

**THE SUNFLOWER PROJECT – IMPROVING
QUALITY OF LIFE OF WOMEN LIVING WITH
HIV/AIDS IN COLOMBIA**

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Abstract

The experiences of women living with HIV/AIDS were studied by means of the analysis of how a government and non-governmental project have improved their lives. In Colombia, the ratio of infected men to infected women was 7:1, in 2002, indicating great women suffering from HIV/AIDS. In-depth, semi-structured, open-ended interviews were applied to explore women's journeys, their relationship to health services and their experiences of stigmatization and discrimination. Women involved participate in the Sunflower Project, a grassroots initiative also called the Colombian Network of Women Living with HIV/AIDS, and the Mother-to-Child-Transmission Project, a government initiative. Examinations of the programs outcomes show the need for more information; education and empowerment allow women to continue their journeys towards self-determination. Findings highlight women perceptions of life improvement with social network support and economic stability as a result of their participation in these projects. Such projects are essential for women with AIDS.

Keywords: HIV/AIDS; Women with HIV/AIDS; HIV/AIDS projects; Colombia and HIV/AIDS; Latin America and HIV/AIDS, Colombia.

Subject Terms: Social support and HIV/AIDS, women support and HIV, women support with AIDS, Social support in Colombia

Resumen

A través de las experiencias de mujeres viviendo con VIH/SIDA se analizaron dos proyectos, uno gubernamental y otro no gubernamental, denominado Proyecto Girasol, a fin de conocer como estos proyectos mejoran la calidad de vida de las mujeres positivas en Colombia. Mientras se considera el VIH/SIDA como epidemia concentrada en hombres que tienen relaciones con hombres, al 2002 las infecciones hombre-mujer eran de 7:1, y para el 2005 era de 4:1, esto indica que las mujeres son afectadas en gran medida por el VIH/SIDA. Entrevistas semi-estructuradas y abiertas sirvieron para explorar las relaciones de estas mujeres con los servicios de salud, la estigmatización y discriminación de que son objeto y otras experiencias vividas. Las mujeres participantes han estado vinculadas al Proyecto Girasol, conocido también como la Red Nacional de Mujeres Positivas y el Proyecto de Transmisión de Madre a Hijo. Al revisar los logros obtenidos por los proyectos se encontró que es necesaria más información, educación y empoderamiento que les permita a las mujeres su propia autodeterminación y continuar con su vida y el cuidado de su familia. Así mismo, los hallazgos demuestran que es indispensable fortalecer la red social de apoyo y realizar proyectos económicamente sostenibles que les asegure a las mujeres un ingreso permanente. En resumen las mujeres obtuvieron mejoramiento de su calidad de vida gracias al apoyo social y mejoraron su estabilidad económica, como resultado de su participación en estos proyectos que son esenciales para mujeres viviendo con VIH/SIDA.

Palabras claves: VIH/SIDA; Mujeres y VIH/SIDA; proyectos de VIH/SIDA; Colombia y VIH/SIDA; VIH/SIDA en Latinoamérica.

Resumen para el Lector

El siguiente trabajo presenta las experiencias de mujeres viviendo con VIH/SIDA en Colombia. Como introducción al tema se esboza la situación de las mujeres viviendo con VIH/SIDA en todo el país y en un marco específico se analizan las acciones que se han realizado en Colombia desde que se presentara el primer caso de VIH/SIDA en una mujer en 1983. Para el 2005 la infección hombre-mujer fue de 4:1, indicando como las mujeres son afectadas por el VIH/SIDA. Dentro de las acciones gubernamentales la Ley 100 o reforma de salud elimina el programa nacional de SIDA y coloca el VIH/SIDA con las otras enfermedades transmisibles, escaso presupuesto, y la fusión del Ministerio de Salud y el Ministerio de Trabajo y Seguridad Social redujeron el personal. De otra parte, las funciones de promoción y prevención fueron delegadas a las Entidades Promotoras de Salud que hasta el momento de esta investigación no las estaban ejecutando forzando al gobierno a decretar nuevas normas que obliguen al cumplimiento de la ley. Las historias muestran los inconvenientes en la atención en salud; la universalidad y equidad del servicio de salud incluidas en la Ley 100 no llega a la totalidad de la población; igualmente a pesar que el suministro de medicamentos ARV para los pacientes con VIH/SIDA según decreto 282 no está a disposición de los pacientes en forma integral. Además de recoger la información sobre las acciones de gobierno, este trabajo revisa la participación de organizaciones no gubernamentales que han existido desde la aparición del primer caso de VIH/SIDA en Colombia y las acciones donde estos grupos han sido clave en la obtención de logros tales como el reconocimiento de los derechos y deberes de las personas viviendo con VIH/SIDA y la inclusión de medicamentos ARV dentro del plan de salud y la red de apoyo y educación que han brindado a la comunidad. De la misma manera se reconoce el invaluable

