them access to necessary drug and medical treatments. This health work is part of the socialization girls receive as they develop in African families. Not enough is known about the participation of African-American women in family and community health in the United States as their roles in family health are the focus of a limited body of literature in health promotion studies. Some of the evidence shows they articulate healthy eating goals for their children; set and enforce rules prohibiting risky behaviors; and advocate for better health care services in underserved communities (Williams, 2007). These are issues that are not well understood. Contemporary examples of the ways females work to reduce health problems and promote better health in families and society.

#### **Theoretical Framework**

The Ecology of Human Development is one framework for understanding factors associated with the health experiences of African-American women. It requires that health not be defined as an individual issue, but as one linked to factors embedded within a system of multiple and varied settings that construct a person's social, historical and cultural experiences. Urie Bronfenbrenner (1977, 1986) contends that four nested structures influence the experiences of developing individuals: microsystem, mesosystem, exosystem and macrosystem. The microsystem is the innermost structure wherein individuals experience interactions with their most immediate settings such as home, school, place of employment. In these settings, consideration is given to the setting's physical features, activities, participants and their roles. The next structure of the ecology is the mesosystem, a structure that consists of the interrelations between individuals and their immediate microsystem settings. For example, an adolescent girl's mesosystem may include interrelations among family school, peers, and church. An adult female's mesosystem may include

interactions among family, work, church and health care facility, with the last becoming common in the situation of personal illness or disease.

The exosystem is the next layer of the ecology. The exosystem requires an examination of the external environment to include larger social structures that don't contain the developing individual but may exert a substantial influence on how he or she experiences his or her life. Structures of the exosystem may include but are not limited to a child's neighborhood, parents' world of work, the mass media, government, and the family's social networks. The final structure is the macrosystem.

The macrosystem comprises the social and cultural patterns that effect a person's ideas, beliefs and behaviors in their real life settings. Embedded in this structure are society's rules, policies and laws and how they are internalized by individuals where they live. As explained by Bronfenbrenner: "Macrosystems are conceived and examined not only in structural terms but as carriers of information and ideology that, both explicitly and implicitly, endow meaning and motivation to particular agencies, social networks, roles, activities, and their interrelations" (1977, p. 515).

The use of an ecological framework stresses the importance of the reciprocal nature of human interactions within settings. In the family context, it is understood that parental verbal and non-verbal actions influence their children's outcomes and children have a unique way of shaping the behavior of their parents. Ecological theory requires the consideration of the role of social systems in settings and how the presence of multiple people in a person's life may influence his/her experiences. Within family settings, important social networks may include mothers, fathers and children, or siblings and a parent or members of an extended family. Social networks may also exist external to the family and include individuals in schools, workplaces, churches, health facilities and other relevant community settings.

This examination of female health will use statistical information collected annually

by trusted national health organizations. Book chapters, journal articles, and empirical studies focused on the women's health movement, family influences on youth health and innovative health education models will be utilized. Information about the National Black Women's Health Project will be drawn from book chapters, organizational publications, videotapes, microfiche, and health policy statements. Information contained in national and international health organizations publications such as conference proceedings and health policy reports will be explored as well.

#### **Organization of the Thesis**

The present chapter has sought to introduce the National Black Women's Health Project and to draw attention to some of the key issues that emerge from studying its linkage to the women's health movement and future efforts to improve the health of African American women.

#### chapter two.

Chapter 2 titled, *Developmental Health Issues of Girls and Young Adult Women* presents a developmental overview of key health issues of girls and women from infancy to early adulthood. National and state health data collected and analyzed by federal agencies with programs on child and adult health help illustrate the health status of females with respect to a number of important indicators. Data from The Centers for Disease Control and Prevention, SafeKids Worldwide, the U.S. Department of Health and Human Services, National Center for Health Statistics, and the Office of Research on Women's Health at the National Institutes of Health contributes to this chapter.

Health statistics are provided for the youth population based on a number of indicators including sex, age, race, family income, poverty status, and health insurance coverage. Perspectives on the health of girls and women and the ways that ecological factors influence health outcomes will also be addressed. Health educators,

researchers and activists acknowledge the need for comprehensive interventions that stress the unique health concerns of African-American youth and adults. Increasingly, researchers and practitioners call for utilizing ecological theory to inform the development of relevant family-focused health interventions.

## chapter three.

Chapter 3 titled, "We are the Ones We Have Been Waiting For": Founding The National Black Women's Health Project examines the developmental stages of the National Black Women's Health Project as the first national organization to give dedicated attention to the health needs of African-American girls and women. The chapter covers its mission, organizational components, programs and initiatives.

## chapter four.

Chapter 4 titled, *Breaking the Silence: Overcoming Barriers to Better Health Through Intergenerational Family Communication* is the final chapter of the thesis. Silence among African-Americans around health issues is identified as a serious problem that carries serious consequences for individuals and families. The role of families in influencing youth health outcomes is discussed. Case examples of family-based health education interventions are reviewed.

## CHAPTER 2

## DEVELOPMENTAL HEALTH ISSUES OF AFRICAN-AMERICAN GIRLS AND YOUNG ADULT WOMEN

High infant mortality, diabetes, hypertension and HIV were among the dominant health issues disrupting the lives of African-American women and their families when NBWHP founder Byllye Avery began collecting data on the status of African-American female health in the early 1980s. The disparities in the health data clearly revealed gender and race disparities. Although in her clinic work, Avery observed more White women than African-American seeking reproductive health services, it was apparent that African-American women faced greater challenges trying to achieve health care in general for themselves and their families due to scarce economic resources. Since that time, increasing awareness of health disparities in the United States, growth in terms of new areas of specialized research and the increased use of this research to inform innovative treatments are helping to extend and improve the lives of girls and young adult women. While the importance of this progress can not be denied, considerable research indicates that we are not seeing the type of progress that is necessary to alleviate the disproportionate health burdens in the African-American community and among African-American women, in particular.

For example, while the age at which individuals can expect to live at birth has been on the increase since 1900, gender and race disparities persist (Heron et.al., 2009). In 2006, life expectancy for American females and males was 80.2 and 75.1 years respectively. Overall, life expectancy for African Americans in 2006 was 73.2 years a figure below the 77.7 years which was the reported life expectancy for the U.S. population. In 2006 White females had the highest life expectancy (80.6 years) followed by African-American females (76.5 years). Life expectancy drops to 75.7 years for white males and 69.7 years for African-American males (Herron, et.al.,

2009, p. 7). In both groups of women, the life expectancy was higher than that reported for men. In comparative terms, the life expectancy of women exceeds that of men, however, it must be clear that as women live longer lives, many are facing experiences challenged by chronic illness and disease.

Heart disease, cancer and stroke are the leading causes of death in the U.S. with African Americans carrying a disproportionate amount of the mortality burden. African-American infants die at a rate that is more than twice that of white infants. The maternal mortality rate of African-American women is 3.4 times that of White women. African-American females between two and nineteen years of age are more likely to be overweight compared to White peers. More African-American children suffer from asthma and are less likely to be insured for health care than White children under the age of eighteen. Further, African-American women are overwhelming over represented among cases of HIV/AIDS in the U.S.

#### **Theoretical Considerations in African-American Female Health**

The Convention on the Rights of the Child defines childhood as a human being under the age of eighteen (UN, 1989). This definition is widely accepted by many nations including the U.S. National data collected from U.S. federal agencies that focus on children and families reveals that in 2008, children under eighteen years of age represented 24 percent of the U.S population or 73.9 million residents (Federal Interagency Forum on Child and Family Statistics, 2009). Among this group, the majority are White (56 percent), 15 percent are African American, 4 percent are Asian, 5 percent include other races and 22 percent are Hispanic.

In addition to showing population size differences, data also indicate poverty status. In 2007, African-American children were more likely than White children to live in poverty, 35 percent and percent respectively (Federal Interagency Forum on Child and Family Statistics, 2009). A child under the age of 17 years who lived with two

parents was less likely to live in poverty compared to his/her peer who resided with just one parent. In 2007, 5 percent of White children living in two-parent, married family units were impoverished compared to 32 percent of their White peers residing in single family situations with an adult female parent. The poverty rate for African-American children living with both married parents increases to 11 percent and to 50 percent for those living with a single, female parent.

Given the lower economic conditions in African-American households, differences in health insurance coverage are not unexpected. In 2007, eighty-eight percent of African-American children had health insurance compared to ninety-three percent of White children. These data indicate a modest increase from the previous year (Federal Interagency Forum on Child and Family Statistics, 2009, p. 21). Despite this optimistic trend, African-American children are far more likely to be uninsured and without consistent access to a health care provider than White children. Continued patterns of economic disadvantage among children living in single parent households relative to two parent households suggests that over the course of their development, numerous children may not have access to needed health services.

Developmental experts propose a variety of different theoretical frameworks for explaining patterns in human development change (Santrock, 2004; Feldman, 2010). Developmental changes in health among African-American girls and women identified in this project are revealed in lifespan and ecological theories. Lifespan theorists examine changes in human development covering conception, infancy, childhood, adulthood and death. Throughout each developmental stage, attention is directed at the influence of key changes in such areas as physical (or biological), cognitive, behavior and socio-emotional on individual outcomes. The theory is useful for researchers interested in learning the implications of early developmental trends later periods of a person's life.

Ecological theory supports research about the influence of contextual factors on human development and can be applied to different stages of growth. Data on contextual influences inform the construction of innovative programs and interventions including health promotion. Bronfenbrenner (1986) emphasizes factors within the multiple layers of family, community, and society as the basis for relating such influences to a wide range of human development outcomes. The use of lifespan and ecological theories is consistent in investigations of patterns and trends that may be negatively impacting critical developmental processes.

As African-American scholars increase their focus on health issues confronting girls and women, the lifespan and ecological approaches provide a useful interface and interdisciplinary framework for understanding developmental processes across the lifespan. It is favored by some contemporary researchers and women's health advocates who relate African-American women's health to a state of crisis and call for close analysis of contextual factors influencing their lives. Norma J. Burgess and Eurnestine Brown (2000) in African American Women: an Ecological Perspective use ecological theory to frame discussions about Black women's health challenges citing the limited available literature about the diversity of their lived experiences and the need to further the research about how women and their families develop and survive. The authors state: "Various systems (intrapersonal, community, societal) directly mediate self-perceptions and identity behaviors, beliefs, values and life outcomes for African-American girls and women," (Burgess and Brown, 2000, p. 2). They stress the need for increased understanding about how health relates to family formation, roles and relations; employment status and educational attainment within the context of changing circumstances around housing, insufficient job opportunities and difficulty access to health care. They further urge examining the consequences of these challenges in the lives of children.

Developmental theorists acknowledge that health changes bring new challenges and levels to all connected to an ill person, his/her family and community contexts.

Changes at the individual, family and community role are often suggested in efforts to alleviate stress associated with the health condition and prevent additional long term risk. Knowledge, attitudes and beliefs about health have been shown to influence individual behaviors. Studies of family influences reveal that parents shape their children's outcomes through the quality of the parent-child relationship, level of monitoring and the consistency with which they model the type of health behaviors they would like their children to adopt. There are also health factors not directly related to children's immediate experiences that undermine their personal health such as parents' access to employment-based health insurance and the availability of healthy foods in neighborhood retail shops.

Studies on health risk factors in the U.S. reveal a predominate focus on White youth and families. In the African-American context, the low volume of available information has left gaps in knowledge about critical health problems in the African-American community and viable health innovations to prevent long term health risks. Experts are needed to further the research in these areas.

A number of important questions are relevant when considering health concerns across developmental periods. In the African American context, what are major risks associated with illness and disease during different developmental periods? How does gender relate to health outcomes? In what ways do parents and other family members contribute to youth health comprising and health promoting behaviors? What are the long term costs of risky health behaviors developed in childhood? In this chapter, data on African-American female health between the developmental periods of childhood and early adulthood give indication of the seriousness of the challenges women face in this area. While it is not possible to present everything about health during these

periods, my aim is to highlight selected health conditions and present evidence that offer a basis for relating such issues to key contextual factors.

## **Infancy**

Characteristics of positive development in infancy (birth to 18-24 months) are strong infant-caregiver attachment, symbolic thought, speech sounds and basic word expressions, sensory perception, motor development. A critical health problem during infancy is death within the first 12 months of life, a terrible disproportionate event in the African-American context. As previously mentioned, African-American infants die at a rate that is 2.4 times greater than White infants (Heron, et. al., 2009).

Unintentional or accidental injuries contribute to fatality trends during infancy. Safe Kids (2008) indicates that accidental suffocation associated with choking and strangulation is a leading cause of death among infants under the age of 1 year that disproportionately affects African-American infants. The National Center for Injury Prevention and Control reports that Black infants die from accidental suffocation at twice the rate of White infants with 31.7 and 12.7, respectively (CDC, 2007).

#### **Early Childhood**

Changes that appear to be consistent with children's development between ages 24 months and 5 or 6 years are relative increases in body weight and height, brain maturation and improvements in motor skills. While chronic illnesses or diseases are relatively uncommon among most young children, data show that unintentional injuries account for the most fatalities during childhood especially among poor and minority children (Feldman, 2010).

#### unintentional injuries.

The data on unintentional injuries during childhood give clear indication that accidents such as motor vehicle related traffic incidents, drowning, fire and burn injuries, poisonings are the leading cause of death among children between the ages of

1 and 14 years. The Centers for Disease Control and Prevention (2007) estimate the injury death rate by number of deaths per 100,000 children and report that the rate varies by race. In the U.S., the highest rates of unintentional juries were found among Native American/ Alaskan Native and African-American children. Between the ages of 1 and 9 years, the accidental death rate stemming from motor vehicle incidents for Native American/ Alaskan Natives was 7.0 compared to 4.9 for African-American children and 3.1 for White children. African-American children suffered a higher rate of injury from fires/burns compared to White children (3.0 and 0.9 respectively). More incidents of drowning were found among Native American/Alaskan Natives (3.0) compared to African-American children (2.1) and White children (1.9) (CDC, 2007).

As children age, the racial disparities in the rate of accidental injuries persist. Between 10 and 19 years of age, African-American children had the highest rate of death due to drowning compared to Native American/Alaskan Native children and White children (2.5, 2.2 and 0.9 respectively). Death due to poisoning was more prevalent among Native American/Alaskan Native children (2.1) compared to African-American children (0.4) and White children (1.2). The rate of injury due to motor vehicle traffic incidents was highest for Native American/Alaskan Native children (27.6), followed by White children (16.7) and African-American children (10.9).

The disproportionate impact of accidental deaths on Native American/Alaskan Native and African-American children may be a consequence of low income conditions associated with substandard housing, limited financial resources and lack of compliance with safety recommendations (CDC, 2008). While the data show high rates of unintentional injuries beginning in infancy and extending into adolescence, it is important to note that all of these trends can be prevented through appropriate

programs and initiatives.

# toxins and pollutants.

In addition to accidental injuries, the health of young children may also be jeopardized following exposure to toxic chemicals and other pollutants in their homes and neighborhoods. Chemicals from cleaning detergents and pesticides along with lead and asbestos found in aging housing structures are among the health hazards confronting young children (Feldman, 2010). The health of children living in low income and poorly resourced communities may be further threatened as a result of poor sanitation services, deteriorating buildings and high levels of air pollutants emitted from public transportation depots located in the neighborhoods.

