THE "SISTERSONG COLLECTIVE": WOMEN OF COLOR, REPRODUCTIVE HEALTH AND HUMAN RIGHTS

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Abstract: Reproductive health among women of color suffers in the absence of true rights-based health care; the human rights framework should be an integral component of the health care system in the United States. This paper is a case study of the SisterSong Women of Color Reproductive Health Project founded in 1998 and its efforts to address the current reproductive health situation of women of color in the United States. The paper will then argue that the human rights movement can incorporate the needs of women of color into its agenda. And finally, it will also discuss the reconceptualization of human rights by women of color. The organizations involved in SisterSong are responding to and using their own histories and experiences in organizing their communities to develop and apply human rights standards to reproductive health education and services for women of color.

Around the world, the reproductive health needs for women of color are sadly neglected or actively harmed. Whether through the neglect of health care delivery systems or through aggressive population control strategies, the reproductive health rights of women of color are constantly compromised by poverty, racism, sexism, homophobia, and injustice. There is a dialectical relationship between what happens to women of color in other countries and what is visited upon women of color in the United States: all of our human rights are restricted by a white supremacist construct that de-prioritizes our needs while exploiting our bodies for the reproduction and maintenance of the economic system.

In the United States, the racial, gender and economic discrimination faced by women of color interferes with our ability to acquire services or culturally appropriate reproductive health information. Mental health issues such as oppression; depression; substance abuse; physical and sexual violence; lack of education, the lack of availability of services and income, are related to racial, gender and economic inequalities that specifically limit the potential of women of color to live healthy and fulfilled lives. The salient issues are not the diseases that affect women of color, but the poverty, homelessness, inadequate health care, and the denial of human rights that are the root causes of many problems.

In 1987, the International Women's Health Coalition (IWHC) formulated the concept of "reproductive tract infections" (RTIs) to draw attention to a serious, neglected aspect of women's sexual and reproductive health, and to stimulate the development of necessary health services and technologies, as well as information dissemination and wider program efforts. Reproductive tract infections affect the ovaries, fallopian tubes, uterus, cervix, vagina, and external genitalia. They affect both men and women, but infection rates differ due to obvious anatomical differences (Native American Women's Health Education Resource Center, Lake Andes, South Dakota, 1999).

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There are three known types of RTIs, and they are grouped by cause of infection:

- Sexually transmitted diseases (STDs) such as gonorrhea, genital warts, chlamydia, syphilis, and HIV are caused by bacterial or viral infections.
- Endogenous infections result from an overgrowth of microorganisms (bacteria, yeast) that are normally present in the reproductive tract. Endogenous infections are not normally transmitted sexually.
- Iatrogenic infections result from medical procedures such as improper insertion of an IUD, unsafe childbirth/obstetric practices, and unsafe abortions (Native American Womens' Health Education Resource Center, Lake Andes, SD, 1999).

Reproductive tract infections kill thousands of women each year through their association with cervical cancer, unsafe deliveries and septic abortions (Brabin, Gogate, Karde, 1998). They can cause emotional distress, pain, and relationship discord. The economic costs to society include the loss of women's productivity and the expense of treating the severest consequences of RTIs, such as pelvic inflammatory disease (PID). Each year, 12 million people in the United States become infected with a sexually transmitted disease (Centers for Disease Control and Prevention, 1999). Of that number, roughly one quarter occur among young people between the ages of 15 and 19 years (Sexually Transmitted Disease Information Center, 1999).

Women's health advocates around the world have been addressing some of these issues and identifying what can be done locally, nationally, and globally to bring awareness and action to improving women's reproductive health. To the extent that RTIs have been recognized as a public health issue, they have been approached as diseases to be mapped by epidemiologists, prevented through public education, and cured by health professionals. Yet these conventional approaches are not working; RTIs are rampant in many countries, and their prevalence is increasing (Villarosa, 1994).