trabajo de estas organizaciones, algunas de ellas de muy corta existencia pero de gran valor para las personas viviendo con VIH/SIDA.

De otra parte, mediante entrevistas semi-estructuradas y abiertas con mujeres viviendo con VIH/SIDA, ellas compartieron sus historias de vida que sirvieron para explorar el camino andado por estas mujeres, sus relaciones con los servicios de salud, la estigmatización, discriminación y otras experiencias vividas a partir de su diagnóstico como VIH positivas, sus relaciones con la familia, y con grupos de apoyo especialmente el proyecto Girasol, sus comentarios sobre educación y promoción en salud y lo que perciben para el futuro. Las mujeres participantes han estado vinculadas con el Proyecto Girasol – conocido también como la Red Nacional de Mujeres viviendo con VIH/SIDA que realiza sus acciones de apoyo y que ha venido trabajando de mujer a mujer desde su conformación como organización de base en 1997. Girasol trabaja en todo el país y tiene representantes en cada una de las regiones geográficas colombianas brindando apoyo social a otras organizaciones e instituciones gubernamentales, especialmente al proyecto de Transmisión de Madre a Hijo. Este último es una iniciativa del gobierno y presta servicios a las mujeres en estado de gestación donde se ofrecen la prueba de diagnóstico y confirmación, seguimiento durante el embarazo, prueba posparto tanto a la madre como al bebé; prueba de seguimiento a los seis meses; leche sustituta, y la vinculación al sistema de salud que corresponda, bien sea contributivo o subsidiado.

Al revisar los logros obtenidos por los proyectos de acuerdo con las respuestas suministradas se encontró que es necesaria más información, educación y empoderamiento que les permita a las mujeres su propia autodeterminación y continuar con su vida. De igual modo, los hallazgos muestran que es indispensable fortalecer la

red social de apoyo y proyectos económicamente sostenibles que les asegure un ingreso permanente.

A pesar de que la calidad de vida de las mujeres vinculadas al proyecto Girasol ha mejorado y que los proyectos socio-económicos mejoran su estabilidad económica para las de menos recursos la situación no mejora totalmente.

Por ultimo, aunque se haga promoción y prevención en salud, que los comportamientos con respecto al uso del condón cambien, y que haya tratamientos antiretrovirales disponibles, la calidad de vida de las mujeres no mejorara sino se cubren las necesidades básicas inmediatas y si no hay una mínima alimentación.

Quotation

...My friend died from AIDS six years ago; she had a professional title, a good socio-economic status. She had a good life, but her family was very negative, her self-esteem was very weak and her mental health very fragile. She wanted us to get organized into a support group so we could work for other women. She said we would name it SUNFLOWER. The seeds in the center are the women getting together because they need help, and the yellow petals are the projects and dreams that we could develop. The name is masculine because she did not want it to be a closed feminist group and a masculine name will tie many things and project is a dynamic word...

Sunflower Project - National Coordinator



Dedication

To my daughters Natalia and Laura, who inspired me to learn more about women, who we are, what we can do, what we capable are of, and how much can we give back.

To my husband for the wonderful times we share together, his support with the house chores and encouragement.

To my father (In memoriam) and my mother, for their strength and support at all times, and who encouraged me to value the people around us, to share what we have, to look for the good we have inside, and give always the best especially to those who need the most, and most importantly, for teaching me to be the person I am today.