For example, in New York City, six of the eight bus terminals operated by its Mass Transit Authority (MTA) are located in neighborhoods with predominant African-American and Latino residents. These neighborhoods have been exposed to some of the highest levels of toxic air pollution known in the entire city increasing residents', especially children's, risk of asthma and other related health problems (Northridge et.al., 1999; Perera, et.al., 2002). Children exposed to lead and air pollution not only face increased risk of asthma and other respiratory problems, but are also placed at increased risk of learning and behavioral difficulties and cancer.

# overweight and obesity.

The weight status of preschool children aged 2-5 years is receiving close scrutiny by public health professionals, federal and state policy makers. The CDC monitors the prevalence of overweight and obesity among low-income children who are recipients of federally funded health programs (Polhamus et.al., 2009). Using CDC guidelines for calculating BMI or body mass index, overweight among children is determined by a BMI between the 85<sup>th</sup> and 95<sup>th</sup> percentiles and obesity corresponds to a BMI at or above the 95<sup>th</sup> percentile. Polhamus et.al. (2009) report that Native American and

Hispanic preschoolers lead the way in terms of obesity prevalence (20.2% and 18.3%, respectively) followed by Whites (12.6 percent), African Americans (12.0 percent), and Asian or Pacific Islanders (12.3 percent). Between 1999 and 2008, there was an increase in obesity prevalence for all children except those in the Asian or Pacific Islander group. The prevalence of overweight and obesity among young children raises serious concerns about the potential for continuing weight gain during adolescence and adulthood. In many cases of overweight and obesity, young people and adults have been shown to be at enhanced risk of other health problems including diabetes and heart disease. In fact, data indicate that the trend in overweight and obesity, among preschool African-American children changes dramatically after age 5 years (Hedley, et.al., 2004).

Key indicators of obesity risk among preschoolers are excessive television viewing (i.e. more than two hours each day), inadequate physical activity and poor nutrition (Polhamus, Mackentosh, Smith and Grummer-Strawn, 2009). The CDC calls for early interventions that decrease children's television viewing, improve healthy eating and increase physical activity.

Over-consuming foods loaded with fat, sugar and salt, under-consuming fruits and vegetables are leading contributors of obesity in early childhood. Increasingly public health advocates are calling for parents to more effectively monitor the types of foods their children consume. While it is true that parents are very important in influencing their children's nutritional habits, their efforts to reduce unhealthy eating are often beset by serious obstacles. Sherry et.al. (2004) show that peer influences, limited supply of nutritious food, child illness, picky food habits, and beverage consumption before meals were some of the major challenges noted by African-American mothers with children between the ages of two and five years old. Despite these challenges, the study showed that some mothers tend to have healthy nutritional goals for their

children, as determined by their provision of vegetables and proteins during meals, that can help promote healthy child outcomes.

Sherry et.al. (2004) suggest that a general acceptance of their children's overweight status by some African-American parents is a factor that may influence children's health outcomes over time and require relevant intervention approaches. The discussion of obesity will continue in the childhood developmental period. In addition to accidental injuries, exposure to harmful toxins, and weight concerns, other important albeit less common health issues of Leukemia and HIV/AIDS have been associated with early childhood health in the U.S.

Health insurance is a precondition for favorable health status and general sense of well-being. When families in the United States don't have a regular place to receive health care, many seek treatment in hospital emergency rooms. In circumstances of low economic resources, others may be forced to forgo medical care altogether or delay treatment until a time when their finances improve (Bloom and Cohen, 2007). In 2007, ten percent of African-American children visited an emergency room followed by White children (7 percent) and Asian children (4 percent). Eleven percent of children raised in single-parent households had two or more emergency room visits. This figure decreased to six percent for children in two-parent homes. Although more than half (54 percent) of African-American children visited a dentist in 2007, fifteen percent had not had a dental visit in the prior two years.

# Childhood

A major event experienced by children between ages 6 and 11 years in the U.S. and many other world nations is entering their society's system of formal education.

Maturing muscle movements, enhanced motor coordination, advancements in language, memory and social skills are consistent achievements of this period. While childhood is considered a period of relatively good health for many children, the data

reveal a pattern of persistent accidental injuries that are the leading cause of physical harm and fatalities (Santrock, 2004; Feldman, 2010). Between 1987 and 2006, motor vehicle accidents with children as passengers was the leading cause of death among 5-9 year olds and 10 to 14 year olds.

#### asthma.

Asthma and obesity are two common health challenges facing millions of African-American school-age children with particularly severe consequences for those who are poor and without adequate health insurance. National asthma prevalence data show that African-American children are more likely to be diagnosed with asthma (20 percent) compared to White children (11 percent). Further, more African-American children were living with asthma (15 percent) compared to White counterparts (7 percent) (Bloom and Cohen, 2007). It was also shown that twelve percent of children living in poor economic circumstances were more likely to have asthma than their wealthier peers (8 percent).

Asthma is more prevalent among boys than girls and as expected given the documented racial disparity, some research indicates this prevalence is greater among African-American girls than White girls, impacting more children in low-income homes compared to children in more affluent homes (Taylor and Newacheck,1992). In this study, mothers' reports of children's asthma-related experiences showed that race and income predicted a number of asthma related outcomes. About eight percent of African-American children with asthma had difficulty functioning in play activities and in school. This figure is five times greater than the percentage for White children. Asthmatic children from low income households spend more days in bed and miss more days of school compared to their more affluent peers. Lack of access to health care adds to the illness burden for some children. African-American children had fewer doctor visits, were hospitalized at twice the rate of white children and died from

asthma at a rate that was four times that of White children.

## overweight and obesity.

As previously mentioned African-American children have a lower prevalence of overweight and obesity under the age of 5 years, however this finding may be misleading due to the fact that as these children age, incidence of overweight and obesity increases substantially. Hedley et. al. (2004) report that between 1999 and 2002, 31 percent of children ages 6 to 19 year were at increased risk for overweight or were overweight and 16 percent were overweight. The prevalence of overweight was higher among African-American girls (40.1 percent) compared to White girls (27 percent) between the ages of 6 and 19. These figures compare differently among boys ages 6 to 19 with those of Mexican descent having a higher prevalence of overweight (42.8 percent) than African-American (31 percent) or White boys (29.2 percent).

#### Adolescence

Human development professionals characterize adolescence as a critical period of transition beginning around the age of 10 or 12 years and ending around the age of 18 or 22 years, depending on different social and cultural contexts. Adolescence brings more mature physical, cognitive, and psycho-social developments as well as new cultural role expectations. Physically, adolescents are advancing into puberty wherein height, weight and hormonal changes are occurring. Logical thinking and abstract problem solving are consistent cognitive milestones. Close family and peer relationships are at the center of salient developmental tasks. Acquiring understanding and acceptance of all aspects of one's identity such as race, ethnicity, gender, sexuality, and religiosity is also an essential task confronting youth at this time. Theorists suggest that it is through the achievements of these diverse tasks that maturity required for adulthood is possible. Unfortunately, misconceptions about puberty as triggering patterns of risky sexual experimentation, drug use, dysfunctional

parent-adolescent relationships and other antisocial problems have long overshadowed the complex realities of adolescent development among youth in different contexts. For example, there is a tendency to stereotype African-American adolescents as oversexed and intellectually inferior and therefore responsible for many of the social problems in the U.S. These misconceptions have contributed to opportunity gaps in promoting better awareness of actual challenges specific to adolescence and effective methods for protecting them from poor health outcomes.

In the U.S. the Youth Risk Behavior Surveillance System (YRBSS) is a component of the national public health agenda to document and promote adolescent health. Data on adolescent health is collected every two years aimed at tracking the health status of school students in grades nine to twelve (CDC, 2008). The data show important achievements in adolescent health as well as areas of youth health disparities that require ongoing investigation. Six areas of selected health-risk behaviors associated with adolescence and young adulthood are assessed by the YRBSS: unintentional injuries and violence, alcohol, drug use, tobacco use, nutrition, physical activity, sexual behaviors linked to unplanned pregnancy and sexually transmitted diseases (STDs) including HIV infection. Changes in obesity and asthma prevalence are also monitored.

# unintentional injuries.

Data on accidental injury among adolescents show that when individuals fail to wear seatbelts and helmets when traveling in a car or on a bicycle, risk of serious injuries and even death increase. The prevalence of "rarely or never worn a seat belt" was higher among African-American males (14.7 percent) and African-American females (10 percent) than White males (13 percent) and White females (7.3 percent) (CDC, 2008). For the majority of bicyclist (85.1 percent) indicated that they had rarely or never worn a helmet during the 12 month period prior to the survey. Rarely or never

wearing a helmet while riding a bike was more prevalent among African-American males (95 percent) and African-American females (93 percent) than White male (85.6 percent) and White females (79.5 percent).

# intimate partner violence.

Violence in the context of dating relationships is undermining the health of girls. The experience of being deliberately harmed, slapped or hit by a boyfriend was more prevalent among African-American girls (13.2 percent) than White girls (7.4 percent). Also, being forced to have sex against their will was more prevalent among African-American girls (13.3 percent) than White girls (11 percent).

## tobacco and alcohol use.

In contrast to the aforementioned factors, tobacco use is lower among African-American adolescents compared to whites. African-American girls are least likely to use tobacco (8.4 percent) compared to White females (22.5 percent), White males (23.8 percent) and African-American males (14.8 percent). The data on lifetime alcohol use also show race and gender differences. Alcohol use was more prevalent among White female adolescents (76.4 percent) compared to African-American girls (70.0 percent). For boys in the survey, White boys used alcohol more than African-American boys, 75.8 percent and 68.4 percent, respectively (CDC, 2008). Low use of tobacco and alcohol among African-American girls and boys during adolescents does not mean that this pattern is likely to continue into adulthood.

The higher prevalence of alcohol and tobacco use among African-American adults relative to Whites has been documented (French, Finkbiner, and Duhamel, 2002). Studies on substance use show social and economic inequalities in unemployment, housing and education as contributors to substance use among African Americans (Dawson, 1998; Wallace, 1999). Research on tobacco use indicates the quality of the parent-adolescent relationship, parental support and control contribute to low tobacco

use among African-American youth (Nasim et.al., 2009).

# nutrition and physical activity.

A small percentage of American adolescents consume the five or more servings of fruits and vegetables recommended by the CDC for promoting healthy outcomes and preventing such health problems as diabetes, heart disease and cancer. Similar to the patterns of tobacco and alcohol use, African-American boys and girls were more likely to make healthier lifestyle choices compared to their White peers (CDC, 2008). The percentage of African-American females who consumed five or more servings of fruits and vegetables was 23.4 percent compared to 17.6 percent for White girls. Among the males, African-American adolescents, this percentage increased to 26.6 percent compared to 20.1 percent for White boys. Interestingly, this pattern does not compare favorably with the one regarding consumption of soda, as data indicate African-American females drank more soda than White females.

Another serious problem for adolescent health is the lack of adequate physical activity. Among students surveyed in 2007, African-American girls (21 percent) were less likely than White girls (27.9 percent) to engage in 60 minutes of activity for 5 or more days per week as recommended by the National Association for Sports and Physical Activity and the CDC (CDC, 2008). For the males, White boys (46.1 percent) were more likely to have met the physical activity recommendations than African-American boys (41.3 percent).

#### overweight and obesity.

Unhealthy eating habits and insufficient physical activity are triggering overweight and obesity among adolescents in the U.S. particularly for African-American girls. The pattern of overweight among African-American girls begins in early childhood and continues with adolescence enhancing the potential risks of diabetes, cardiovascular disease and cancer in early adulthood (Flegal, Carroll, Ogden, Curtin,

2010).

As previously indicated, African-American female adolescents are more likely to be overweight than White adolescent males and females and African-American males. Interestingly, among this group of overweight females, African-American girls were less likely to describe themselves as overweight compared to White females or to report deliberate attempts to lose weight (CDC, 2008). Some research on body image shows that African-American adolescents tend to have more favorable attitudes about their body size than White girls and those who are overweight tend to believe their body sizes are smaller compared to other girls (Kemper et.al., 1994). While there is not full consensus on this finding, research has suggested that positive attitudes about body weight may be due to a general appreciation of larger female body size held by some in the African-American community (McGee, 2005). Given this positive perspective, it may serve to protect girls from risky weight management practices and related health disorders, however it does not erase the reality of overweight or its negative health consequences for African-American girls and women (Belgrave, 2009).

## sexual activity.

The prevalence of adolescent sexual intercourse significantly decreased between 1991 and 2007 and the use of condoms during sex increased between 1991 and 2003. In 2007, African-American girls were shown to have a higher prevalence of ever participating in sexual intercourse (60.9 percent) compared to their White female peers (43.7 percent). Among those students who had had sex before turning thirteen years old, African-American girls lead the way relative to White girls (16.3 percent and 4.4 percent, respectively). It was also shown that while sexual activity was more prevalent among African-American girls (43.5 percent) compared to White females (35.1 percent), African-American girls were more likely than their White peers to

report using condoms during sexual intercourse (60.1 percent and 53.9 percent respectively).

Public health experts suggest that when adolescents use condoms consistently, they are less likely to contract STDS including HIV. While it is not clear what accounts for the higher prevalence of condom use among African-American adolescents, some research on condom use suggests that positive attitudes about condoms, knowledge of AIDS and self-efficacy may contribute to adolescent use (Reitman et.al. 1996). Being sexually active during adolescence, is a risk factor associated with HIV, another serious health problem for adolescents, particularly African-American adolescents. Between 2001 and 2004, African-American girls accounted for 68 percent of diagnosed HIV/AIDS cases among females aged 13 to 24 years. This percentage drops to 44 percent for African-American males in the same age group (CDC, 2006). Nationally, the CDC estimated African-American adolescents and adults were ten times more likely than Whites to be diagnosed with AIDS in 2007 and that African-American women were diagnosed with AIDS at a rate of 22 times the rate of White women (CDC, August, 2009).

# Adulthood

While opinions differ regarding the precise age when individuals transition from adolescence to adulthood, developmental theorists in the U.S. generally agree young adulthood covers the ages between eighteen and forty (Santrock, 2004). In many American families, perceptions of adulthood continue to be influenced by societal expectations that men and women assume primary responsibility for themselves through securing gainful employment, establishing an independent household and moving through the family life cycle as an intimate partner, spouse and parent. Illness, disease, underemployment and/or unemployment, lack of social support especially around parenting may have a negative effect on young adult progress

toward achieving such cultural expectations.

The state of Black female health is a serious matter of concern in the literature on African and African American health owing to the historical and cultural roles women have played in the area of family health. In countless African societies, the health of the family has depended almost exclusively on women and girls. Studies on women in Mozambique and Zimbabwe show they play essential roles in promoting health in families (Cliff, 1991; Loewenson, 1991) and that their health work includes crop cultivation, collecting safe water, taking young children for immunizations, securing prescription drugs, caring for elderly and disabled family and community members. In traditional Nigerian society, women particularly in rural areas work to maintain a clean household with adequate fuel and water supplies while making sure all family members receive adequate nutrition (Mebrahtu, 1991). Children, especially young girls, participate in food processing and other related household activities. Networks of wives, co-wives, mothers-in-law and daughters along with local women-led community organizations ensure that poor women dealing with difficult economic and health issues receive needed support.