Rather than accept the medical model of a diseasebased approach, women in developing countries and women of color in the United States have led a reconceptualization of women's health as a women's human rights issue. This needs-based approach shifts the focus from service providers to the women they serve by interrogating the way women are treated within the service-delivery system, including communication and information-sharing, establishing minimum standards for procedures and examinations, and assessing whether women receive services appropriate to their needs. Services must be accessible and must be offered in an environment that enables women to use them effectively. Women's biological and social vulnerability to sexual and reproductive health problems means that they need to be able to exercise choice in their sexual and reproductive lives. It is precisely in this area, the promotion of the ability to choose and to have choices that make sense, that the human rights framework is critical. Improvement in women's health requires more than improvements in science and health care; it also requires government action to correct injustices faced by many women and to help create enabling conditions necessary to fully exercise these rights (Turmen, 2000).

From this perspective, women of color have raised a number of new questions, such as the following:

- In what ways are women of color vulnerable to RTIs, and how do they experience their infections, personally and culturally?
- 2. How can women of color protect their sexual and reproductive health in the private context of a power imbalance with their male partners, and in the public context of stigma, inadequate information, discrimination, and inaccessible services?

The high rate of RTIs among women of color is associated with a number of interrelated socio-cultural, biological, and economic factors, including poverty, low social status of women, low levels of education, racism, rapid urbanization, and local customs. The synergistic effect of these factors often reduces women's decision-making power regarding their own sexuality, and constrains their ability to seek quality reproductive health care. As Tomris Turmen of the World Health Organization describes:

Reproductive ill health is different from other forms of ill health because of the centrality of intimate human behaviors. Human sexual and reproductive behaviors are heavily dependent on social relationships, on custom, tradition, and taboo. It is therefore inevitable that social groups and individuals with the least power, with the most limited ability to make decisions, with the most constrained capacities for choice, will suffer the major portion of the burden of ill health results from these behaviors and relationships.

Appropriate health services for women, particularly marginalized women (poor women, women of color, rural women, lesbians) has always posed a challenge for modern Western medicine. Typically, medical approaches within the U.S. still cling to the assumption that there exists a uniform treatment for all people in all cases for a particular health problem and often the hegemonic model for such assumptions is the White male. Rarely is enough priority given to the benefit of health care that is tailored to the individual and the environment in which she lives. Although recently there has been a resurgence of some approaches to health care that do not constrain themselves to the usually strict delineations of modern Western medicine, service accessibility is still too frequently dependent on the impersonal and uniform structure of the medical industry (National Institutes of Health, 2000).

U.S. studies estimate that of 36 million women of color, almost one-fourth are uninsured, with limited or no access to quality health care (U.S. Bureau of the Census, 1996). Studies also show that many women of color infrequently undergo preventive health screening tests such as Pap smears, which are critical in early detection of RTIs. While researchers attribute these findings to financial, cultural, informational and access-related issues, the absence of data on subpopulations of women of color has produced inadequate and sometimes inappropriate policies and programs. Deficiency in comprehensive research regarding the reproductive health of women of color and current as well as historic lack of support in the medical community, as a whole, for effectively addressing the conditions faced by women of color have left a void in formal knowledge regarding their health.

PROGRAM DESIGN AND IMPLEMENTATION

THE SISTERSONG MODEL

In an attempt to fill this knowledge void, to promote research on reproductive health issues faced by women of color, and to ensure appropriate medical treatment of women of color, sixteen organizations across the country collaborated in collecting reproductive health data, sharing experiences in treatment and prevention, and addressing societal factors that impact the reproductive health of women of color. In 1997 and 1998, the Ford Foundation selected sixteen women of color organizations to participate in planning meetings designed to form

the SisterSong: Women of Color Reproductive Health Project. These two meetings and continued consultations identified common concerns, problems, and needs that contribute to poor reproductive health. The groups also recognized the lack of coordinated and effective efforts among women's and children's health initiatives in their communities, and the impact of biased health policies on poor women.

SisterSong created a process for planning and implementing a three-year program, including the development of a collective vision which identified basic needs, leadership issues, resources and common ground within the collective. Throughout the process several concurrent themes appeared. These needs are listed as follows:

- There is a general deficiency of knowledge in communities of color across the United States regarding RTIs.
- There exists a scarcity of current, accurate, and culturally-sensitive materials on RTIs.
- Funding available to institute programs to increase awareness of RTIs is sparse.
- Language and attitudinal barriers often prevent open access to information and services.
- Women often experience challenges in communicating health needs and concerns to sex partners.
- Medical analyses fail to contextualize the social and economic conditions (often experienced as human rights violations) that inhibit women from obtaining adequate health care.