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Glossary

UNAIDS	The Joint United Nations Programme on HIV/AIDS
SGSSS	General System of Health and Social Security
MSM	Men having sex with men
ARV	Anti-retroviral treatment
EU	European Union
MTCT	Mother-to-Child Transmission
EPS	Health Promoters Entities
IPS	Health Lending Entities
ESSE	Social and Solidarity State Entities
POS	Compulsory Health Plan
NGO	Non-governmental organization
SISBEN	System for Selecting Beneficiaries of Social Spending
PLWHA	People living with HIV/AIDS
PLWA	People living with AIDS
WLWA	Women living with AIDS
STI	Sexually Transmitted Infections
ARS	Administrators of the Subsidized Regime
PAB	Basic Health Plan
IEC	Information, education, and communication
ICBF	Colombian Institute of Family Welfare
INS	National Health Institute
INVIMA	National Drug and Food Surveillance Institute
UNFPA	United Nations Population Fund
INRAVISION	<i>Instituto Nacional de Radio y Television</i>
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
UNCHR	United Nations Commission on Human Rights
WB	World Bank
UNODC	United Nations Office on Drugs and Crime
ILO	International Labour Organization
UNIC	<i>United Nations Information Centre</i>

Chapter One. Introduction

The International AIDS Crisis

*“...AIDS is not a matter of death, but of life...”
Jose Antonio Gomez Hermida¹*

In order to understand the AIDS epidemic faced by women in Colombia, I needed, first to see the country from a global perspective. At the HIV/AIDS and Development Workshop in 2004, Nafis Sadik, the UN Ambassador for HIV/AIDS in Asia, pointed out that there are ten new infections per minute around the world: more than fourteen thousand people - men, women and children - are infected every day. By 2003, there were over two million people in Latin America and the Caribbean living with HIV, with one hundred thousand deaths that same year destroying families, communities and, potentially, the countries' economies and development². UNAIDS estimates that in 2005, 4.9 million people worldwide were infected with HIV, 40.3 million were living with HIV/AIDS, and 3.1 million died from HIV/AIDS.

¹ Mr. Jose Antonio Gomez Hermida, Colombian Senator, International Conference Tel Aviv, Israel, *AIDS Education – Interventions in Multicultural Societies*, 1996, p.64

² “VIH/SIDA y Desarrollo: derechos humanos, derechos sexuales y reproductivos” presentation at the VIH/SIDA Y Desarrollo – Economic Impact. Contribution to the Social Sciences and Culture to stop the pandemic in Colombia and Latin America, document edited by the Colombia Agenda Foundation and sponsored by Colciencias, UNFPA, International Planned Parenthood Federation and Pan American Health Organization. 2004

Additionally, there were one million more women living with HIV in 2005 than in 2003. Women's infection rates have progressively increased not only due to the sex trade but also due to heterosexual relations with their permanent partners, adding to the risk of HIV/AIDS transmission during pregnancy, delivery, and breastfeeding. It is hard to compare the regional causes of these increasing numbers, especially in those countries where heterosexual relations are the primary means of infection.

...HIV/AIDS is linked to poverty, ignorance, gender relations, culture influenced by cultural and religious traditions, lack of sexual and reproductive health along with mobility of population and political stability. In order to fight it, we have to work with families, community groups at the ground and more marginalized levels and work with youth, and where promiscuity levels are very high, population should be bombarded by media (radio, TV and highway ads)...

*Alfredo Witschi-Cestari,
UN Humanitarian and Resident Coordinator³*

While in 1997, women comprised 41% of the total global number of infections among adults; by 2000 this percentage had climbed to 50%. Out of 3.2 million new infections in Sub-Saharan Africa in 2005, 4.6% were found in women between the ages of 15 and 24, for a total of 13.5 million infected women. Asia saw 1.1 million new infections, increasing the total number of infected women to two million and increasing the nationally HIV infected population to 8.3 million. In 2004, Central Asia and Eastern Europe had 1.6 million people living

³ VIH/SIDA and development – Impacto economico. Contribucion de las ciencias sociales y la cultura para detener la pandemia en Colombia y America Latina. 25 & 26 Noviembre 2003. UNFPA, International Planned Parenthood Federation and Pan American Health Organization. 2004, page 32

with HIV. Out of 8,200 new infections in Oceania, women between the ages of 15 and 24 accounted for 1.2% of the total HIV infected population; and 74,000 people in total were living on the continent with HIV. In 2004, 30,000 new infections occurred in the Caribbean, with women accounting for 49% of the total infected population, which was estimated at 300,000. In Latin America, 1.8 million people were living with HIV in 2003, and it was spreading at a rate of 200,000 new infections per year.