In Côte d'Ivoire, women in the southwest and south east regions not only take charge of household maintenance and food production tasks for the family, but also participate in making key decisions about their children's education and health care needs (Guillaume, 1991). Children, particularly girls tend to work closely with women in household and child care tasks. Other studies have shown that these historical and cultural health work roles of women have continued in African diaspora communities in the Caribbean and United States and deserve further investigation.

A major challenge for women's health in the U.S. during the early 1980s was the

limited number of studies focusing on specific health issues confronting African-American women. The relative lack of discourse among health professionals on such problems as infant mortality, domestic violence, sexual abuse, diabetes, hypertension, and HIV frustrated Byllye Avery as she tried to understand the realities of the African-American woman's experiences. She was convinced that lack of knowledge about risk factors associated with different health conditions was undermining the health of women in their families and communities.

This problem is being given increased attention in contemporary publications on African-American women's health written by predominantly African American women. In much of the literature, heart disease, stroke, HIV/AIDS, domestic violence, mental illness, hypertension, reproductive health problems such as fibroids and cervical cancer, and overweight and obesity are common in the discourse (McBarnette, 1996; Leigh, 1995; Taylor, 2001; Clark, 2003; McGee, 2005). Data on health related risk factors stress the role of limited economic resources, low education levels, lack of health insurance (McBarnette, 1996), genetics, racial discrimination and John Henryism (Leigh, 1995).

African-American women are struggling with a heavy illness and disease burden which carries serious consequences, especially in the lives of poor women. In a 2006 self report health assessment, White and Asian women were more likely than Black women to rate their health as very good or excellent (U.S. Department of Health and Human Services, 2008). It was also indicated that there is a connection between these health ratings and a woman's age and family income. As women age, their perceptions of very good or excellent health decline. Women living in low income family circumstances are less likely to report very good or excellent health.

## cardiovascular disease.

National data show that cardiovascular disease, cancer and stroke are the top three leading causes of death among Americans. In relation to these health problems, African Americans are disproportionately affected. In 2006, cardiovascular disease which includes high blood pressure, coronary heart disease, heart failure and stroke was prevalent among 80,000.000 Americans (American Heart Association, 2009). In 2007, the prevalence of heart disease, coronary heart disease, hypertension and stroke among White adults over the age of 18 was 11.4 percent, 6.1 percent, 22.2 percent and 2.2 percent, respectively. For African Americans, the prevalence of heart disease and coronary heart disease drops to 10.2 percent and 6.0 percent respectively however, the prevalence of hypertension and stroke is higher at 31.7 percent and 3.7 percent, respectively. Similar disparities are found in the mortality data.

In 2005, the American Heart Association (2009) showed that cardiovascular disease accounted for 56 percent of deaths in the U.S. Population. In the report, *Heart Disease and Stroke Statistics 2009 Update At-A-Glance*, the rate of cardiovascular deaths as defined by deaths per 100,000 adults varied by race and gender. The highest rate was among African-American males (438.4) compared to White males (324.7) and African-American women (319.7) while the lowest prevalence was among White females (230.4). During the ten year period between 1995 and 2005, deaths due to cardiovascular disease declined by 26.4 percent. Despite this hopeful trend, African Americans continue to be disproportionately affected.

The American Heart Association (2009) indicates the incidence of cardiovascular disease reveals different risk factors. Among adults 18 years and older, tobacco use is associated with cardiovascular disease and stroke. Overweight, obesity and physical inactivity increase the risk of coronary heart disease and stroke for African-Americans and White men and women irrespective of age. High levels of LDL cholesterol

(equal to or greater than 130 mg/dl) otherwise known as "bad" cholesterol are consistent with heart disease (American Heart Association, 2009).

#### cancer.

Statistics on cancer incidence and mortality are as dismal as heart disease and stroke. For most forms of cancer, African Americans have a higher mortality rate compared to White Americans (American Cancer Society, 2007). For women, breast cancer rates are a source of serious concern. Females under the age of 40 comprise a group with high rates of breast cancer (CDC, 2010). For example, in 2006, 7.6 percent of females aged 25-29 with breast cancer were White compared to 10.2 percent of African-American women. The prevalence of breast cancer for White women aged 30-34 was 24.4 percent and 31.7 percent for African-American women. Between the ages of 35 and 39, African-American women were more likely to have breast cancer than White women (66.7 percent and 58 percent respectively). Breast cancer mortality rates vary among females of different races in the U.S. The rate was higher among African-American women (31.7 percent) compared to White women (22.9 percent) (CDC, 2010).

A number of cancer risk factors relate to women's ability to prevent cancer and increase their rates of survival (American Cancer Society, 2007). Women with limited economic resources are less likely to have access to health insurance which means they lack the benefits of preventive screenings and quality care services. In the absence of early detection and related health treatment, these women die. It has been previously indicated that overweight and obesity are growing health problems among Americans which have their roots in early childhood. These problems, found disproportionately among African-American females, increase the likelihood of breast cancer.

Physical inactivity negatively increases women's cancer risk, particularly breast

cancer. In the U.S. men engage in more physical activity than women, however this participation is less prevalent among African Americans compared to Whites. In 2005, African-American women were less likely to report having engaged in leisure time physical activity (36.5 percent) compared to White women (23.1 percent) (CDC, 2007).

#### hiv/aids.

In 2005, HIV was declared the leading cause of death among African-American women between the ages of 25 and 44 years old eliminating lives at a rate of 20.7 per 100,000 population (CDC, March 27, 2009). Between 2001 and 2006 African-American females comprised the majority of newly reported HIV/AIDS cases among women in Washington, D.C. (District of Columbia Department of Health, 2007).

## overweight and obesity.

Overweight and obesity are critical health issues in adulthood affecting men and women aged 20 years and older. For nearly all age groups of men and women in the U.S. the prevalence of obesity is over 30 percent (Hedley et. al., 2004). The pattern of overweight and obesity prevalence places females in the lead. Between 2007 and 2008, the prevalence of overweight and obesity for white men aged 20-39 was 62.6 percent and 26.3 percent respectively. For African-American men in the same age group, 61.5 percent were overweight and 34.7 percent were obese. African-American women had the highest levels of overweight (78 percent) and obesity (47.2 percent) compared to White women who were found to be 54.9 percent overweight and 31.3 percent obese. These high rates of overweight and obesity have placed the health of men and women at serious risk. As previously mentioned, heart disease and stroke are associated with obesity. Diabetes, high cholesterol and some cancers have also been linked to obesity in adults (Hedley et.al., 2004).

Data on overweight and obesity among adults in the U.S. show that insufficient

consumption of fruits and vegetables and lack of access to these healthy foods contribute to poor health outcomes. Physical inactivity particularly in low income communities has been attributed to the absence of safe spaces to exercise in neighborhoods. Neighborhood farmers markets and the construction of community walking trails are some suggestions health experts are currently proposing to reduce overweight and obesity and promote better health outcomes.

In conclusion, despite more recent attention to African-American female health by national health institutions and academics, the problem of disparities continues to persist. Important achievements have been made in the area of female health as evidenced by increases in the rate of life expectancy for women in general. However, African-Americans and females continue to carry the disproportionate burden of many of the leading causes of death in the U.S. such as heart disease, cancer and diabetes. The data presented in this chapter are drawn mostly from sources that monitor health in the general population and the few that focus solely on African Americans.

In the decades since Byllye Avery began her exploration of African-American female health issues, research has been conducted to learn more about the incidence and prevalence of diseases associated with high mortality rates including cancer, heart disease and diabetes. Considerable attention is also being given to developmental health concerns beginning in childhood. Given the growing consensus among health professionals that many of the more serious health problems are preventable, it seems odd that there aren't more proactive national, state and local campaigns to enhance public health education in schools, employment settings, and the media. As research indicates, there are important strategies that can help reduce health risks and protect girls and women from poor health outcomes.

Responding to the need to treat the health needs of African-American females in their own right, the National Black Women's Health Project was founded. What is needed to create a culturally authentic agenda to alleviate the heavy health burdens facing girls and women and promote good health is the question that inspired my examination of the organization's mission, agenda and contributions in the U.S., Africa and the Caribbean.

# CHAPTER 3

# "WE ARE THE ONES WE HAVE BEEN WAITING FOR": FOUNDING THE NATIONAL BLACK WOMEN'S HEALTH PROJECT

On June 24, 1983 approximately 2,000 concerned African-American women gathered at Spelman College in Atlanta, Georgia for the first national conference dedicated to the theme of African-American women's health and sponsored by the Black Women's Health Project at the National Women's Health Network. Traveling from the deep South, Washington, D.C., Philadelphia, and New York, and other areas in the United States and the Caribbean, women brought their daughters, mothers, sisters and sister friends to hear African-American female health professionals share information about health the sort of health topics that concerned them. Meeting on the campus of an historically African-American women's college, many of them for the first time, these girls and women overflowed the classrooms and lecture halls at Spelman taking in information about a myriad of little known health issues and exchanging personal stories of struggle and resilience.

In the conference keynote presentation, Dr. June Jackson Christmas, former President of the American Public Health Association, addressed a number of complex issues regarding the health status of African-American youths and adults. She stressed the importance of evaluating racism and economic disadvantage, especially as they relate to health risks and access to health care in the experiences of girls, women and also men (Christmas, 1983). She called on participants to take action on behalf of their health by engaging in healthy lifestyle behaviors and seizing opportunities to stand up against all forms of injustice that blocked their access to and receipt of quality health care.

The passionate visionary health educator, activist, Florida native and founder of the Black Women's Health Project, Byllye Avery who had conceived the national meeting

understood how racism, sexism and classism undermined the emotional and physical health of African-American adolescent and adult women and made sure the many workshops, panel discussions and demonstrations focused on these realities. One particularly popular workshop that resonated with conference participants was titled, "Black and Female: What is the Reality?" presented by, Lillie Pearl Allen. Allen, who was a family medicine educator at Morehouse Medical School in Atlanta, Georgia, introduced the concept of internalized oppression, discussed it in terms of the related consequences to a person's physical and emotional health and explored strategies to alleviate it.

In the absence of national action focused primarily on alleviating health problems in the African-American community, conference hosts and session leaders seemed to be encouraging participants to imagine a community-based action agenda for identifying goals, objectives, and plans (both immediate and long term) towards the establishment of education, research, policy, economic and advocacy initiatives—all geared towards improving female health. In the short space of a few days, girls and women from diverse geographic and socioeconomic contexts interacted with African-American female experts in areas such as nutrition, cancer, heart disease, substance abuse and reproductive health. These professionals presented health data that showed African-American women how their health was connected to their every day realities. In the sessions, lack of knowledge about risk factors associated with leading causes of death, insufficient community resources, racism and gender discrimination, violence in families were revealed as common to personal experiences of women.

By sharing information on relevant topics, conference presenters sought to reverse the harmful trend of silencing communication about health concerns within families and provide models for disrupting patterns of negative health outcomes. As revealed in individual reflections about organizing African-American females in this way, the outcome was remarkable. Beverly Guy-Sheftall, director of the Spelman College Women's Center which she founded two years prior to the conference, referred to the meeting as "historic and unforgettable." She noted the significance of having the event on Spelman's campus in the statement: "The 1983 National Black Women's Health Project (NBWHP) conference was the most successful community outreach effort in which the college had been involved over its 103-year history (Guy-Sheftall, 1993 p. 85). Avery described the gathering as "magical" citing the importance of June Jordan's contribution to the conference theme, "We Are The Ones We Have Been Waiting For" and the conference title taken from the historic words of Fannie Lou Hamer, "We are sick and tired of being sick and Tired" (Avery, 2005).

Committed to meeting women where they lived, sites in Black communities and institutions became salient for expanding NBWHP's cadre of health educators and advocates. Many girls and women in predominantly African-American public housing communities and historically Black colleges and universities answered NBWHP's membership call to help lead the development of health education programs and campaigns to ensure that the nation's health policy discourse was connected to the experiences of Black females.

In a closing session of the conference, exhilarated conference participants unwilling to end the conversations about their common realities queried Avery about her next steps on their collective behalf (Avery, 2005). One year later, Avery's response was delivered in the significant act of founding the National Black Women's Health Project, the realization of a long held dream of working primarily with African-American women to achieve a better pattern of health outcomes. Between 1985 and 1995, Avery led the organization in its mission to promote national awareness of critical health issues among African-American women and remove barriers to quality and affordable health care.

From NBWHP's inaugural conference to its changing leadership and national project location in later years, the organization became known nationally and internationally for its holistic and grassroots approach to female health. Initially, NBWHP organized within African-American communities to increase the involvement of African-American women in the pursuit of improved reproductive health services and rights for women in general. NBWHP's leadership opposed all types of discriminatory policies and practices that sought to deny women's access to quality health care and the right to be agents of their own health care decisions.

Realizing the important role females play in family health, the national project insisted that medical professionals provide women with all necessary information for identifying the best available health treatment options. NBWHP health communication experts assisted other public health institutions with the development of culturally consistent outreach activities and print materials that targeted people in African-American communities. Through its advocacy for women's health rights and self-help, NBWHP, following in the tradition of earlier African-American women's club organizations and other such widely known institutions as the National Council on Negro Women, was intolerant of oppression in the lives of African-American women, their families and communities (Avery, 2005).

# From Conception to Reality

The combined influence of the sudden loss of her husband in 1970 from a massive heart attack when he was 33 years old, a developing awareness of health disparities and observations that African-American women underutilized available well woman services were leading factors that convinced Byllye Avery that the health of African-American families and communities depended on educating and empowering African-American women to become strong advocates for their personal and family's health. Employed in the Children's Mental Health Unit of the

University of Florida in Gainesville, Avery's work in the area of special education held no apparent connection to female reproductive health until she and two other colleagues were asked by a supervisor to develop a presentation about women's health issues with an emphasis on abortion. Although it was becoming more well known that Black women were seeking abortions similar to White women, the issue of abortion was not discussed widely or openly within Black families and communities. It was Avery's growing concern about the exceptional challenges that poor and Black women faced while trying to access needed reproductive health services for abortions that became a precursor to her involvement in that area of women's health activism.

In 1971, Avery and her two colleagues Judy Levy and Margaret Parrish designed and implemented the presentation on women's reproductive health issues that they would replicate many times in the local communities. Although neither of the women had direct experience in women's health services, local women seeking abortions began to regard them as trusted resources. Given that abortion was illegal, mostly White women contacted them about reliable services in other states. As the requests became more frequent Avery, Levy and Parrish were prompted to research abortion services in other states and located a health professional working in a New York city clinic. They passed on the contact information to interested women. As Avery encountered similar requests for referrals from African-American women, she grew aware of the differences in their realities. Because African-American women had so few resources, obtaining an abortion in New York City was not an option available to them. Unfortunately, these women, compared to their more privileged White peers, were more likely to be placed at risk of injury and even death by questionable practitioners performing cheap abortions under hazardous circumstances (Avery, 2005).