METHODOLOGY/STRUCTURE

SisterSong consists of sixteen organizations equally representing four primary ethnic populations in the United States: Black/African-American; Latina/Hispanic; Native American/Indigenous; and Asian/Pacific Islander. The member organizations are:

Native American

The Moon Lodge Native Women's Outreach (anchor)
The Wise Women Gathering Place
Minnesota American Indian AIDS Task Force
Native American Women's Health Education Resource Center

African American
SisterLove, Incorporated (anchor)
Project Azuka Women's AIDS Services
California Black Women's Health Project
The National Center for Human Rights Education

Asian/Pacific Islander

The National Asian Women's Health Organization (anchor) Asians & Pacific Islanders for Reproductive Health T.H.E. Clinic, Asian Women's Health Project Kokua Kalihi Valley Comprehensive Family Services

<u>Latina/Hispanic</u>
Casa Atabex Ache (anchor)
Grupo Pro Derechos Reproductivos
The Women's House of Learning
The National Latina Health Organization

The collective represents a diversity of women of color organizations, all of which work on reproductive health issues either by providing direct services or through advocacy. The national geographical reach of the collective includes groups in the continental United States,

Hawaii, and Puerto Rico. Among the reproductive health issues addressed are midwifery, AIDS services, abortion and contraceptive services, clinical research, health rights advocacy, sexually transmitted diseases, and reproductive tract infections.

In order to address identified concerns and to achieve its goals, SisterSong formed four mini-communities within the main body. Each mini-community was established in order to maintain the representation of the cultural experience and sensitivity of each respective ethnic group. Each mini-community consists of four grass-roots organizations, including at least one national, one state, and two local organizations from that ethnic group. This format maintains commitment to the ability of grass-roots organizations to effectively reach a diverse group of women. One organization of each mini-community was chosen to serve as the "Anchor Organization" in order to facilitate and coordinate the communications, efforts, and contributions of the respective mini-community. Together the four anchor organizations formed the coordinating body which assumed the administrative duties. The responsibilities of the anchor organizations are to maintain cohesion of both the mini-communities and the main body of the collective, while advancing the agenda toward its ultimate objective of improving the reproductive health of women of color by reducing the risk and impact of RTIs.

DECISION-MAKING PROCESS

Collective Consensus - The collective makes decisions by consensus. This form of decision-making has the positive effect of allowing all parties involved to have a voice in the outcome of issues that affect the entire group. Issues are introduced, discussed, analyzed, and implemented collectively. This decision-making process is appropriately democratic, and encourages the development of new leadership voices within the collective.

Representative Voice - The anchor organizations accept responsibility for making some decisions for the entire collective, with the understanding that each anchor's input represents an entire mini-community. This mode of decision-making facilitates management by magnifying the anchor groups' ability to move the agenda of the collective through the planning and implementation phases.

Grievance Process - In order to maintain cohesive unity, redress that maintains the focus of the organization is necessary. Miscommunication, silence, and misinformation are three destructive forces that often inhibit the ability of emerging efforts to succeed. All too often there is no structure available for resolution of grievance issues. SisterSong agreed to integrate and use a self-help process pioneered by the National Black Women's Health Project as one method of addressing issues and concerns, as well as a process for maintaining an open and safe space for the redress of any challenges that arose between individuals and/or organizations.

PROGRAM FOCUS

The SisterSong collective includes the expertise of women who have spent years developing, implementing, and analyzing programs designed to address women's lives and improve their well-being. The leadership of each organization is committed to a reproductive health movement that is founded by diverse communities of women and that integrates concepts of women's power and equity

with health and well-being.