India and Brazil are producing and providing Antiretroviral treatments, without restriction, to all reported cases. Indian pharmaceutical companies have reduced the cost of ARV cocktails from \$12,000 per person per year to between \$300 and \$350 per person per year, including the free distribution of ARV treatments to the infected population in Africa. The World Trade Organization's decision to enforce their regulations surrounding compulsory licenses for drug production and the adoption of HIV/AIDS as a priority topic by the Human Rights Commission in Geneva have been considered advancements toward controlling the epidemic.

National reported numbers of case prevalence and national registry cases supported by sentinel surveillance systems reveal that UNAIDS data may not be accurate due to the under-registry of cases and/or difficulties with successfully obtaining information from rural areas. An additional challenge to obtaining accurate international information is the fact that epidemics vary characteristically from country to country. The epidemic in Sub-Saharan Africa is considered

generalized, while the Asian, Latin American, and Caribbean epidemics are concentrated. In wealthy countries such as those in North America and Western Europe, men having sex with men have historically accounted for the largest number of infections, yet the number of infections occurring due to heterosexual relations has increased in recent years. Another variable, IV use, varies in high-income countries such as the USA and Canada, in which some indigenous groups face infection via contaminated injection equipment. In Central America, sexual intercourse is the major means of infection. However, the rate of infection among female sex workers is lower than the rate among MSM. In the Caribbean, the epidemic is predominantly heterosexual, and in some places it is concentrated between sex workers. In the Caribbean, Haiti holds the highest number of infections, followed by the Dominican Republic, where prevention and education programs have reinforced the dangers of high-risk sexual behavior and have focused on the health benefits of having fewer sexual partners.

According to UNAIDS In Latin America, the HIV/AIDS epidemic is low in prevalence, but it is concentrated. In Mexico and Brazil, the epidemic is concentrated among men having sex with men (MSM); in Peru and Colombia, however, women are contracting the infection heterosexually, particularly from partners' bisexual encounters. Because roughly 95% of the population in Latin America is Catholic⁴, religion has a significant impact on social behaviors, even though contraceptive practices are not unusual. Added to that, there is a

⁴ World Almanaque 2006. Editora Cinco

predominant patriarchal foundation, or “machismo,” in most Latin American societies. Women are the child-bearers while men are the breadwinners; the latter exercise authority and decide what is and what is not permissible. Despite the fact that marriage means monogamy for women, it tolerates extra-marital affairs for men; in fact, men often have more than one sexual partner in order to assert their masculinity and their superiority. As a result, women are at risk of contracting AIDS from their regular partners (Cohen, & Durham, 1993). Despite the gender inequality embedded by this patriarchy, culturally this is reinforced by mothers and grandmothers, whose strong religious beliefs have naturalized the status quo; this is what I heard from friends and school classmates during my high-school years.

The gap between the permissibility of female and male sexuality is exaggerated in the low-income population. In this socio-economic class, women whose education levels are either very low or non-existent often find themselves unprotected and, as a result, they are often the victims of violence. Cultural and familial conventions force women to comply with men’s requests, including being forced to have sex whenever the men desire. A woman is taught that because her husband is the most important person in the household, his needs come first, followed by the needs of her children. Ironically, once infected women are diagnosed they are questioned about their behaviors by members of their own family by performing acts of rejection such as putting dishes and cutlery aside, asking them not to use the same washroom and stigmatizing her by expressing feelings of shame for her situation as a result of bad social behavior. The

stigmatization and discrimination faced by women in these patriarchal societies only serve to perpetuate silence and denial about HIV/AIDS, reinforcing women's marginalization and discrimination that challenge the possibility of their receiving proper care and treatment.