In 1974, driven to make abortions more accessible to women, Avery along with

Judith Levy, Margaret Parrish, Betsy Randall-David and Joan Edelstein opened the Gainesville Women's Health Center (Silliman et.al., 2004). By this time, Roe vs. Wade had succeeded in legalizing abortions thus enabling Avery and her partners to obtain needed funds to support the clinic's comprehensive health services. In addition to performing abortions, clinic staff also provided education workshops on birth control, preventive gynecology, sexuality and menstruation. The clinic was established to remove barriers that restricted women's rights to chose the type of care most suited to their needs. Avery stressed the importance of making sure Black women were aware of the clinic's existence. She states, "I did not want the center to be seen as a place just for white women" (Avery, 2008 p. 222). This unwavering commitment to empowerment was essential to health promotion goals and priorities.

The passage in the U.S. Congress of the Hyde Amendment in 1976 authorized the federal government to cut Medicaid payments to facilities conducting abortions. For poor women and African-American women, this meant a tremendous reduction in their options for acquiring safe abortion services. For other women, requests for abortion services were diminishing. Responding to these changing health service needs led to new opportunities for Avery to contribute to female health.

In 1978, Byllye Avery, Judy Levy and Margaret Parrish pulled out of the Gainesville Clinic and established Birthplace, an alternative birthing center. Through numerous conversations with local women, Avery and her colleagues had been made aware of their dissatisfaction with conventional birthing services in hospitals. These women wanted to deliver their babies in the safe spaces of their homes and appealed to Avery, Levy and Parrish to support them. Similar to the Gainesville Center, Birthplace was established with the aim of providing with women with safe, affordable and comprehensive health services. At Birthplace, a certified midwife delivered the babies and other staff took charge of outreach, birthing education programs and child care

services (Avery, 1989).

In the initial years following the establishment of Birthplace, the number of clients outpaced the clinics resources. The founders grappled with the serious challenge of how to increase the staff of midwives in the midst of limited financial resources. Avery made the final decision to resign her post. She states: "I left the birthing center around 1980 or '81, mostly because we needed more midwives and I wasn't willing to go to nursing school" (Avery, 1989, p. 15). Keeping the clinic alive meant moving on to a new opportunity, one that would greatly enhance Avery's preparation for NBWHP.

A new job offer presented Avery with the opportunity to work primarily with young African-American women enrolled at the Santa Fe Community College in Gainesville. The job with the Comprehensive Education and Training Program (CETA) involved creating learning opportunities for a group of students. Eager to understand their personal histories, Avery spent time talking to the women about many aspects of their lives including childhood health issues, family member health condition, health seeking behaviors and other related social and economic challenges. Through her engagement with these young women, Avery reached a clearer understanding of the different ways that family and community factors influence a person's life. Many of the women were living with similar serious emotional and physical health conditions such as depression, diabetes and sexual abuse. In addition many of the young women had primary responsibility for parenting multiple young children.

In the absence of education and support resources, young women in difficult circumstances faced considerable stress. These interactions added new understanding of what it meant to be both female and African-American in the U.S. (Avery, 1991). The awareness that African-American women had varying experiences would prove

essential to Avery's capacity to lead NBWHP and build coalitions among other groups of women representing different social, economic and ethnic backgrounds.

At Santa Fe, Avery responded to a public announcement from the National Women's Health Network (NWHN) calling for applicants to serve on their Board. Between 1977 and 1979, Avery participated both as a member of the Network and served as one of the Board of Directors. In 1981, she joined the Network's Executive Committee (BWHP, 1983). During this time, Avery noticed how few African-American women participated in the Network's sponsored programs and in the organization's leadership roles. The Network's staff was predominantly White and the health priorities they raised were related to their common experiences. Similarly, organizational publications reflected the images and issues of White women. Avery concluded that African-American women needed an independent agenda centered around protecting family and community health and preparing generations of health advocates.

Assured of support from the Network, Avery took the lead on an initial project investigating the state of African-American women's health in the U.S. The data she reviewed told of a terrible reality for many African-American women. High blood pressure, diabetes, overweight and obesity were among the conditions ravaging the African-American community (Null and Seaman, 1999). Realizing the critical importance of the data, Avery sought additional funding to create a separate unit that would focus solely on the health priorities of African-American females. With endorsements from June Jackson Christmas, president of the American Public Health Association and technical assistance from Belita Cowan, director of the National Women's Health Network at the time, Adissa Douglass with the Joint Center for Foundation Support and Julia Scott (who would later become an executive director of NBWHP) with the Ms. Foundation, with Avery succeeded in acquiring a seed grant

from the Ms. Foundation and in 1981 she created the Black Women's Health Project under the auspices of the National Women's Health Network (Avery, 2005).

As financial support began to grow in support of Avery's developing agenda, she realized that the type of project she had in mind would need a strong base of input and support from other African-American women. Up to that time, her engagement around women's health issues had involved predominantly white women whom she interacted with the clinics and other organizational work sites. To maximize her networking opportunities with other African-American women, Avery resigned her position at Santa Fe and relocated to Atlanta.

In Atlanta, Avery met African American women interested in her health agenda through her NWHN colleagues. She was initially introduced to Lillie Allen, a professional health educator and Eleanor Hinton-Hoytt, an employee of Essence Magazine with conference planning experience. With continuing support from NWHN colleagues, Avery worked for two years with a group of about 20 women committed to designing and implementing a health conference on topics unique to concerns of African-American women. Avery's beliefs in self-persistence, collective collaboration and cultural relativism were consistent with her world view.

As part of the planning group's development work, Avery took advantage of opportunities to meet African-American women in their home communities to learn first hand what they perceived to be major challenges in their lives. One opportunity was made possible in a rural Florida community where a group of women were struggling with obesity and invited Avery to meet with them. Having accepted this invitation, Avery prepared to present information about obesity risk factors and commonly recommended methods to change behavioral patterns. Realizing that the women were already informed about obesity health prevention and were living in the midst of deeply troubling life circumstances, Avery modified her approach to

incorporate an analysis of the impact of stress on health. The expanded approach involved sharing personal challenges with other women, identifying constraints on lifestyle behaviors, and adopting more productive behavioral health strategies. As one of the women said to Avery:

"I work for General Electric making batteries, and from the stuff they suit me up in, I know it's killing me. My home life is not working. My old man is an alcoholic. My kids got babies. Things are not well with me. And the one thing I know I can do when I come home is cook me a pot of food and sit down in front of the t.v. and eat it. And you can't take that away from me until you're ready to give me something in its place" (Avery, 1989, p.15).

These community visits led to conclusions that Black women lacked effective support systems. The example of the Florida women showed the effects of social and economic marginalization that was unlike the realities in communities where more privileged women resided. There was no doubt that this pattern of unhealthy living had serious implications for personal and social development.

Avery's team based its program proposals on life events of Black women nationwide. Reviews of the research literature informed the identification and development of applied health improvement programs and activities. The planning team modeled the steps they were recommending for achieving personal and community health. For example, Avery and Lillie Allen agreed that group discussion about personal issues and concerns and dedicated outreach strategies were essential for ensuring the participation of African-American women. Questions that resonated with the group were: "What were we concerned about? How Do we learn who we are? What is the most effective way to reach African-American women? (Avery, 2002, p. 572). The answers were critical for institutionalizing the signature health initiatives of National Black Women's Health Project.

At an earlier period of project conception, Avery envisioned organizing a one-hour informational workshop about selected health issues (Avery, 2000). As she became aware of the complexity of the research data on African-American women's health and the reality that information alone would not enable the kind of impact she and the others imagined, she reformulated the project aims. Avery realized that a project dedicated to improving African-American women's health had to respect female agency; foster trust and confidence in the communication process around issues relevant to the African-American female experience; model ways to overcome barriers to good health; conduct comprehensive outreach to low income women in urban and rural communities; and build collaborative networks with women's groups and institutions evidencing mutual commitment to the survival of African-American women. On the basis of these ideas and goals, NBWHP was launched (Avery, 1990a; Avery, 1990b).

## **NBWHP Mission Statement**

From the outset, NBWHP was dedicated to eliminating factors responsible for varying health indicators that were disproportionately impacting African-American women. Poverty, racism, and social inequality are major constraints on youth and adult development and on their pursuit of good health. Despite wide concerns about these issues within African-American communities, they were not prioritized in the discourse among health professionals and policy makers during the women's health movement of the 1970s. As leading White women's health collectives applauded their achievements in securing women's rights to select their preferred type of reproductive health services, the disadvantages poor and African-American women faced as a consequence of unjust federal and state mandates were silenced. Government sponsored sterilizations and the elimination of health care grants for poor women enhanced their health risks and blocked access to quality treatment. The urgency of

these concerns and many others must certainly have resonated in Sister's Chapel on Spelman's campus when participants at the inaugural conference called out Byllye Avery to take action regarding next steps in the area of African-American women's health and well-being.

Ascertaining the critical needs of African-American women from different Socioeconomic and geographic contexts in the U.S. was central to NBWHP's aim to develop culturally appropriate health promotion interventions. In Avery's words,

"What we have to do as organizers is to bring these women together, to get them to sit and talk openly and to start sharing what things have worked for them. What has your life been like? What has it been like for you growing up as a black woman? What did your parents talk to you about in terms of sex and sexuality and feelings of being in charge?" (Avery, 1896, p. 246).

The success of these actions was facilitated by grassroots organizing within rural and urban communities and a strong emphasis on female empowerment through self-help strategies. Women struggling alone and in silence with personal and family health problems tended to lack adequate resources and access to trusted health institutions and services. By engaging females in an empowerment process, NBWHP sought to alleviate stress through the identification of their major challenges and introducing resources to help facilitate change (Avery, 1989).

Within the initial five year of NBWHP's growth, the national leadership took steps to institutionalize their signature health promotion programs and approaches. During this time, the self-help methodology helped to enhance the success of project goals (Avery, 1991). Dramatic growth in the development of national chapters in cities throughout the U.S. helped spread NBWHP aims and objectives. The chapters shared the national office's commitment to improving the health and well-being of women and their families and frequently contributed to different national activities (Braxton, 1991). In addition to endorsing the national organization's major campaigns and

events, chapters also designed and implemented projects based on the needs of their local constituents.

Operating under the umbrella of the national office, some chapters became officially incorporated as independent structures with their own board of directors. This strategy facilitated their long term stability relative to other chapters that depended more on the national office (Avery, 2005). Appreciating the influence of the chapters in communities nationwide, the national office extended technical assistance and guidance to support operations. The additional outreach included regional training institutes, instruction around policies and procedures, recommendations for program development and evaluation and strategies for enhancing member recruitment. Most importantly, the national office stressed that all chapter leaders and members understand its perspective on the meaning of good health:

"For us, health is not merely the absence of illness, but the active promotion of the physical, spiritual, mental and emotional wellness of this and future generations. Such wellness is impossible without individual and group empowerment, which is essential to the redefining and reinterpretation of who Black women are, were and can become" (Springer, 1999, p.37).

NBWHP evolved as a critically important organization grounded in the cultural belief that girls and women play are essential health caretakers. NBWHP served as an exemplary model upon which other women's collectives health developed their priorities and programs.

## **Organizational Structure**

## mother house.

A former family home in Atlanta, Georgia became the national headquarters of NBWHP after staff briefly occupied an office in the King Center. A local family foundation donated the house which NBWHP affectionately titled, "Mother House". From this base, Byllye Avery guided the national office as Executive Director (see

Appendix for complete list of NBWHP leadership). Lillie Allen, co-founder, served as Director of Training and a small staff undertook a full slate of responsibilities that included community outreach and organizing; chapter development; social networking; conference and event planning; and designing and disseminating publications. Staff worked long hours to meet the enormous expectations imposed on them by their constituency. NBWHP leadership was concerned to strengthen its foundation by building trusted regional, national and international partnerships. Under Avery's leadership, the organization's work directly with local people using community-based methods to improve health would remain a leading defining commitment until 1995 when NBWHP headquarters were relocated to Washington, DC and the organization sought a heavier role in health policy (Avery, 2005).

## **NBWHP** board.

From the beginning, NBWHP demonstrated its commitment to self-reliance by filling its board positions with African-American female experts. In addition to the position of founding board member held initially by Byllye Avery, other board positions included board chair, president/CEO, treasurer, vice-president, vice chair/secretary and federal liaison. Board members consisted of academics, activists, medical professionals, public health practitioners, and administrators. For example during select years, Angela Y. Davis, Beverly Guy-Sheftall, Shiriki Kumanyika, Camara Phyllis Jones, and Barbara Love served on the board (NBWHP, 2003).

NBWHP relied on the knowledge and skills of its board to advise project staff on a myriad of issues pertaining to the organization's operations and management.

NBWHP founder and program staff directed the education and community outreach activities. Avery and colleagues tended to engage community residents in aspects of the organization's program development activities.

## chapter structures.

Local state offices and chapters were integral to NBWHP efforts to respond to community health needs. Chapter leaders accepted the national office's priority on educating women through community-based initiatives. In 1983, the Philadelphia Black Women's Health Project was established and became one of the most active and successful chapters (NBWHP Vital Signs,1997). By 1986, active chapters evolved under the leadership of local community members in Los Angeles, Detroit, Philadelphia, Columbus, Twin Cities, Baltimore, Columbia, Upstate New York (covering Albany and surrounding Northeastern communities), New York City, Denver, Cincinnati, Houston, New Orleans.

By 1999, there were 10 chapters, one state office in California and 12 emerging chapters in such cities as Atlanta, Boston, Chicago, Cleveland, Lansing, Nashville, Langston, Metro DC, Berkeley (CA), Lawrenceville (NJ), Rochester, and Wichita (NBWHP Vital Signs, 1999). Chapter development was encouraged on campuses of Historically Black Colleges and Universities. In 1998, students at Fisk University announced plans to form a NBWHP campus chapter (NBWHP Vital Signs, 1998).

The number of community members needed to form a chapter was no fewer than three and no greater than 12 individuals. NBWHP stipulated that all members pay dues (NBWHP Vital signs, 1996). NBWHP expected chapters to participate in all aspects of national office activities such as recruiting new members; promoting national and local events and activities; educating the public about health issues; raising funds; advocating for local and state policies that benefited girls and women; and complying consistently with all NBWHP bylaws (NBWHP Vital Signs, 1996).

The national project office provided support and technical assistance to chapters as they took the lead to design and implement projects that were defined by their community constituents. For example, the California Black Women's Health Project (CBWHP) in a special partnership with Concerned Citizens of South Central, a community organization that provides housing for low income residents established "The Well", a resource center for adult and adolescent females. NBWHP designated The Well as a state office and assisted with the wide range of programs developed for CBWHP members and female residents of California, in general. Self-help groups and family support programs were created to increase awareness about health issues and provide services focused on improving nutrition, physical activity, and healthy births (NBWHP Vital Signs, 1996).