SisterSong has made promising strides in bringing together women of color to address reproductive tract infections in the United States. A primary innovation of this project is the increased capacity of grassroots groups to amplify their impact by building a wide-reaching, national collective. The collective's assets include:

- The powerful capacity of SisterSong to develop effective strategies in treating and preventing RTIs; the all-woman composition of the collective affords the strength, creativity, and experience to create change in the face of social inequality.
- The impowering effects of SisterSong's unified purpose that allow the collective to reach beyond cultural differences to seek common ground to benefit a common goal.
- The cultural diversity of SisterSong that provides for a multiethnic exchange of information.

OBJECTIVES AND GOALS

The formation of SisterSong united sixteen organizations that share common goals regarding reproductive health and RTI issues faced by women of color in the United States. This unity increased the capacity of individual organizations to access a stronger support network, provide a larger advocacy base for reproductive health and RTI issues, and explore innovations.

SisterSong organizations acquired the ability to interlink and form relationships that did not previously exist. These relationships increased the organizations' abilities to function more effectively. This interlinking improved capacity in the following areas:

- Proficiency in communicating with other organizations through improved telecommunications/ Internet access, computer skills and expansion of existing equipment capabilities.
- Development of a cumulative data base of current information regarding reproductive health and women of color such as culturally-sensitive/appropriate educational or resource material.
- Development of multi-media materials (e.g., audio and visual recordings, pictures, and graphics) for use in program formation and the creation of additional educational materials.
- Recording of current accurate information in understandable terminology for the production of educational material.
- Creation of a reference list of informative articles, books, and documentaries relating to RTIs and women of color.
- Cross-cultural training in evaluation methodologies, fundraising, organizational development, self-help, and human rights education.

The collective identified the following goals:

- Achieve a funding source that empowers organizations to create, adapt or initialize programs and materials that address RTIs in communities of color.
- Coordinate the efforts of organizations forming the collective to achieve maximum impact.
- Reach the optimum number of women possible with current, accurate, and culturally appropriate information regarding RTIs.
- Establish an advocacy campaign to raise a communal voice on behalf of women of color to address the effects of RTIs on women and communities.

INITIAL PROGRAM FINDINGS

SisterSong's first step in developing materials and advocacy strategies aimed at improving reproductive health care for women of color was to create an opportunity for shared learning. The SisterSong collective structured symposia to facilitate dialogue about issues faced by women of different cultural groups. Lack of comprehensive medical research and a history of inappropriate medical treatment of women of color encouraged SisterSong to gather its own data. By working with researchers from the Centers for Disease Control, the Office of Minority Health, and the National Institutes of Health, SisterSong began the process of identifying the research needs of women of color.

At the Savannah, Georgia, symposium in 1998, members of SisterSong identified various barriers and challenges to RTI prevention and service work in communities of color. Among these are issues based in social, cultural and economic contexts, as well as civil and political conditions. Many women's health programs lack the cultural competency to provide a safe and accessible environment for women of color to pursue good health care and to make sound health decisions. There is also a lack of awareness and sensitivity among providers and consumers regarding human rights issues. Inadequate information concerning contraceptive choices as well as RTIs and specific behavioral patterns that increase risk is also a challenge in providing services. These barriers, shared by all women of color, mandate that health organizations and initiatives develop more holistic approaches to reproductive health, including stronger emphasis on advocacy, education and training.

The outcomes of the symposia allow SisterSong to develop education, outreach, and advocacy strategies that increase awareness of reproductive health issues among women of color, inform practitioners of more appropriate treatment strategies to consider, and advocate for more effective legislation regarding women's health. The following is a brief account of the findings of the symposia.

COMMON THEMES

The two symposia revealed alarming health data for women of color:

- Approximately 77 percent of women with HIV/ AIDS are women of color. In 1996, African-American women represented 56 percent of reported U.S. female AIDS cases; another 20 percent were Hispanic women. HIV infection is the third leading cause of death among all women age 25-44, and the leading cause among African-American women of that age group. These women tend to be young, poor residents of disenfranchised urban communities (National Institute of Allergy and Infectious Disease and National Institute of Health, 1997).
- The Public Health Service's Office on Women's Health reported that less than 1 percent of Asian/Pacific Islander and American Indian/Alaska Native women have HIV/AIDS, but the highest rate of increase in new HIV/AIDS cases in recent years occurred among these two groups (U.S. Public Health Service Office on Women's Health, 1996).
- Occupational hazards pose a significant health threat to women of color. Disproportionate numbers of Latina and Asian/Pacific Islander (A/PI) women are employed in farming, forestry, fishing and service occupations that hold higher risk for occupational diseases and injuries (Occupational Safety and Health, 1994).
- Native American women have the lowest screening rate for cervical cancer among all ethnic groups, and Asian/Pacific Islander women have the second lowest rate. Fifty-five percent of API women, compared to 43 percent of Hispanic women, and 37 percent of African American women were not screened in 1995 (The Commonwealth Fund Quarterly, 1996).