Selection of Projects, Sample, Sites and Data Collection

I looked at the work of all community groups and organizations in Colombia (Chapter Two) in order to learn about the populations they serve and the activities and projects they are implementing. The majority of these organizations are part of the HIV/AIDS Working Group. Some of the organizations offer pre- and post-test counselling; social support, advocacy, training workshops, legal support, and many conduct research. The projects I have chosen have been selected not only because HIV/AIDS is depopulating countries, diminishing their economic sustainability, but also because women's infection rates are increasing disproportionately, especially among women with one permanent partner. In response, these projects have developed national initiatives that specifically address women's needs. The coordinating offices of both projects are located in Santa Fe de Bogotá, the capital of Colombia, and both have received funding through UNAIDS. The Mother-To-Child-Transmission Project is a government project premised on the administration of services (tests and health care services provision) through the health care system by way of municipal and departmental health secretariats for pregnant women and HIV-positive babies. Interestingly, a male doctor leads the project,

with a female nurse responsible for case follow-up as well as a female information assistant and a female administrative assistant who coordinate at the national sites. The initiative functions through the National Health Institute, and is service-oriented. The Sunflower Project – also called the Colombian Network of Women Living with HIV/AIDS - was conceived as a grassroots, woman-to-woman community organization. This initiative has received funding from NGOs other than UNAIDS, but at this point it is looking for alternative means to be self-sufficient.

The women interviewed are linked to the Sunflower Project. During their journey with HIV/AIDS, they have received information and social support from the project; they took part in training workshops, also participated in local and national encounters with HIV-positive women organized by the Sunflower Project. The National Coordinator and the Vice–Coordinator provided me with information about the national network, its activities since its inception, its current needs, and the ideas in development for the future. Additionally, the coordinators assisted me in contacting interviewees by seeking their willingness and consent to participate in my research.

Of the women interviewed, 60% live in Santa Fe de Bogotá, the capital of Colombia, and the remaining 40% live in the mid-sized city of Villavicencio, the capital of the department of Meta, situated approximately 75 kilometres southwest of Santa Fe de Bogotá. Santa Fe de Bogotá is located in the middle of the country, and with a population of over seven million inhabitants, it is the country's largest city. The city is also responsible for delivering roughly 60% of

Colombia's health services, programs which have been especially critical in light of the fact that the city has received a large number of displaced people due to the ongoing civil war's that are engrossing the surrounding slums areas increasing possibilities for risky behaviors and the limited services. Santa Fe de Bogotá has a high incidence of heterosexual infection, and it is one of the cities with the highest HIV/AIDS infection rate among women with one permanent partner. Organizations listed in Chapter Two work with different populations (MSM, orphans, women, and youth).

Villavicencio, in turn, is located to the southwest of Santa Fe de Bogotá on the Guatiquia River, and has a population of approximately 420,000. With its great tropical climate, Villavicencio is well-known as "The Door to the Savannah," "La Puerta al Llano," with huge cattle ranches, fruits and vegetables having provenance in this area. Historically, the city is known as the Liberty path, where "The Lancers," a strong group of men, followed Simon Bolivar "Liberator" to the Liberty battle that concluded in the Boyaca Field and sealed Colombia's independence from Spain in 1819. Politics continue to be tense, and rivalry between parties is strong. Women in Villavicencio receive support from San Antonio de Padua, the Sunflower Project's local satellite. The coordinator of this satellite helped me contact the women. Initially, Santa Fe de Bogotá, with its high rate of infection, was selected as the sole sample site, but there were not as many women willing to speak as I had anticipated.

Women participating in the study are between 24 and 61 years of age. Of the total women interviewed, 21% women were diagnosed while pregnant by the

Mother to child transmission (MTCT) program in Villavicencio. Prior to their diagnoses, these women, however, did not know anything about the project. It was not possible for me to interview a single woman receiving services through the MTCT project in Santa Fe de Bogotá. I was invited to the MTCT National Evaluation, where I had the opportunity to interview governmental and NGO staff participating in the MTCT project at various locations across the nation. The two-day evaluation took place in Cartagena, and during a visit to their office, I also had the opportunity to interview the National Coordinator and the nurse responsible for program systematization. In addition, I visited the Simon Bolivar Hospital, taking the time to interview the nurse responsible for receiving and processing transferred patients from local health units. From the Sunflower Project, the Principal Coordinator and Vice-Coordinator in Santa Fe de Bogotá and the Coordinator in Villavicencio were interviewed. I was also able to speak with the UNAIDS advisor, the UNFPA reproductive health advisor, the San Antonio de Padua coordinator, the director of the François-Xavier Bagnoud (FXB), and the Ministry of Social Protection HIV/AIDS advisor (who is the coordinator of the 40-person team responsible for all transmissible and chronic diseases).