# **Education and Training**

# **Self-Help**

Prior to NBWHP's founding, Byllye Avery had begun meeting with groups of girls and women to talk about issues related to their physical and emotional health. As previously mentioned, these meetings tended to take place in individuals' home communities in such locations as schools, churches and community centers. In group discussions, Avery introduced the concept of f self-help as a mechanism for dispelling myths about health topics and empowering women to take an active role in protecting their health The self-help approach involved sharing information about health issues identified by group members, encouraging open discussion and input from the collective and offering recommendations for removing barriers to good health and well-being. Null and Seaman (1999) state that self help involves bringing women together in discussion groups to share their health concerns, examine factors impacting health outcomes and identify potential steps toward alleviating the problems.

Observing the relevance of the self-help approach, Byllye Avery, Lillie Allen,
Barbara Love and others members of the NBWHP applied it widely to the
organization's health promotion agenda nationally and internationally (Avery, 2005).
Self-help complemented the organization's aim of enhancing female efficacy by

incorporating aspects of women's social and cultural perspectives and drawing from their realities to create change strategies. In an interview, Avery explained that the self-help approach originated from a need to "bring the women together to talk abut the realities of their lives, to do the analysis, to share, because mostly when you hear the story of someone else's life, you sort of relive your own life and you come to understand why you made decisions or why other people made decisions" (Null and Seaman, 1999, p. 1048).

From Avery's perspective, the self-help process was critically important in assisting women break the "conspiracy of silence" about troubling health matters and guiding them towards clear insights regarding the social, emotional, and economic barriers that impeded achievement of optimal health. As introduced in the 1983 national conference workshop, *Black and Female: What is the Reality?* Lillie Allen identified the concept of internalized oppression as a serious problem effecting the health of African-American women. For many of these women, internalized racism contributed to poor health outcomes and disrupted their relationships, particularly with other women. Allen stressed:

"Internalized oppression exists anytime you feel intolerant of, irritated by, impatient with, embarrassed by, ashamed of, not as black as, blacker than, not as good as, fearful of, not safe with, isolated from, mistrustful of, not cared about by, unable to support or not supported by another black woman" (NBWHP, 1993, 40-42).

Self-help offered a culturally relevant approach in the process to help women better accept themselves and others while simultaneously learn ways to alleviate risks to their health and overall wellbeing.

Self-help groups contributed to both individual and community empowerment (Null and Seaman, 1999). For individual women, discussion groups helped to identify the stressors in their lives such as racism, classism, sexism and homophobia. Through

these discussions, group facilitators work with participants to analyze how these stressors interfere with their state of health and share ideas about viable options for reducing stress and improving health outcomes. At the community level, empowerment emphasizes the importance of residents organizing within neighborhoods to promote the health of African -American women, advocate for quality services in settings where health outcomes are influenced such as schools and clinics and push for appropriately responsive public policies.

Since the formation of the first self-help group in rural Monteocha-Gordon, Florida, many others were established with female adults and teens in diverse community contexts such as schools, public housing centers and private homes. Byllye Avery and Lillie Allen developed the self-help process with input from other members of NBWHP leadership and conducted numerous self-help groups for the national office, chapter affiliates and other organizational partners (Silliman et.al., 2004). Self-groups in the McDaniel-Glen and Dunbar public housing communities in Atlanta, Georgia were so successful in mobilizing residents around local campaigns to raise awareness about health problems affecting residents that the communities became sites for NBWHP's newly established Center for Black Women's Wellness (NBWHP, 1991). In 1988, funding from the Kellogg Foundation and the Fulton County Department of Human Service enabled NBWHP to support the development of health education projects and employment preparation programs for females interested in pursuing health careers and other professions in which women are typically underrepresented (NBWHP, 1990a).

The Wellness Center filled a tremendous gap by providing needed programs and services that most residents would not have been able to afford at hospitals and other medical facilities requiring insurance. By carrying out responsibilities linked to shared goals, female residents experienced ways to build trust and confidence among each

other and in the larger community.

# on becoming a woman: mothers & daughters talking together.

A major priority of the NBWHP self-help mission was to "break the silence" within families, particularly among females, regarding reproductive health and other related issues. In 1987, African American filmmaker Cheryl Chisolm produced the film, "On Becoming a Woman: Mothers & Daughters Talking Together" based on a workshop Byllye Avery she developed and had been implementing in schools and communities about family communication on sex and girl's reproductive health (Avery, 2000).

Having recognized the trouble young girls faced when they were unable to confide in their parents about intimate aspects of their growth and development, the film shows Byllye Avery and Lillie Allen applying the self-help process in groups of mother-daughter pairs. The purpose of self-help in the film is to provide eight mother-daughter pairs with skills to ease the difficulty of talking openly with their daughters about issues related to their sexuality. Avery and Allen lead discussions of male and female physical development, menstruation, sex and love. Different types of birth control methods are also presented.

In these group discussions, mothers and daughters are shown experiencing the emotional pain of exposing their sensitive personal feelings about themselves and their family relationships. Evidence of healing is depicted when group facilitators help mothers and daughters interpret and validate individual feelings and the importance of the family relationship.

# it's o.k. to peek.

Myths about gynecological health and the avoidance of regular well woman gynecological check-ups by some women inspired the production of *Its O.k. to Peek*, a video produced and directed by Sandra Sharp for the National Black Women's

Health Project. The video shows a health consultant and NBWHP volunteers leading a self-help workshop on how to perform a vaginal self-exam (NBWHP, 1997).

#### **Conferences**

As part of the NBWHP approach to promoting African-American female health, medical professionals, public health educators, and activists were frequently invited to to make public presentations as keynote lecturers, workshop and seminar speakers on a broad range of health topics such as reproductive health, cancer, heart disease, domestic violence, HIV/AIDS and related treatment, prevention and policy developments. The NBWHP viewed these meetings as integral to their efforts to create collaborations and expand professional networks.

The national office and chapter affiliates hosted annual conferences, colloquiums, workshops and other special meetings invited the participation of leading figures in entertainment, education, literature, government and activism such as S. Epatha Merkerson, Danny Glover, Sweet Honey in the Rock, Toni Morrison, Alice Walker, Sonia Sanchez, Maxine Waters, Dorothy Height and Angela Davis. These cultural icons contributed their resources and status to help heighten awareness of the NBWHP mission, programs and goals. While it is not possible to mention all of the various meetings and activities, it is important to note they were convened in the U.S. and other African diaspora contexts to educate constituents, motivate organizational collaborations and expand professional networks:

- "On Our Side The Congressional Black Caucus: Taking the Lead on Black Women's Health", May 25, 1999.
- Women Empowered for the New Millennium Conference, February 18-21,
   1999, Nashville, Tennessee.
- Afro-American Caribbean Women's Health Conference, August 1-8, 1986,
   Barbados, West Indies.

- National Black Women's Health Project Annual Conference, 1992, Los Angeles, California.
- The Power of Spirituality and Healing Conference, May 10, 1998 Crystal City, Virginia.
- A Celebration of Activism, April 28, 1997 Washington, DC.
- National Black Women's Health Project Wellness Conference and Annual Meeting, June 27-28, 1997, Detroit Michigan.
- 1<sup>st</sup> National Conference for African-American Women on Reproductive Rights
   Sisters in Session About Our Reproductive Health, 1990, Washington, DC.
- Women of Color: Thoughts on Policy, Reproductive Health, Safe Motherhood, and Racial/Ethnic Health Disparities, September 18, 1999, Washington, DC.
- National Colloquium on Black Women's Health, April 11, 2003, Washington,
   D.C. (NBWHP Vital Signs, 1996; NBWHP Vital Signs 1997; NBWHP Vital Signs; 1998, NBWHP Vital Signs 1999; NBWHP SisterInk; 1999; NBWHP, 2003).

# **Practice**

### regional training institutes.

An integral component of NBWHP's training mission was to build leadership capacity among staff and volunteers at state offices and affiliated chapters through special training institutes. At these Institutes, chapter representatives were invited to discuss efforts to establish and sustain viable chapter groups. Leadership/community organizing, self-help group development, public education/policy activism, event marketing, fundraising and membership recruitment were incorporated into the training activities. Separate training institutes were implemented to assist chapter representatives based in South/South West, East and Midwest Regions of the U.S.(NBWHP, Sister Ink, 1999a; NBWHP, Sister Ink, 1999b).

Through summary reports of chapter activities and group discussion, participants learned about the challenges and opportunities of expanding the NBWHP health agenda within local communities. The institutes attracted members from established chapters and others proposing to launch future chapters in cities across the country. Chapter representatives received a training manual describing all aspects of chapter development with technical assistance forms to enhance communication between chapter offices and the NBWHP main office. Byllye Avery and other NBWHP board members frequently attended the Institutes.

### nbwhp/hbcu substance use and abuse program.

In 1997, NBWHP collaborated with the Center for Substance Abuse Prevention Program (CSAP), Centers for Disease Control and Prevention, Office of Minority Health, Health Resources and Services Administration, Bureau of Primary Health Care, Office of Research on Women's Health and National Institute of Drug and Alcohol to invite the participation of young adult women in a two-year, campus-based substance abuse prevention demonstration project (NBWHP Vital Signs, 1997). Funded by the Robert Wood Johnson Foundation, the overarching goal of the project was to reduce risks of alcohol, tobacco and other drug use among female students at seven Historically Black Colleges and Universities. The mission of the program was to prepare undergraduate students to develop campus health programs, and assume leadership roles in the areas of public policy and activism.

The project's curriculum was designed to equip students with information and skills to serve as mentors to local community youth placed at risk for substance use. The self-help model was used as the basis for educating students in the following areas: (a) increasing awareness of reproductive health, mental health, substance abuse and their possible linkages to violence, sexual abuse, unwanted pregnancy and other related issues essential to women's health; (b) developing public policy through community

organizing; and (c) applying health information in health prevention activities.

During the funding period, approximately 2,000 students from Bennett College, Fisk University, Jackson State University, Langston University, Morgan State University, Southern University campuses undertook a wide range of health projects identified as important among their peers. Projects consisted of empowerment and wellness seminars; student research presentations on health issues, distribution of STD/HIV brochures in residence halls; proposals to hire female counseling staff and include health courses in academic curriculum; and strengthen campus policies regarding abuse prevention were implemented on the NBWHP/HBCU participating campuses (NBWHP SisterInk, 1999a). In a major culminating event in 1999, students at Fisk University organized their 1<sup>st</sup> Leadership Development Institute "Women Empowered for New Millennium". Faculty, staff and students from other participating campuses met at Fisk to present on a range of topics related to developing and implementing health programs (NBWHP SisterInk, Spring 1999).

# walking for wellness: protecting hearts, saving lives.

A critical component of NBWHP's broadened prevention and empowerment agenda embraced physical fitness in an effort to influence the adoption of healthy lifestyle behaviors among youth and their families. *Walking for Wellness* stressed the health benefits of walking through workshops and community wide campaigns. Girls, twelve years and older, were the target population defined by NBWHP in a unique collaborative with the American Heart Association (AHA) and the National Conference of Mayors (NBWHP Vital Signs, 1997).

The goals of *Walking for Wellness* were to enhance awareness of health issues of African-American girls and women, increase the participation of females and their families in walking groups and inculcate knowledge of the linkages between exercise and disease prevention. The collaborative enabled a valuable opportunity for NBWHP

to combine health education practice with research. In U.S. cities, the national office and local chapters succeeded in bringing hundreds of people out to walk in cities throughout the U.S. In addition to the physical activity, walkers received essential information about topics such as nutrition, weight, the benefits of physical activity and were invited to participate in health screenings and assessments conducted by health professionals (Boston Women's Health Book Collective, 1998).

At NBWHP's annual conference in Detroit, Michigan, June 27-28, 1997, the *Walking for Wellness* initiative was officially launched during a special session moderated by Byllye Avery (NBWHP Vital Signs, XII, 2, 1997). The full project was demonstrated during another session and featured health screenings, health education presentations and entertainment for conference participants. Before the end of the conference, Avery led a final session that provided information and technical assistance to chapter members interested in organizing walking groups in their home communities.

In 1997, Walking for Wellness was piloted in Detroit, Michigan and Baltimore, Maryland. Following the success of its debut, NBWHP partnered with AHA chapters to bring the project to Columbus, Ohio, Atlanta, Georgia, Oakland, California and back to Detroit and Baltimore for repeat engagements in 1998. In 1999, NBWHP scheduled Walking for Wellness in seven other cities reaching more than 30,000 women and their families (NBWHP Sister Ink, 1999). Walking for Wellness became a signature event at continuing NBWHP conferences and community events.

## **Publications and Research**

NBWHP attached tremendous importance to research on African-American female health largely given the scarcity of existing documented information and details regarding African-American women's health. Seeking to make health data, reports and other relevant material more accessible to NBWHP members, concerned health

professionals, policy makers and the community at-large, NBWHP produced it's own publications including news magazines, books, surveys, and empirical articles.

Through NBWHP publications *Sister INK*, *Vital Signs*, *Body & Soul*, *An Alter of Words*, empirical studies, and policy statements, the organization sought to fill in the knowledge gaps about female health among organizational members, other health organizations and the general public. Featured in many of the publications were essays examining the impact of racism, classism, sexism and homophobia on female health outcomes. Strategies and interventions for ameliorating and preventing health problems were consistently addressed. In addition, NBWHP monitored national health policy legislation and assessed the extent to which the different policies contained provisions for protecting female reproductive health rights, improving general health, and eliminating disparities in access to quality health care.

#### sister ink.

Sister Ink was a leading publication at NBWHP that provided essential information and details for members seeking knowledge about health issues impacting the lives of girls and women. Reviews of proposed national and state legislation, actions and implications directly related to female reproductive health rights and health care were consistently presented. Specific attention was placed on enhancing NBWHP members understanding of health policies about areas such as abortion, domestic violence, family planning, HIV/AIDS treatment services, drug use and pregnancy, depression, adolescent health programs, gynecological services and Medicare reform.

Other *Sister INK* sections summarized NBWHP projects and activities at the national and chapter levels of the organization. Risk factors associated with African-American health topics were integrated with evidence-based health intervention strategies and sources of medical assistance and support in articles written by health educators and practitioners. Selected achievements of leading NBWHP members in

education and health were also detailed.

## vital signs.

In addition to *Sister INK*, *Vital Signs* was a newsmagazine published by NBWHP for the purpose of providing comprehensive information on intergenerational health issues relevant to African descended women, their families and communities (NBWHP Vital Signs, XII, 2, 1997). Following the first issue published in 1983, the newsmagazine introduced health topics that were not typically discussed openly in families or the larger African-American community. These included menstruation, internalized racism, contraception, gynecology self-exams, STDS, AIDS, hysterectomy, menopause, domestic violence, poverty and mental health. Careful attention was given to demystifying these health concerns and providing reliable information to assist women of different ages and sexual identities. For example, interested readers could find articles and essays that focused on health issues specific to adolescence, early, middle and late adulthood for females representing different sexual orientations.

NBWHP youth members were encouraged to contribute their perspectives on health in selected issues of Vital Signs. In1987, a special issue titled, *Teen Talk*, adolescent girls wrote articles and served on the newspaper's editorial committee. The essays and poetry submissions revealed the girl's insights on the joys and pains of growing up, dating, peer relationships, identity development and parent-child relationships (NBWHP Vital Signs, 1987).