Each mini-community then reported on their priority health and RTI issues as follows:

Native American Community

For many Native Americans, health care is controlled by the federal government. Just 34 Indian Health Service (IHS) clinics serve over 1.3 million Indian people nation-wide, leaving 75 percent virtually without health care. Urban Indians, the majority of all American Indians, receive less than 1 percent of the IHS budget (Carr, 1996). To exacerbate the problem, the government suppresses more traditional approaches to reproductive health care, such as midwifery (National Institutes of Health, 2000).

The suppression of more traditional and community-based approaches explicitly devalues any approaches not congruent with the federally-funded modern Western style medicine. The devaluing perspective of the government and the prohibition of the Native health care practices have led the Native American community to lose faith in its own ability to care for itself. American values have been grafted onto Native culture and have limited traditional learning. The confidence of Native American women in regard to self-initiated, self-controlled health care has been seriously damaged.

As a result, women are often vulnerable to government care that is not only inadequate but also pervasively manipulative. Coerced temporary sterilization through Norplant is an approach interpreted as responsible population control by some doctors. Women are pressured into a procedure that limits their reproductive capacity and then are unable to return their bodies to their normally functioning patterns due to financial constraints.

Oftentimes, physicians do not take the time to explain health care options, and there is little information available to educate the community. In addition, information that is accessible is not always congruent with literacy levels.

Culturally appropriate health education material that is "tradition-inclusive" is necessary to increase public awareness of health options. Approaches that empower the community to take control of their health choices are paramount. Train the trainer sessions for Native American women would ensure culturally-appropriate education by providing a forum for one-on-one woman-based discussions. The focus on an all-woman education group would prevent any discomfort in discussing health issues in mixed gender situations. Ultimately, knowledge regarding health options is imperative in ensuring safe and appropriate reproductive care for Native American women.

ASIAN/PACIFIC ISLANDER AMERICAN COMMUNITY

Reliable information on the health status and needs of Asian/Pacific Islander (A/PI) Americans is scarce, and many available national statistics regarding this community come from pooled data, resulting in misleading information that sometimes overlooks serious health problems, diverts health care resources to other groups, and limits A/Pis' access to health care services (U.S. Commission on Civil Rights, 1992). Nearly one-third of the A/PI community is non-English speaking, and mainstream health education and disease prevention efforts have had little impact on these communities. The quality of care that many A/PI women receive is also compromised by language barriers (Health Access, 1994). Moreover, health care professionals have limited knowledge of the cultures and endemic diseases of immigrants' countries of origin and lack the expertise to serve clients from such a diverse community. In addition, for many immigrants, accessing health care is complicated and confused by fear of deportation and jeopardizing immigration status (National Asian Women's Health Organization, 1996). Lack of income to cover health costs also poses a concern for many A/PI women.

A/PI women have typically grown accustomed to placing the health needs of the family before their own. Cultural taboos surrounding sexuality and pregnancy also contribute to the low rates of health service access. Open discussion of reproductive health issues such as anatomy, menstruation, sex, or RTIs is not common. Popular perceptions of A/PI cultural traits also pose barriers to health care service availability. The myth of A/PI women as the model minority contributes to a lack of both research and culturally appropriate services (National Institutes of Health, 2000).

It is critically important for A/PI women to control their bodies and health. In accomplishing this, a national presence is necessary, and more voices need to be heard both in the public arena and within policy-making circles. Collaborative efforts to make resources known are a crucial first step. Increased research conducted in non-traditional methods to ensure a culturally appropriate approach is also necessary.