In the prospectus, I proposed to carry out my participant observation by accompanying female interviewees for one full day in order to develop a better understanding of their daily lives. Most of the women, however, preferred to participate only in the interview. They selected a place to meet in which they felt most comfortable. Only 10% of the interviews were conducted in a public space,

in the government HIV/AIDS treatment center for subsidized regime patients. A further 60% of the women were interviewed in their homes, and I made observations regarding their surroundings and their attitudes toward their children. The other 30% of participants preferred to meet outside of their own homes but in a space in which they felt safe and comfortable. For some women whose families do not know about their diagnoses, revealing their infection means risking rejection or stigmatization. Some women simply had commitments in a particular part of town, and they chose their meeting locations based on convenience. In Chapter Four, I present the participants' voices.

From a very young age I learned about the needs and suffering of others, and why it was important to share what we have with others. I was raised within a catholic family where honesty, truthfulness and compassion were always put first. As a family we spent a day a year accompanying elders and sharing candy with them in the Bogotá elderly hospice. The First Communion celebration was turned into a donation and spending a day with abandoned children in the national orthopedic hospital, where we have supported. I volunteered for different social causes and most important I had the opportunity to work with two international organizations and see poverty and population needs around Colombia. During the 1980's , my job responsibilities allowed me to work with community organizations working with HIV/AIDS and I got the pleasure of meeting someone living with HIV/AIDS who made a great impact on me for the attitude towards life approach he had of respect, value of time, understanding to people situations that made me realize that life is short and sometimes we spend

too much time searching for material things, money etc but like the little prince we forget the obvious and the little things that make life and in the search for materials things we take the selfish attitude and forget people and the self satisfaction of doing good for someone. As a woman and knowing patriarchal attitudes toward women I felt I had a commitment with these women and the need to help them to spread their voices and let the world know what they are going through.

Role of Health Communication in Health Promotion Projects

In 1978, the WHO's International Conference on Primary Health Care in Alma-Ata determined a need to establish strategies that would allow the lower-income population access to primary health care. In the 1980s, health promotion strategies began to be developed internationally. Informative, communicative, and educative activities were defined to promote healthy behaviors. In 1986, the Ottawa Charter (International Conference of Health Promotion) determined that health promotion should focus on promoting the health care sector's accessibility to the general population by increasing equal opportunities. The Conference emphasized the fact that people should assume control of their own health and behaviors and, furthermore, that the health sector should work in partnership with the socio-economic sector (education and economy), the private sector, and NGOs in order to develop a healthy community.

Health is a product not only of an individual's actions and behaviors within a social environment but also a result of conditions that permit people to make

healthy choices and to live in a healthy environment. Health promotion, in turn, is defined as attitudes and behaviors impacted by the community's call for change in the socio-political environment (WHO 1986, Bunton and MacDonald, 1992). With the implementation of health promotion in the American region, the PAHO designed strategies to help countries recuperate healthy living; for instance, Healthy Cities was supported through the Health Service and Health Promotion Divisions of PAHO/WHO. Healthy Cities, or Healthy Municipalities, included initiatives at the municipal level, including incentives for community participation, recollection of information regarding community needs, and education for the population regarding processes, leadership, decision-making, rights and responsibilities at all levels in order to fulfil their needs. Social communication strategies were adapted to local needs based on socio-cultural values and economic differences within the community, and they served to establish a dialogue between health care professionals or institutions and the population. As defined by Paulo Freire (1970), communication is a dialogue that necessitates group participation, aiming to achieve consciousness, trust, commitment, a sense of ownership, and empowerment among communicants.

Health communication strategies endeavor to inform and to impact individual and community decisions and, finally, to improve health. As such, it is crucial that communication strategies work within the health sector in order to improve personal and public health. Health communication experiences have been shown to contribute to all aspects of prevention and health promotion. For instance, positive communicative relationships between health care professionals