NBWHP's emphasis on public policy was evident in issue sections updating readers on federal and state health policy developments. Descriptions of NBWHP events and programs produced by the national office and individual chapter affiliates were prominent. Contemporary research findings about numerous health conditions; advantages and disadvantages associated with various medical procedures and

innovations; along with health tips and recipes were also regularly featured.

The national office expected its chapters to be models for good health in the local communities. By mobilizing community residents to take action against poor female health and become advocates for supportive health policies, chapter members expanded the organization's influence. Detailed announcements of newly formed chapters, planned events and activities were highlighted. NBWHP showed dedicated interest to new publications by African-American female authors and organization members. Some of the books featured in different issues were *Blues Legacies and Black Feminism: Gertrude "Ma" Rainey, Bessie Smith, and Billie Holiday by* Angela Y. Davis; *Words of Fire* by Beverly Guy-Sheftall; Alice Walker's *Anything We Love Can Be Saved; Body & Soul* by National Black Women's Health Project; and *An Alter of Love* by Byllye Avery.

## body and soul.

This important publication addresses a myriad of diverse issues in understanding and protecting the health of African-American women. Angela Davis and June Jordan state in the Foreward that "This book maps the terrain of Black women's health consciousness, marking a moment when we finally give ourselves permission to be concerned about ourselves and to look at the range of issues implied by our quest for physical, spiritual and emotional health" (Davis and Jordan, 1994, p. xi).

The editor, Linda Villarosa uses Byllye Avery's concept of "conspiracy of silence" to make the case that family members should talk to one another about health risks and assist each other in understanding ways to reduce risk and prevent disease. She goes on to discuss that women should exercise their personal power towards becoming informed about their health and health treatment options. Villarosa takes a comprehensive approach to improving health among women by making certain that chapters emphasized the importance of understanding the female anatomy, various

issues in reproductive health, preventive care options, personal and emotional wellbeing, intimate relationships and the influence of racism, gender discrimination and economic injustice on female health..

our bodies, our voices, our choices: a black woman's primer on reproductive health and rights.

In this publication, NBWHP provides historical and current contextual information—and policy statements on such issues as sexual health and education, prenatal care, reproductive health problems, and self-help (Null and Seaman, 2002). In 1998, the manuscript was introduced at a NBWHP press conference attended by leading women of color reproductive health groups and organizations.

#### research studies.

While the aforementioned texts and publications have been very useful in increasing general awareness of key health concerns among African-American women, major gaps in the literature continue to exist. Specifically, data on incident rates regarding major illnesses and diseases impacting women, individual knowledge of certain health issues and outcomes of women's participation in clinical research. Research is needed on these issues and others among African-American women in the United States and women of African descent in Africa and Caribbean contexts. Byllye Avery and other researchers affiliated with NBWHP have contributed to research projects on topics relevant to Black women.

During February and March of 1999, NBWHP conducted a multi-city focus group discussions with African-American women aged 25-44. These focus group members represented diverse socioeconomic backgrounds levels responded to questions about their knowledge of reproductive health issues for the purpose of shaping public policy development. The project included participants from Philadelphia, Pennsylvania; Gary, Indiana; Greensboro, North Carolina; Oakland, California; Atlanta, Georgia;

and Prince George's County, Maryland. Through this research inquiry, NBWHP discovered gaps in women's understanding of basic information such as the meaning of pro-choice, reproductive health and rights, and leading female health concerns. The study also showed that women encounter major barriers in their efforts to talk openly about sexual health (NBWHP, Sister Ink, 1999).

Increasing African-American women's participation in cervical and breast cancer screenings was the focus of a joint study between the Morehouse School of Medicine and NBWHP (Sung et.al., 1992). The study aimed to provide a detailed examination of an education intervention to encourage women's participation in cancer prevention, increase their knowledge about breast and cervical cancer and explore barriers related to screenings such as Pap smears, breast exams and mammography. Women 18 years of age and older were recruited from low income public housing communities and senior residences to educational sessions featuring information about breast and cervical cancer and related screening exams detailed in print and videotaped presentations. Women, who were both familiar and trusted members of the local community, served as Lay health Workers in the study. They complemented the program's information component with one-on-one education and consultation sessions.

The study authors conclude that health education interventions which are responsive to the cultural expectations of African-American women are needed. Such interventions require:

- The delivery of program components by trusted African-American women health professionals
- Print and video materials with African-American role models
- Materials prepared at appropriate reading levels
- Presentation of realistic and user friendly cancer screening exams

Relevant health concerns and Lay health workers (Sung et.al, 1992).

Colditz, Hankinson and Avery (1993) cite serious gaps in the clinical research on ovarian cancer among African-American women. While studies show that incident rates of ovarian cancer among African-American women are lower compared to White women, little attention has been given to the specific factors that increase African-American women's risk for the disease. To increase work on diseases impacting African-American women, the researchers stress involving these women in the design and implementation of empirical studies and preventive programs.

Evidence from research on breast carcinoma suggests that relationships between behavioral risk factors and specific health outcomes is lacking among culturally diverse populations in the U.S. (Lythcott, 2000). For example, proposals of empirical research reviewed by Lythcott in her role as NBWHP Breast Cancer Liaison, revealed that researchers tended to request funding for biomedical research despite the need for studies investigating the effects of behavioral risk factors and health issues in understudied communities such as Latino, African American, Asian American, Native American, Hawaiian and other Pacific Islander, or Native Alaskan. Based on evidence of developing interest in research trials by members of different cultural groups, Lythcott suggested that researchers take time to learn about their realities including values, norms, cultural leaders and organizations. By incorporating details of their findings into their research proposals and inviting community leaders and interdisciplinary professionals to work on all aspects of the research methodology, investigators stand a better chance of recruiting participants (Lythcott, 2000).

### **Alliances and Coalition Building**

### congressional black caucus.

In a concerted effort to partner with members of the Congressional Black Caucus around ways to increase public awareness of disparities in African-American female health, NBWHP hosted a series of events inviting the participation of Caucus members. Congresswomen Maxine Waters, Cynthia Mckinney, Stephanie Tubbs-Jones, Carolyn Cheeks Kilpatrick, Donna M. Christian-Green along with Congressmen James Clyburn and Major R. Owens were among the attendees. Caucus members brought their knowledge and expertise of public policy formulation to NBWHP's work and participated in problem solving around issues such as HIV/AIDS, violence against women, reproductive health and rights.

In 1999, NBWHP hosted its 3<sup>rd</sup> annual "Awards Celebration on Our Side-The Congressional Black Caucus: Taking the Lead on Black Women's Health" an event which highlighted African-American women's health concerns and honored Congressional Black Caucus members who were taking the lead on policy initiatives to help improve the health and well-being of African-American women and their families (NBWHP Vital Signs, 1999).

On April 11, 2003, NBWHP along with The Congressional Black Caucus Health Brain Trust and the U.S. Senate Black Legislative Staff Caucus with support from over 80 national and regional partner organizations convened the National Colloquium on Black Women's Health in Washington, D.C. The objectives of the meeting were

"to explore issues impacting the unequal burden in health, health care access and quality of care borne by African American women; to facilitate dialogues and policy recommendations relative to those issues toward the elimination of racial and gender health disparities among African American women and; to generate a national sense of urgency to address the unequal burden of health issues borne by African American women" (NBWHP, 2003. p. 8).

African-American women leaders in areas of medicine, public health, law, private industry research, community organizing delivered presentations and engaged in brainstorming discussions with members of the Congressional Women's Caucus.

# nbwhp, national asian, women's health organization, national latina institute for reproductive health.

In addition to focusing on the heath related concerns of African-American women in the U.S., emphasis was also placed on enhancing awareness of the struggles of women from other underserved ethnic groups in the U.S. due to racism, discrimination and oppression as they sought quality health care and treatment for themselves and their families. NBWHP hosted numerous meetings inviting women of Asian, Latina and Native American health collectives to address health issues and conditions among females in their communities.

At a special leadership symposium titled, "Women of Color: Thoughts on Policy, Reproductive Health, Safe Motherhood, and Racial/Ethnic Health Disparities", NBWHP gathered representatives from these women of color groups, other local organizations and policy officials in Washington, DC. Organizers of the gathering called for increased participation among women of underrepresented ethnic and racial groups in policy decision making und all aspects of their reproductive health. Avery, along with other staff, spoke about African-American women's health and presented examples of their model health programs and initiatives.

#### sistereach.

As previously stated, NBWHP's inaugural conference provided a foundation for creating a health improvement agenda for women of African descent. In its mission to educate women towards better health outcomes for themselves and their families, NBWHP extended its advocacy to women in the U.S. and abroad. Good health for all women meant positive physical, emotional and spiritual functioning, access to quality services, and the opportunity to participate in decisions made about their health care. Improving the health of women involved dedicated implementation of a number of key strategies. This health improvement agenda included strategies for encouraging

the mutual sharing of personal stories, teaching methods for challenging difficult social and economic realities in a technically and culturally competent manner, increasing the use of trusted health education information (Avery, 2005).

Formally established in 1989 and guided by an advisory group, Avery and NBWHP envisioned SisteReach as a network linking NBWHP with women's health groups in Canada, the Caribbean, Central and South America and Africa. Towards that end, it was anticipated that SisteReach would help promote reciprocal support among women's collectives and encourage the sharing of model programs on reproductive and other health issues and also female empowerment. In addition, SisteReach was targeted to raise awareness of women's global health issues, establish international Self-Help groups and create intercultural travel and learning opportunities (NBWHP Vital Signs, 1990). Although plans for the development of SisteReach were not fully realized at NBWHP, Avery and her colleagues did contribute to a number of significant international women's health activities.

Prior to 1989, Avery had begun her involvement in international women's health work through her participation in international conferences on women's issues, accepting invitations to visit women's health organizations and providing information and technical assistance to women's collectives in their work to establish operating agendas and develop Self-Help and other community programs. In 1985, Avery led a delegation of twenty six to the United Nation's Third World Conference on Women held in Nairobi, Kenya. In addition to leading selected conference sessions, Avery and other NBWHP members met with a group of rural Kenyan women to share challenges and opportunities about health and other related experiences. These meetings and interactions were documented in a film titled, *It's Up to Us* (Milwe et.al., 1986).

In the film, Avery narrates her perspective on NBWHP's contribution to the UN conference and includes snapshots of the workshops she and her colleagues led. Brief

conversations with women delegates representing other countries about the significance of the conference are documented. One of the most interesting features of the film is the day Avery and the other NBWHP members spend with a group of Kenyan women in their rural community outside Nairobi. The African and African-American women talk to each other about how they live their lives in their distinctly different social/cultural settings. The women discuss the similarities and differences associated with their health realities. Avery describes details of the self-help and other community-based health programs NBWHP has developed. The Kenyan women, in turn, show the African-American women examples of the work they do in their communities to sustain themselves and their families.

In August, 1986, NBWHP's SisteReach project co-sponsored an international conference with women at the University of West Indies in Barbados (NBWHP Vital Signs, 3, 1986). A year later in 1987, women from the U.S., parts of the Caribbean and Latin America attended a conference in Belize, a country which acquired its independence from Britain in 1981. Among the issues addressed at the conference were reproductive health and violence against women. The hosts, the Belize Rural Women's Association (BRWA) invited a small group from NBWHP led by Byllye Avery and Lillie Allen to present their model programs Black and Female and gynecology self help (NBWHP Vital Signs, 1988). In 1995, NBWHP participated in the Fourth World Conference on Women held in Beijing.

Encouraging discussion about sexuality among mothers and daughters in Yaounde Cameroon, was the objective of a unique program organized by Kongadzem, a local women's cultural and social association with involvement from the International Women's Health Coalition and the National Black Women's Health Project (Kongadzem et.al., 1992). In July, 1992, a three day conference held in Cameroon focused on educating Kongadzem women and their daughters about their bodies,

fostering positive attitudes regarding open discussion about sexuality issues and demonstrating skills for improving family communication. The event sought to remove personal, social and cultural barriers that kept women from talking openly about such issues as puberty, sex, menstruation, pregnancy, contraception and love. African women from different local women's groups served as conference organizers, facilitators, and evaluators.

In addition to her work with women in Barbados, Belize, and Cameroon, Byllye Avery, and other representatives of NBWHP traveled to Jamaica, South Africa, Brazil and Nigeria to work with women's organization around reproductive and other health issues of concern to their members including domestic violence, HIV/AIDS. These are among initial activities which formed the basis for what would be Avery's continuing aspirations for working on global health issues. Unfortunately, despite her initial vision for this project, Avery confirms that it was not fully realized at NBWHP (Avery, 2005). Six years after SisteReach was created, Julia Scott, NBWHP President/CEO at the time, announced its suspension due to "lack of funding" (NBWHP Vital Signs, 1996).

### **Advocacy**

From the beginning, NBWHP worked in its development of programs, publications, outreach activities and research to influence local, state and federal public policies and funding decisions around a myriad of health areas pertaining to girls and women. Priorities initially emphasized reproductive health and rights and were broadened to include other critically significant areas for improving women's health within a health policy agenda free from inequalities based on race, sex and class. African-American women have had limited opportunities to participate in decision making around policies in the area of health. Yet, when women do take on these roles, they make significant contributions to the development of programs and policies that promote

better health for children, women and families. For example, in the U.S. Michelle Obama, the First Lady, is using her status to promote healthy eating and physical activity among children in efforts to reduce obesity. Increased attention to these issues has led to the launch of a national campaign to end childhood obesity with emphases on increasing community access to fresh fruits and vegetables through neighborhood farmers' markets and health education for children and their parents.

NBWHP monitors and makes recommendations in a number of areas of state and national policymaking including health insurance, reproductive health, preventive health, health care needs of low income women and AIDS testing (NBWHP, 1996; NBWHP, 1997). Lack of employment-based health insurance, pre-existing conditions, and maternity leave are critical factors impacting women's ability to secure health insurance coverage. Lack of benefits in the workplace restrict women's decisions to seek immediate treatment following diagnoses of serious health problems and provide for the care of their children. To achieve expanded health coverage for women, NBWHP has supported the elimination of actions by insurance companies to deny coverage on the basis of pre-existing conditions; expansion of benefits for domestic violence; provision of benefits for those unable to secure insurance due to genetic factors; and regulations to increase access to maternity leave benefits (NBWHP, 1997).

Reproductive health policies have been shown to reduce women's rights to decide for themselves if and when to give birth. Limited insurance coverage for abortions, lack of access to contraceptives and family planning services have been major obstacles to women's reproductive health. NBWHP has urged improved access to abortion and contraceptive options (NBWHP, 1997). Women's participation in health prevention services has been hindered by underdeveloped federal regulations. One area concerns efforts to decrease teen tobacco use and another relates to effective

cancer screenings. NBWHP supported government sponsored initiatives to reduce teen access to tobacco and related advertising campaigns directed at adolescents and also provide effective breast and cervical cancer screening services (NBWHP, 1997).

The 1996 welfare reform legislation enacted during the Clinton presidential administration had a profound impact on low income women through the termination of some Medicaid benefits and the addition of provisions to reduce benefits to pregnant women and limit services to unmarried women with children. The legislation titled, "Temporary Aid to Needy Families" which replaced the longstanding program "Aid to Families with Dependent Children" sent a powerful message to poor women about the federal government's expectations regarding marriage and parenting. For example, the legislation gave states power to impose a "family cap" that would reduce the amount of benefits mothers already receiving social services could continue to receive if they had more children.