LATINA/HISPANIC COMMUNITY

Approximately 23 percent of the Latino population lives below the poverty line, and nearly half of all poor Hispanic families are female-headed (Amott & Matthaei, 1996). In 1995, 78 percent of Latinas lacked health insurance coverage (The Commonwealth Fund Quarterly, 1996). Many women who are left without care then turn to self-medication and the sharing of medicines to promote self-care.

The data available on STDs among Latinas is alarming. Comprising 10.2 percent of all women in the United States, Latinas have a cervical cancer rate almost twice that of non-minority women (The Commonwealth Fund Quarterly, 1996) Latinas are also over-represented in the number of AIDS cases among women (20.3 percent) (National Institute of Allergy and Infectious Disease and National Institute of Health, 1997).

Lacking U.S. citizenship often deters undocumented immigrant Latinas from using public clinics and other health facilities for fear of detection and deportation (National Institutes of Health, 2000). In addition, Latinas traditionally seek family members' advice before getting professional health care, which contributes to their delayed utilization of health care services. In many families, women's low status impedes their ability to seek and negotiate for their own health care. Reproductive health care, particularly for HIV-positive Latinas, is often interrupted by frequent border crossings to Mexico and Central America, and extended stays in Puerto Rico.

Other factors limiting Latinas' access to reproductive health care include strong religious belief systems that inhibit open discussion about sexuality and safer sex practices, unequal gender relationships, and domestic violence (National Institutes of Health, 2000).

High rates of caesarians and sterilization abuse cause distrust of the medical community among many Latinas. According to a national Fertility Study conducted in 1970 by Princeton University's Office of Population Control, 20 percent of all Chicana women had been sterilized (Davis, 1981). The disproportionate number of Puerto Rican women who have been sterilized reflects U.S. government policy that dates back to 1939 when an experimental sterilization campaign was implemented. By the 1970s, more than 35 percent of all Puerto Rican women of child-bearing age had been surgically sterilized (Davis, 1981).

To counter the effects of structural bias and cultural traits on Latina reproductive health, the presence of women health activists needs to be apparent to the community. Women in power, not only grass-roots leaders, need to be identified. It is ultimately important for these Latina voices to be heard by policy-makers and local politicians.

AFRICAN AMERICAN COMMUNITY

According to statistics, African-American women exhibit very high rates of cervical and breast cancer and reproductive track infections (RTIs) (National Institutes of Health, 2000). Yet, despite high rates of serious health problems within the community, one in four African-American women did not receive a Pap smear in 1995, and one-third failed to receive a clinical breast exam in the same year. More than half of African-American women age 50 to 64 did not receive mammography screening between 1994 and 1995. One in seven (14 percent) rely on emergency rooms for basic health services.

Services geared toward African American women are rare in all communities and virtually nonexistent in rural areas. This lack of health care access has led to a gap in research regarding Black women's health. As a result, there is a lack of adequate information regarding birth control, HIV/AIDS transmission, and RTIs (Roberts, 1997). Mental health services are similarly inadequate. The influence of racial and gender oppression as it relates to depression, substance abuse, physical abuse, access to quality education, and the availability of services is often overlooked (Villarosa, 1994).

Research based on experimental tests without the informed expressed consent of the patient, such as the Tuskegee Syphilis Study, have created a distrust of the medical industry. More recent accounts of doctors pressuring women patients, particularly poor Black women, to accept birth control methods not requested by the patient have been popularized by the media and women's rights activists (Littlecrow-Russell, 2000). This distrust of the medical field also manifests itself in a fear of disclosure and of the risk of discovering a health problem upon a doctor visit (Villarosa, 1994).

SisterSong cited inadequate income as a factor in determining health care access among many African American women. Further, many Black women are disproportionately affected by welfare and immigration reform, deepening their poverty and hindering their access to health services (Roberts, 1997). Also, the religious community often prevents openness regarding sexuality and health issues (Ross, 1998).

The lack of appropriate services, information, and research calls for holistic approaches to health care that include advocacy and education. In addition, powerful and positive women motivators from the African-American community need to guide and lead dialogue around reproductive health issues. African-American women have made significant contributions in advocating for birth control, family planning, and abortion rights, however, organizing among African-American women on reproductive health, particularly regarding RTIs, has been insufficient.