and patients improve patient health by creating an environment in which professionals can clearly provide patients with instructions regarding health regimes and treatments to follow. Furthermore, having clear information available assists the population in selecting health plans and insurance providers and in following appropriate treatments. In essence, health communication involves public health messages and education campaigns in order to promote social change, awareness, and an environment conducive to healthy attitudes and behaviors. Other campaigns disseminate information in order to raise awareness of health risks and possible solutions; they encourage the acquiring of skills, attitudes, and behaviors that reduce health risks. They also help community members' network in order to find social support from others in similar circumstances. Some campaigns have used health images, messages and mass communication for public service announcements in mass media such as radio and television, and have integrated mass media into community-based programs or have used social marketing strategies. Colombia has used Social Learning Theory (SLT) as the basis for its diffusion of health campaigns surrounding vaccinations, breastfeeding practices, cholera prevention, and the Integrated Management of Childhood Illnesses (IMCI), known in Spanish as the IAEPI strategy. The SLT has also been used in promoting HIV/AIDS awareness and condom use. Printed materials complement campaigns in the delivery of health messages, educating health consumers on the obligations and locations of health services and on the rights of the patient.

Overall, the community widely benefits from health communication, and, in turn, the community can influence public agenda, lobby for policies and programs, and promote positive changes in the physical and socioeconomic environments. Also, the informed community becomes more self-aware; it becomes concerned with the delivery of health care services and the promotion of social practices that achieve better health for the community. By improving communication between health professionals and the general population, better health promotion and more work in disease prevention can be carried out, as we can see in some initiatives that are premised on health promotion and health communication.

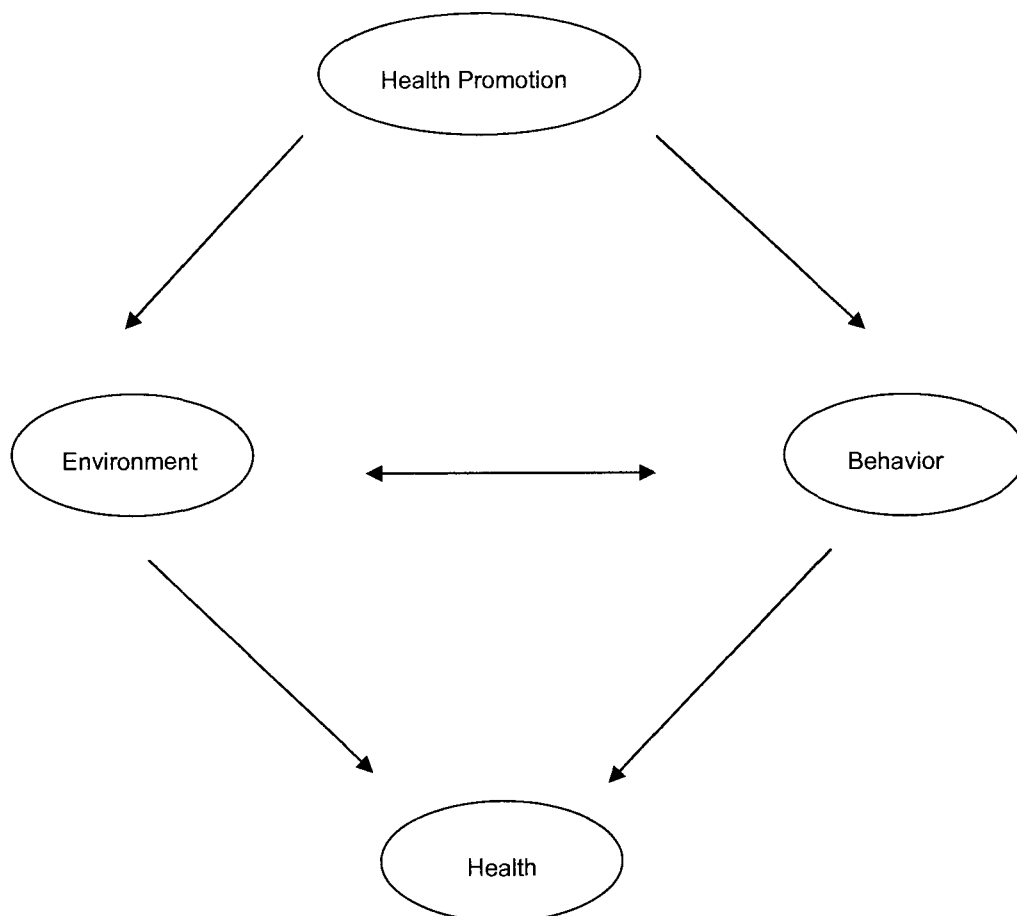
The MTCT Project - has produced radio and television commercials through a communication agency as well as materials tested for language and message, which emphasize the Social Learning Theory's concept of role modelling. Margarita Rosa De Francisco, a former Miss Colombia pageant, actress and news anchor, provides in these health promotion messages a positive statement offering support to women.