NBWHP monitored the federal government's call for mandatory HIV testing of infants born in the U.S. and the regulations proposed during the late 1990s. Included among these regulations were requirements that both pregnant women and their infants undergo HIV testing and that these women also participate in counseling.

NBWHP viewed mandatory testing as violation of both a woman's right to decide the course of her own reproductive health and confidentiality regarding her health status.

Policies that NBWHP suggested would enable women to be agents of their reproductive health and the health of their unborn children without deterring them from seeking needed health treatment included "voluntary, anonymous testing and counseling that is age-appropriate and culturally sensitive" (NBWHP, 1996, p. 25) and allocate resources to community-based women's health clinics that includes testing and counseling as well as other kinds of necessary health treatment services for women and their children (NBWHP, 1997).

## Same Dream, New Opportunity

The first five years of NBWHP's life was marked by tremendous achievements in terms of the organization's growth, expansion of signature programs, receipt of major funding and close collaborations among staff and between the organization and other institutional allies in the health arena. Increasingly, NBWHP was becoming well known as a model program and Avery and other staff were heavily sought after to teach aspects of the organization's philosophy and programmatic approach to women's health collectives and groups across the U.S. Approximately five years after NBWHP's founding, developing internal ideological struggles between board members and staff, the inability of the board leadership to assist the organization around problem resolution threatened the organization's stability. Financial problems, disagreements regarding organizational priorities, inability to define policies contributed to internal rifts that persisted within the organization during the 1990s (Avery, 2005).

In 1989, Avery was awarded both the prestigious McArthur Award and the Essence Award which brought her and NBWHP added national attention. Unfortunately not everyone in the organization delighted in these achievements. Around this time tensions were developing between Avery and Lillie Allen in part due to misperceptions about each other's priorities and roles. Discussions about the continuing significance of self-help groups in the midst of developing financial problems in the organization had emerged among project staff and board members. At the same time, the realization that Avery's strength as a leader did not include management skills prompted board members to initiate a national search for a qualified executive director.

The 1990s represented a period of heavy difficulties for Avery and the organization she founded as staff and board members struggled to achieve what had long been

stressed among its constituents and members which was effective and open communication. Confronted by growing internal problems stemming from opposing views on a myriad of issues such as organizational functioning, board members roles, fund raising, policy decision making and community engagement, lack of experience rendered individuals unable to resolve their conflicts (Avery, 2005). By the time the executive director position was filled initially by Julia Scott in 1989 (on an interim basis) and then later Cynthia Newbille-Marsh in 1990, evidence of the organization's trouble had begun to spread. Some of the chapters closed, insufficient funds halted many of the longstanding self-help groups and some disillusioned staff at the national office left and others were let go for financial reasons.

In 1996, realizing its inability to continue independently maintaining the *Mother House* and the decision to reorganize priorities to include a greater focus on policy development and decision making, the national project office was moved from Atlanta to Washington, D.C. The move and the organization's new direction were led by Julia R. Scott. in the position of NBWHP president. In a statement introducing herself as the new president, Scott maintained that the organization was moving forward better prepared to address future challenges and opportunities. Self help groups, chapter structures and activities and the walking groups program were slated to continue. However, *SisteReach* and the annual NBWHP conference were cancelled and changes were proposed to increase the financial sustainability of *Vital Signs* (NBWHP, 1996).

One year later, Scott repeated the organization's need for increased funding while also announcing the launch of new collaborations with the Historically Black Colleges and Universities to prevent substance abuse on campuses and the formal start of the Walking for Wellness project involving a different partnership with the American Heart Association and the National Conference of Mayors. She reaffirmed NBWHP's

commitment to its founding mission:

"Collectively we, individual members, Board, staff and funders, continue to believe strongly in the need for and potential of a strong Black women's health and wellness movement. We can not do it alone. Only with your continued support and guidance will we move strongly into the twenty first century" (NBHWP, 1987, p. 6).

Avery remained with NBWHP throughout its transition continuing to contribute to educational programming and outreach efforts while publicly championing the organization's new proposals to establish national centers that would separately take the lead on education, health policy, research, and knowledge and leadership (Avery, 2002). Privately, however, Avery worried about how the organization's shifting priorities would impact the national fight to eliminate health disparities and improve the health of African-American girls and women. When Lorraine Cole took over as president in 2001 and the organization's title was changed to the National Black Women's Health Imperative, Avery realized that the organization she had founded was no longer what she had imagined nearly two decades earlier.

Aware that the health needs of African-American females required ongoing support and advocacy, Avery turned her attention to a new project. In 2002, she established the Avery Institute for Social Change aimed at engaging experts in shaping the kind of public health policies that will promote better health and survival. Avery (2002) asserts, "Our mission is to provide a platform for grassroots activists, scholars, caregivers, and policy makers to strategically examine health and social policy issues. Through our efforts, we hope to promote linkages between community activism and research that will shape local, national and international public health policies" (p. 1207).

Along with this new endeavor, Avery never completely severed her ties to NBWHP. After her departure, she continued to consult with the leadership around

aspects of the organization's work and kept its historical achievements alive through invited lectures and presentations nationally and internationally.

In conclusion, it is apparent from the experiences at the National Black Women's Health Project, that important factors in promoting health among girls and women include accurate and reliable assessments of their health status, well prepared health education, policy and program management experts, wide institutional support from local communities, funding organizations, and the government entities, and effective culturally authentic programs and activities. All things considered, many of NBWHP long term programs had a positive impact on the lives of girls and women. Women learned to view each other with trust and confidence as they took the lead to address individual, family and community health concerns that had become deeply troubling among African-American females due to neglect and inequality.

The initial years at NBWHP appeared to be the most productive and gratifying for all involved. However, the 1990s signaled the start of a more difficult reality for the organization as internal problems developed and programs were sacrificed. That the organization has served as a model from which other progressive women's health collectives have evolved while informing critically important research is a fact that must not be overlooked. In the next chapter, the examination of NBWHP's influence continues with a specific focus on the parent-child relationship in the area of health communication.

### **CHAPTER 4**

# "BREAKING THE SILENCE": OVECOMING BARRIERS TO BETTER HEALTH THROUGH INTERGENERATIONAL FAMILY COMMUNICATION

"Black women's health is about intergenerational health"
(Byllye Avery, 2005 p. 28).

A major obstacle in achieving good health among girls and women articulated by Byllye Avery and the NBWHP in the early 1980s and subsequently affirmed in contemporary health studies is the lack of open discourse within families and communities about different health concerns. In an interview with Linda Wolf, Avery relates the importance of family relationships and communication to the health of\ girls:

"Psychologically when they and their mothers are able to get their relationships together, things will be a lot better. And if their father is still on the scene, getting together with him as well. Another thing: when they're in the company of other women and they feel comfortable, to be able to really talk about the hard things they go through, to sit and talk with each other about the realities of their lives. To ask each other, "What's really going on? What's been hard? What's happening in your life?" That's where the real growth is going to come from" (Wolf, 1997, 157).

Improving effective communication around health issues is part of a national call to promote better health among individuals, families and communities. Healthy People 2010, the nation's agenda for addressing this vital area specifies increasing communication of health issues in interpersonal and group settings, reducing errors in communication, increasing individuals' access to reliable and evidence base information, and improving cultural competence in communication interventions (U.S. Department of Health and Human Services, 2000). Communication about health issues is an important mechanism in health education and promotion campaigns. NBWHP, through its emphasis on self-help and agency, empowered women to explore the challenges of communicating across generations about health in the settings that

are central to their lives, particularly their families. Further, the organization's aim stressed helping females achieve opportunities for improving knowledge, reducing stress and strengthening intergenerational family ties.

# **Family Communication**

Family communication is an area of study that informs research and practice in a number of academic fields such as human development, counseling, social work, family studies and public health. Arnold defines communication as the "process of creating, negotiating and sharing meaning through verbal and nonverbal channels" (2008, p. 3). Family communication involves an understanding of social relationships, interpersonal and group interactions and the settings in which these interactions take place. Intra-family interactions, intimacy, affection and support, race, class, gender and ethnicity, sexuality, health disability, abuse and conflict are some areas frequently studied in research on family communication (Arnold, 2008).

Communication occurs in all family compositions and among a myriad of family members including grandparents, parents, aunts, cousins, sisters, brothers, sons and daughters. In many examples, communication in families is unidirectional wherein adult caregivers convey information, expectations, beliefs and values to younger dependents. In these relationships, the adult is responsible for the care and socialization of children and functions to help them survive and succeed. Towards this end, caregivers teach those younger about how to accurately interpret information, behave in socially and culturally appropriate ways and develop strategies for responding effectively to individuals, events, and circumstances both in their immediate settings and society at-large.

In the area of health, communication in African-American families tends to be organized around sharing health tips and encouraging practices that support the health of members. This health information is passed down in families generally through

generations of women. These activities center around improving nutrition, preventing disease, managing chronic illnesses and interfacing with health professionals (Fiese, 2006). Developing research on bidirectional health communication in families shows that children and youth are reliable sources of health information and that when parents and children exchange such information, the consequences are mutually beneficial.

## **Parenting Influences and Health**

The relationship between parenting and children's health behaviors is very significant. As the most important socializing agents in the lives of their children, parents play major roles in shaping their children's health knowledge, attitudes and practices, particularly between the human developmental periods of childhood and adolescence. For example, by communicating their disapproval of tobacco use, alcohol consumption and early sexual interactions, parents may help strengthen their children's efficacy to refuse involvement in such high risk behaviors.

Research shows that parents tend to discourage early sexual activity especially among girls due to concerns that they will be mistreated and become pregnant. Helping children develop nutritious food preferences and adopt healthy eating behaviors is very relevant. Effective methods include encouraging consumption of fruits and vegetables and adult modeling of healthy eating patterns. Parents who consistently monitor their children's behaviors help them avoid poor health outcomes. The quality of parent-child relationships as defined by level of nurturance and support has also been linked to poor youth health behaviors. For example, girls are inclined to smoke cigarettes and use other substances when they perceive problems in their families and in the mother-daughter relationship (Gibbs, 1996). Open, positive communication between parents and their children leads to better child health. When parents actively participate in healthy lifestyle practices with their children, the

outcomes are beneficial to both parents and children. In the context of these positive family influences, the health of girls and women is less likely to be placed in jeopardy.

Given the dominance of reproductive health and sexuality issues and the significant attention directed towards girls and women in health studies, it is not surprising that studies of parental influences on adolescent health outcomes tends to focus largely on girls. Although research on parent-child communication indicates that both mothers and fathers talk to their daughters about sex, evidence indicates that boys receive the least amount of communication even from their fathers (Arnold, 2008). Unfortunately, only a small segment of the research focuses on African Americans in the study sample. Given this, it is not surprising that even fewer studies examine this relationship solely on an African-American sample without making cross-racial

the study sample. Given this, it is not surprising that even fewer studies examine this relationship solely on an African-American sample without making cross-racial comparisons. In an event, the existing evidence suggests that when African-American parents and adolescents are studied, the role of mothers in relation to adolescent health outcomes, especially sexual behavior, predominates.

A number of different ecological factors have been explored in studies on what places children and adolescents at risk of problem health outcomes. These factors include but are not limited to family structure, peer influences, neighborhood factors, the media and parenting practices. In the next section, the discussion will give specific attention to studies that have shown how parents influence their children relative to sexual behavior, tobacco and alcohol use, and physical activity.

#### sexual health.

Sex is a topic that many parents find difficult to approach with their children and adolescents. Uncertainty about how to initiate the discussion, what should be said and at what age children should be when parents attempt such verbal interactions are among factors interrogated in some of the literature. Other factors such as parent knowledge, perceptions of efficacy and nature of parent-child relationships are also

examined. While parent-child communication about sex is the focus of considerable study in the U.S., the volume of research on African-American families is relatively low. For some of the research, the primary focus is on mothers and daughters and factors that are salient to having these conversations.

Pluhar, Dilorio and McCarty (2008) showed that when African-American mothers of children aged between 6-12 years were asked if they talked to their sons and daughters about differences between males and females, they were more likely to talk to their older children. These mothers were also more likely to have these conversations with daughters rather than sons. The data indicate that pubertal changes among the girls and their developing interest in boys triggered conversations about sex between mothers and daughters. Mothers who were comfortable and confident in having these discussions specifically reported more opportunities for mother-daughter communication.

The problem of discomfort in parent-child discussions about sex issues and some related consequences has been documented in the literature. Avery (1991) reflects on this issue based on her observations of African-American families and her own personal experience:

"When you think about it, in most of our families, we have not had discussions about sex. I know this. How many of y'all got started out the same way I did, when I got my period Momma said, "Mmm-hmm, its here. First thing, these things happen. If you get pregnant I 'll kill you. And the third thing was you're going to Taledega College" (Avery, 1991, p.151).

In a study with an older sample of daughters, Aronowitz, Rennells, and Todd (2006) examined the influence of predominantly single African-American mothers in discussions about sex with their daughters aged 11 to 14 years. Focus group data showed that some mothers believed sex was natural while others stressed that sex led to negative consequences such as HIV. Still others were convinced that when parents talk about sex with daughters, they send the message that having sex at a young age is

appropriate. These parents feared that such approval increased the likelihood that their daughters would be taken advantage of especially by older males looking for sexual conquests. Interestingly, the data also showed that girls were uncomfortable talking openly about sex. Despite this, many believed what they were told by peers that "everybody is doing it." There was agreement among some mothers and daughters that girls with low self-esteem were at specific risk of being used for sex by older males.

Having two parents in the household contributing to child rearing and parents' consistent expression of love and affection were factors some mothers thought were especially important for protecting girls from early sexual initiation.

Usler-Seriki, Bynum and Callands (2008) explored the potential effect of warmth in the mother-daughter relationship on discussions about sex and girls' sexual behaviors. In the context of high income families, data indicated a low occurrence of sexual activity among daughters. Specifically, in families where mothers communicated their views about the negative consequences of having sex and shared their disapproval of premarital sex, the overall involvement of daughters in sexual intercourse was low. For some girls, the frequency of mothers' communication about sex was read as their approval and was related to increased participation in sexual activity.

#### tobacco and alcohol use.

As previously indicated, tobacco and alcohol use among African-American adolescents is significantly lower compared to Whites. A major factor influencing substance use among youth is the kind of socialization they receive from their parents about smoking and the related health risks (Clark, et.al., 1999). Parents knowledge, attitudes and practices associated with smoking may protect their children from poor health problems. African-American parents were more likely than White parents to believe that having anti-smoking rules at home would deter their children from

developing smoking habits. The White parents anticipated that peer influences had a far greater influence on their children than any policies they may institute at home. Both groups of African-American and White parents limited smoking to adults in their households. Further, White parents were more uncomfortable than African-American parents trying to talk to their children about not smoking given their own smoking histories.

The White parents were more likely to agree that schools should take the lead in breaking adolescents of their smoking habits. In contrast, African-American parents viewed smoking as a serious health problem and identified themselves as effective role models, irrespective of personal smoking history, for controlling tobacco use among their children. In order for schools to be effective in this effort, these parents stressed that active parental support was needed. The fact that neither group of parents did much to prevent their children's access to cigarettes at home might undermine the seriousness with which their children accept their no smoking mandate (Clark, et al, 1999).