COLLECTIVE CHALLENGES

The greatest of SisterSong's external challenges is the "Veil of Silence" affecting the dialogue about all sexual issues and preventing open communication between sexes, among generations and even within the same gender. This veil is cross-cultural, confronting women around the world. It is the source of myth and misinformation that is selfperpetuating. Much of the work of SisterSong is compounded by the difficulties that this silence imposes.

Additionally, cultural diversity can increase communication gaps, and provide ample opportunity for interand intra-cultural misunderstanding. SisterSong addresses this challenge through open lines of communication and a grievance redress policy. Another approach is to integrate cultural sharing and learning into the collective process to limit the impact of communication gaps caused by lack of cultural understanding.

REPRODUCTIVE RIGHTS AND HUMAN RIGHTS: RECONCEPTUALIZING THE HUMAN RIGHTS FRAMEWORK

As evidenced by the mini-community reports, SisterSong contends with both external/societal and internal/organizational challenges. The lack of effective coordinated efforts to ensure the health of women and children particularly for the prevention of STDs and HIV represents an extreme challenge to the vision of SisterSong. The need for policy changes are apparent in states where schools provide only abstinence-based sexuality education and where women are forced to receive spousal or parental permission for reproductive medical procedures such as abortion or contraception. The resolution to many of these and other challenges is possible only with a change in the socio-cultural, political and economic balance of power and representation of women utilizing the human rights framework.

SisterSong, as well as other organizations concerned with reproductive health issues in the U.S., draws inspiration and tools from the international human rights movement. Through the application of human rights education, SisterSong began a process of reconceptualizing human rights in the United States, particularly in its applicability to health care problems. The collective joined other social justice activists in demanding that the United States be held accountable to the same human rights standards that are recognized around the world. Rather than focusing primarily on critiques of other governments, this new generation of human rights activists has called attention to significant human rights violations committed by local, state and federal governments, and by private actors. It challenges the United States' denial of the applicability of human rights treaty norms, standards and mechanisms when developing or implementing domestic policies that negatively affect women of color.

The United States lacks a sufficient legal framework that guarantees women of color safe and reliable access to health care; emphasis on individual civil and political rights neglects economic, social and cultural human rights that address group or collective needs. In order to ensure appropriate treatment and access to health care, and to address the intersectional oppression matrix (class, race, gender) that affects women of color, a comprehensive human rights-based approach is necessary.

The human rights framework challenges the United States to demand that economic, social and cultural human rights receive the same level of priority and applicability as that given to civil and political rights. Privileging of civil/political rights over economic/social/cultural rights is often justified by economics, as Florence Butegwa describes:

Civil and political rights are characterized as negative and cost-free rights in that governments are only required to abstain from activities which would violate them. This is contrasted with economic, social and cultural rights which require governments to do something, thereby committing considerable resources, to ensure individuals the enjoyment of those rights (Butegwa, 1995).

The United States has an obligation to provide an environment in which policies, laws, and practices enable women to realize their reproductive rights, and in which conditions that compromise or restrict such rights, such as coercive policies designed to limit or increase a woman's fertility are discouraged.

Women of color recognize the fundamental and symbiotic relationship between individual and collective human rights, acknowledging that the individual human rights of women of color cannot be protected in a country in which the collective rights of all people of color and women are not upheld. The recognition of reproductive rights as human rights was reflected in the consensus document of the 1994 Cairo International Conference on Population and Development (ICPD), which states that countries should ensure the reproductive rights of all individuals; should provide the information and means to decide the number, spacing and timing of children; should uphold the right to have the highest standard of sexual and reproductive health, and the right to make sexual and reproductive decisions free of discrimination, coercion, and violence.

There are many challenges associated with the awesome task of making domestic, regional and international human rights mechanisms responsive to the needs of women of color in the United States. The United States de-emphasizes the applicability of human rights standards to domestic policies and prevents broad coverage of the human rights treaties it has ratified by attaching crippling reservations. An educated grass-roots human rights movement must apply political pressure toward the ratification and implementation of significant human rights treaties.

This vision of women of color is not limited by enunciation of only legally-enforceable human rights but embraces a vision that gives as much, if not more, weight to the moral and political power of human rights. The United States has not ratified legally-binding treaties that link health and human rights, but women of color are not dissuaded from perceiving their utility. Human rights are as important for their statement of moral principles and their potential as a political organizing strategy as they are for their legal possibilities.

Furthermore, opponents of women's human rights create an artificial dichotomy between "needs and rights" by claiming that a human rights-based approach to health is an elite western imposition designed to counter a "needs-based" approach. These critics ignore the reality that rights are born out of needs; rights are legal articulations of claims to meet human needs and protect human freedoms. Instead of a rights/needs hierarchy, there is, in fact, a rights/needs symbiosis (Petchesky, 2000).

Globally, women organizers and trainers are beginning to increase human rights awareness among reproductive rights and women's health activists. In the United States, many have yet to recognize women's human rights as a framework within which reproductive rights advocates find greater solidarity and strength. The applicability of human rights instruments, specifically the Convention to End All Forms of Discrimination Against Women (CEDAW), to the ongoing struggle for reproductive freedom in the United States is clear and straightforward. For example, Article 12, paragraph 1 of CEDAW recognizes the ability of a woman to control her own fertility as fundamental to her enjoyment of the full range of human rights to which she is entitled, including the right to health care and to family planning (United Nations, 1979). Moreover, the treaty speaks to the obligations of the United States government to pro-actively address social, cultural, or traditional discrimination against women, such as female "circumcision". Likewise, any law that restricts women's access to a full range of family planning options is defined as discriminatory under CEDAW. Unfortunately, the United States has yet to ratify this important treaty to uphold the rights of women.

CONCLUSION

As global problems worsen and policy makers are pressured to find quick-fix solutions, forms of population control are reemerging in overt and covert forms. Many liberal feminist organizations have continued to take a narrow view on reproductive health by equating it only with abortion rights. Even more troubling, many international women's rights organizations are now dependent on the financial and political support of population control organizations. As Asoka Bandarage of the Committee on Women, Population and the Environment reports:

As fertility control is presented increasingly as the means for women's empowerment, feminist criticisms of coercion and experimentation within family planning programs gets softened; the resurgence of eugenics associated with the growth of new productive technologies gets overlooked; and the social structural roots of women's subordination and the global crisis tend to be forgotten (Bandarage, 1994).

Economic incentives offered to poor people to persuade them to accept sterilization, intrauterine devices (IUDs) or hormonal contraceptives make mockery of the concept of reproductive freedom for women of color. A new program called C.R.A.C.K. (Children Requiring a

Caring Kommunity) offers a hefty financial incentive to women who use illegal drugs if they accept temporary sterilization through Norplant or DepoProvera (Bernstein, 2000). Many state legislatures have proposed bills linking public assistance to population control, while some judges in U.S. courts have coerced women into accepting contraceptives as a condition of their probation or parole.

The push to develop new and effective fertility control methods has created a new generation of high-risk contraceptives that are neither safe nor woman-controlled. This often occurs at the expense of the promotion of safer barrier methods that are controlled by women. A new option, quinacrine, is now being promoted around the world. This drug dissolves in the womb and results in the formation of scar tissue at the ends of the fallopian tubes, presumably preventing contraception. Quinacrine is an extremely problematic drug that was developed in the 1920s as a malaria treatment and was never approved by

the FDA for use as a contraceptive. There is even evidence that it may increase the risk of cancer. Since quinacrine is inexpensive and simple to manufacture, and since it can easily be inserted without women's consent, there is great potential for providers to abuse the trust of clients undergoing pelvic examinations (Varzo, 1993). An anti-pregnancy vaccine is also being tested in India that compromises women's immune systems, a danger considering RTI epidemics around the world, particularly HIV.

These issues emphasize the urgency of SisterSong's mission to recognize the inextricable link between health and human rights. The Collective addresses not only medical conditions, but the human rights violations of poverty, homelessness, and inadequate health care. We focus on women's lives, not just women's diseases. SisterSong combines research, training, education and advocacy in powerful efforts to save women's lives and ensure the reproductive health of women of color.

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