Quality of family relationships as defined by parental care and understanding, family attention, amount of time spent with parents and parental encouragement to make independent decisions is an important influence on African-American and White adolescents' alcohol and drug use (Watt and Rogers, 2007). African-American parents consumed less alcohol compared to White parents. While family support and parent control are factors that reduce alcohol use among African-American and White adolescents, African-American girls were more likely to abstain compared to White girls. In addition, due to lower economic resources among African-American adolescents, fewer of them consumed alcohol.

Among African-American adolescents living in rural and urban settings, relationship quality was a factor that enhanced adolescents' confidence to resist the pressure to

smoke and consume alcohol (Nasim, et.al, 2009). Analyses of mother-adolescent and father-adolescent quality in a study of predominantly female adolescents favors a female influence on adolescent health behaviors. For example, a strong mother-daughter relationship enhanced daughters' confidence to refuse tobacco, while the father-daughter relationship had no effect. A close mother-adolescent bond was also shown to increase children's confidence to avoid alcohol consumption.

Parental monitoring, an indicator of parent-child communication, refers to parents' knowledge of where their children are, with whom they spend their time and their activities is another factor that may determine risky sexual behaviors, alcohol and drug use among African-American adolescents (Xiaoming, Feigleman and Stanton, 2007). Failure to closely monitor children enhances their participation in such negative health practices as sexual behavior, tobacco use, and alcohol consumption. Girls, who perceived higher levels of monitoring compared to boys, have a lower risk of substance and drug use.

### physical activity.

The relationship between physical activity and cardiovascular health among women and girls is very significant. This is very evident beginning during childhood and extending into adolescence and early adulthood. Research shows that when parents model physical activity such as jogging, running, walking or team sports, their children are more likely to follow their example and participate in exercise (Madsen, McCulloch and Crawford, 2009). This study of nine and ten year old African-American and White girls during the period 1987 to 1997 shows that girls who reported that their mothers and fathers exercised three or more times each week were significantly more physically active than girls whose parents were reported as inactive. In the context of low family income, parents may be less likely to participate in physical activity due to inadequate time and lack of access to recreational spaces close

to home.

The influence of parents' physical activity may be salient to physical activity outcomes among children in rural areas (Trost et.al., 1997). Data collected from a sample that was predominately African American and female indicate girls' physical activity was higher when their parents were active. Similar to the aforementioned study, this was particularly true for African-American girls. However, in this example, mothers' physical activity was more of a significant predictor rather than fathers' activity. Also significant, the data suggest that girls who lacked confidence in their ability to participate in physical activity due to having to complete homework or feeling tired were less physically active than girls who had higher self-efficacy.

If girls are not helped to overcome barriers to physical activity early in their development, they are less likely to make it a priority as they age and this may enhance their risk of chronic health problems such as cardiovascular disease. Health prevention programs that focus on increasing child and youth physical activity and making physical activity opportunities more accessible have been prioritized in the national agenda to promote health and reduce risk of illness and disease (U.S. Department of Health and Human Services, 2000).

# **Cultural priorities in Family-Focused Health Interventions**

In recent years, the research examining family factors and children's health outcomes has been particularly important for informing intervention programs which have been prioritized in the larger context of health promotion. Noting gaps in intervention approaches targeting adolescents in the literature, Avery stressed: "Part of the problem is that programs on adolescent sexuality deal with the kids, and I maintain that they are not the ones you ought to be dealing with. You need to be

dealing with the mammas and the daddies "(Avery, 1986, p,246). While the literature examining family-based influences on children's health behaviors tends to focus more on investigations of Caucasian parents and their children, studies involving African—American families are developing.

#### Parents as Providers of Health Information

# substance abuse prevention.

A computer-based intervention was implemented to reduce risks associated with adolescent substance abuse (tobacco, alcohol and drugs) among African-American and Caribbean-American mothers and their daughters aged 9-12 years old living in low-income communities (Schinke et.al., 2006). The purpose of the program is to strengthen mothers' ability to protect their daughters' health through positive communication and relationship closeness.

Communication is defined by mothers' involvement in discussions with their daughters about issues such as friendships, household rules, schooling, religion as well as personal conflicts, leisure activities, and family events. Closeness referred to mother-daughter affection, openness, comfort and confidence. The program components emphasized positive communication, strong interpersonal relationships and respect through exercises that promoted the importance of listening, resolving problems, frequent interaction, personality differences and offering special gifts. An African American descended mother-daughter dyad is featured in the computer program modeling the targeted behaviors and an African-American actress provides the narration.

The program findings showed that the program was effective in improving girls' communication with their mothers and that girls reported feeling closer to their mothers. In addition, data indicated that mothers perceived positive communication with daughters and felt close to daughters. Unfortunately, no data was collected

regarding daughters' substance abuse behavior ruling out any conclusions regarding the program's efficacy toward changing girls' health behaviors.

### obesity prevention.

An adaptation of the *Know Your Body Program* was developed to educate African-American mothers and their daughters aged 7-12 years around obesity prevention (Stolley and Fitzgibbon, 1997). The program aims to increase knowledge of healthy eating and physical activity among mothers and daughters. In addition, the program sought to improve attitudes about healthy eating, enhance self-efficacy about eating healthy and encourage parental support and modeling of healthy behaviors. The study showed that 62 percent of mothers were overweight and 19 percent of daughters were obese. The study authors noted that the participants were recruited from low income neighborhoods.

Components of the 12 - week program featured culturally appropriate activities such as food tastings, opportunities to prepare favorite meals, field visits to local food markets, small group discussions on selected health topics and opportunities to participate in physical activity. Materials taken from participants' favorite magazines helped explain facts about nutrition and physical activity. Music and dance routines were also included. A control group of mothers and daughters were presented with a general health curriculum that emphasized communication, relaxation and stress reduction strategies, and methods to manage communicable diseases.

The mothers and daughters were evaluated based on their food consumption, weight, and parental support. The data showed that the program was effective in reducing dietary and saturated fat among mothers, however there was no change in body weight. There were no major changes in daughters' eating patterns or weight, however mothers modeled positive eating behaviors through their healthy food selections and healthy meal items they prepared for their daughters. While daughters'

behaviors did not reveal any significant changes as a result of the intervention, the authors assert that mothers' modeling of healthy behaviors may prove beneficial to daughters over time.

## **Adolescents as Conveyors of Family Health Information**

Another critical dimension in the context of family health promotion in African-American families being addressed in recent studies is the potential role of adolescents as health advisors to their parents. NBWHP's belief in adolescent girls as assets in the organization's work to improve health within families and communities was shown when staff of *Vital Signs* encouraged teens to produce the 1987 issue titled *Teen Talk*. This issue was produced by, for and about health issues of female teens. The consistent valuing of youth input was also demonstrated in the NBWHP/HBCU initiative that placed college women in important leadership roles on 7 campuses. By including adolescent girls in the process of health promotion, NBWHP asserted their significance as health advocates for themselves and their families.

This hypothesis was the focus of a study conducted by Mosavel, Simon and Van Stade (2006). Having observed different aspects of mother-daughter relationships in a community located in Cape Town, South Africa, the authors examined the relevance of shared activities, communication and advice giving to daughters' willingness to share health information with their mothers. The study included 131 mothers and 145 daughters in grades 8-10 and used survey data to explore the three relationship issues from the perspectives of mothers and daughters.

Through the exploration of shared activities, the researchers found that mothers and daughters spent considerable time together in social and daily household activities.

An example of a shared activity was shown when mothers and daughters visited health facilities to receive treatment services. Most mothers indicated that they had positive relationships with their daughters and that their discussions involved agreements and

some disagreements. Mothers also reported that they do tend to rely on their daughters for advice about a myriad of matters including their health. Specifically, mothers indicated that they asked their daughters about when to seek health treatment for problem conditions, how to manage AIDS and resolve personal relationships problems.

Daughters agreed that their mothers asked them for advice about daily activities, social affairs, intimate relationships, the future and health. Regarding health issues, daughters reported that their mothers requested their advice about when to seek health treatment, how to identify different health conditions, strategies for healthy eating, and what to do when confronted by HIV. While most mothers were unwilling to agree that their daughters knew more than them, they agreed that their daughters possessed valuable knowledge about health issues. Given the challenges associated with accessing reliable information and technology in low income communities, adolescents, through their school-based learning opportunities, may be their parents' best sources of health related knowledge (Mosavel, Simon and Van Stade, 2006).

In addition to South African adolescents, African-American and Latina adolescents in the U.S. have the potential to be health advisors in their families (Mosavel and Thomas, 2009). The purpose of this exploratory study was to examine determinants of daughters' willingness to share health information with their mothers. This study aimed to increase awareness of breast and cervical cancer in families, particularly those in low income circumstances.

A total of seventy-eight adolescents assigned to twelve focus groups, six African-American and six Latina were used to assess girls' attitudes, perceptions and experiences regarding their relationships with their mothers, willingness to discuss health information with mothers and advise them about cancer. The girls were between the ages of 12 and 19 years and the majority lived with their mothers or

another female guardian.

Through the focus groups, daughters expressed concerns about their mothers' busy work lives and the distress they faced as a result of the family's low economic status. While the girls understood that their mothers needed to work in order to meet their financial responsibilities, some were bothered that they had so little time to spend with their mothers. Other daughters indicated that they appreciated the emphasis their mothers placed on working hard at school so that they might avoid future hardship. Still others reported that they were close to their mothers, enjoyed being their confidantes and willingly shared useful information they learned at school.

The nature of mother-daughter communication was reported as challenging for some daughters. Ultimatums expressed by mothers were seen as barriers to effective communication according to the girls. In relationships where communication was easier, daughters described giving their mothers advice on matters ranging from hairstyles to intimate relationships. African-American and Latina daughters reported that they had similarly advised their mothers on health issues such as seeking cancer screenings, healthy eating, smoking cessation, birth control and ways to manage illnesses.

The one area where the African-American and Latina girls differed concerned their willingness to provide their mothers with information about cancer. While all of the Latina girls agreed that they would not have any difficulty talking to their mothers about cancer, this topic was more uncomfortable for the African-American girls. Some indicated that their mothers already knew about cancer and others believed that it was someone else's duty to share such information. Still others were not confident that their mothers would listen to them nor follow their health advice as evidenced in one mother's instruction to her daughter that she "stay in a child's place" following the daughter's efforts to talk the mother about giving up smoking (Mosavel and Thomas,

2009, p. 805). From the standpoint of the daughters, the conclusion that they are willing to provide their mothers with useful health information supports the findings of the aforementioned study conducted in South Africa. Adding the views of mothers about the type of health advice they are willing to receive from daughters is a goal of future study.

## **CONCLUSION**

While it is necessary to come to an end to my study, to say this is the last word on the current subject is not only unnatural but unfair. The aim of the research was to analyze the National Black Women's Health Project in its mission to promote awareness and understanding about African-American female health issues. The information presented was premised on the assumption that learning more about NBWHP's mission and programmatic approaches could be instructive to researchers and policy makers currently addressing areas of adolescent and adult female health prevention and management towards a more comprehensive national agenda for improving female health and increasing female participation in future health research and policy initiatives.

The research presented on African-American female health and the National Black Women's Health Project has been informative, however, additional investigation is needed if we are to make sense of the ongoing problem of disparities in female health and the powerful role of grandmothers, mothers, aunts, nieces and daughters as family health protectors in diverse social, economic and cultural contexts. The women's health promotion model presented here is limited in its focus on the concerns of African-American women in low income circumstances. Thus, it was not possible to generalize about all women of African descent. However, the examples documenting female contributions in the areas of family and community health in selected African contexts offer insights that relate to priorities and practices of Black women in the

U.S. and the power of intercultural collaborations. Certainly, no two given situations are exactly alike. However, it is instructive to learn about mutual challenges confronting women in different geographical and cultural contexts and the shared lessons that may have particular relevance for them and their families. Given the current national and global focus on health inequities, it is useful to consider what may be areas of concentration for experts seeking to further research on girls and women.

It is essential that health professionals and policy makers are aware of risk factors that contribute to disparities in health and that they recognize the role of contextual influences, developmental factors, and culturally relevant approaches in improving health outcomes and closing the health inequality gap. The link between health communication skills of parents has been identified as a strategy for enhancing child and adolescent avoidance of risky health behaviors and improving attitudes and practices of children and adolescents. The relative influence of African-American mothers and fathers on male and female adolescent knowledge, attitudes, and values requires greater clarification.

Tremendous emphasis has been placed on close collaborative relationships among women as a precursor for reducing stress associated with tough health challenges.

Simultaneously, the NBWHP literature stressed the essential role of male allies in the struggle for better female health. Male members of the Congressional Black Caucus were cited as participants at special events addressing health advocacy concerns.

Leading Black males in entertainment, for instance, were featured at events celebrating Black female achievements. In a lecture delivered at Russell Sage College, Byllye Avery directed men to become allies in efforts to protect women's health and well being. She specifically called on men to stand up against domestic violence and those men who perpetrate such violent acts (Avery, 1995). Effective ways that grandfathers, fathers, uncles, nephews, brothers and sons can participate in health

promotion activities to reduce risks associated with poor health and disease in their families and communities requires dedicated investigation. It is also important to explore the health concerns of boys and men and the nature of the health communication that they receive in their own families.

Policy implications suggest the need for specific research exclusively on the health status of African-American females to inform policy planning and implementation. National and local campaigns to reduce ecological health risks and improve health education are essential. Incentives for involving community residents in designing, implementing and evaluating studies led by culturally diverse research teams should be considered by educational and research institutions. Funding support for interventions that stress self help and health communication in the design of family and school-based health promotions must also appreciate children and adolescents as major assets in the context of health promotion. Given the way Black, Latino, Asian, and Native-American communities have been largely excluded from national health care reform discussions, careful monitoring of President Obama's commission to evaluate the health issues of girls and women and promote their participation in the implementation of the nation's health reform agenda is warranted.

## **APPENDIX**

## NBWHP LEADERSHIP ROSTER

Founder

Byllye Y. Avery

Chairs of the Board:

1986-1988

Eleanor Hinton-Hoytt

Co-Chair

Julia R. Scott-Co Chair

1988-1989

Frances Jemmott Co Chair

Eleanor Hinton-Hoytt

Co Chair

1991

Frances Jemmott

1992-1993

Jean A. King, Ph.D.

1994

Salima Hicks, Ph.D.

1996-1997

Akua Budu-Watkins

1998-2003

Sharon Lovick Edwards

President/Chief Executive Officers:

1985-1989

Byllye K. Avery, Executive Director

1990

Byllye Y. Avery, President Julia Scott, Interim Executive Director

1991-1995

Byllye Y. Avery, President Cynthia Newbille-Marsh Executive Director

1996-2000

Julia Scott, President/CEO

2001

Lorraine Cole, Ph.D. President/CEO

Source: National Black Women's Health Project (2003). Lasting legacy: The National Black Women's Health Project: An oral history. Washington DC: National Black Women's Health Project.

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