Conceptual Framework for the study

In order to determine how these projects have improved the lives of women with HIV/AIDS, I based my research on the assumption that health promotion projects for HIV/AIDS and information, education, and communication strategies work to promote a healthy lifestyle, a sense of empowerment, and changes in attitude regarding risky behaviors at both the individual and

community levels. Health promotion considers health a product of not only individual actions and behaviors but also of interactions within a social context (See Figure 1).

Figure 1 Health promotion considers health as a product of not only individual actions and behaviors but also interactions within a social context (Community and Population Health Green and Ottoson, 2001).



Ratzan⁵ in *Aids Effective health communication* states that “Health communication should be used when dealing with individual diagnosis, social and institutional potential,” which requires social mobilization, political and governmental actions, and community involvement, – “is the process and effect of employing ethical persuasive means in human health care decision-making” (Ratzan, 1993). Its aim is to catalyze change in individual and community health behavior and to provide a setting in which these changes are sustainable. By extension, health communication involves different actors, such as health care providers, community groups, media, family and patients, and it occurs in many relationships among the aforementioned groups. Each relationship carries a unique level of ethical responsibility. It has been said by some authors that health communication promotes healthy behavioral change in a humanitarian way. As health communication has been recognized as an excellent instrument in promoting health and creating changes in lifestyles (Beltran, 2000), it has been applied in health promotion programs to promote the prevention of communicable diseases and to promote changes leading to a healthy life. Considering that lifestyle is a complex pattern of habituated behaviour that is socially and culturally conditioned and may be health-related but not necessarily health directed (Green & Ottoson, 1999, p. 734). By means of communication strategies, health communication optimizes pro-active behavior. These strategies seek to modify determinants of health so that both the individual and

⁵ Ratzan, S.C. (1993) *AIDS effective Health Communication for the 90's*, Emerson University, Boston Massachusetts, 1993, p.5

society can benefit.⁶ Communication in health projects should pay particular attention to the target audience and their needs (Gumucio-Dragon 2001).

The population health perspective (PHP) defines health not only as a state free from disease but also as “the capacity of people to adapt, to respond to, or control life’s challenges and changes” (Frankish et al., 1996), which indicates why some people are healthier than others (Evans et al. [1994] and Wilkinson [1996]). This perspective considers health and disease, taking into account a variety of issues such as availability of and access to health services, burden of disease, gender, distribution of resources, and social structure. The environment is known to shape social determinants of health within the context of deprivation and to have an impact on population. Once population health distinguishes the social determinants of health of a particular population, it identifies channels and strategies for improving or protecting health, involving in the process public and private sectors and activating community groups, local organizations and individuals to make changes in behaviors, attitudes and practices. Self-care, mutual support, community participation and/or political action influencing public health care practices through education, social support, health communication, and/or literacy’s influence on women’s health are the chief objectives. Social vulnerability as discussed by Wilkinson, has a major impact on population health by combining a person’s exposure with relative risks increasing vulnerability. Social isolation, low social status, and socio-economic inequalities increase vulnerability towards HIV infections.

⁶ Green, L. Ottoson, J.M. (1999) *Community and Population Health, Eight Edition*. WCB

Figure 2 illustrates the relationship between factors that predispose, enable and reinforce behaviors affecting their quality of life. It also charts the interaction of these behaviors with the environment and the social and individual determinants of population health⁷. The arrows represent the ecological relationships created between the population and the environment. Social organization determines culture and norms, which result in values that shape the population's life via beliefs and attitudes that, in turn, become behaviors. At the same time, the health environment forces an adaptation and learning process that produce experience as well as beliefs and attitudes, resulting in determined behaviors that improve the quality of life.

McGraw-Hill Company Inc. USA McGraw-Hill Company Inc. USA

⁷ Green, L. & Ottoson, J. (1999) *Community and Population Health*. Mc. Graw-Hill Co. Inc. Eight Edition

Figure 2 Place of personal lives and motivation in the development of behaviors as a determinant of health (adapted from Green & Ottoson, 1999)

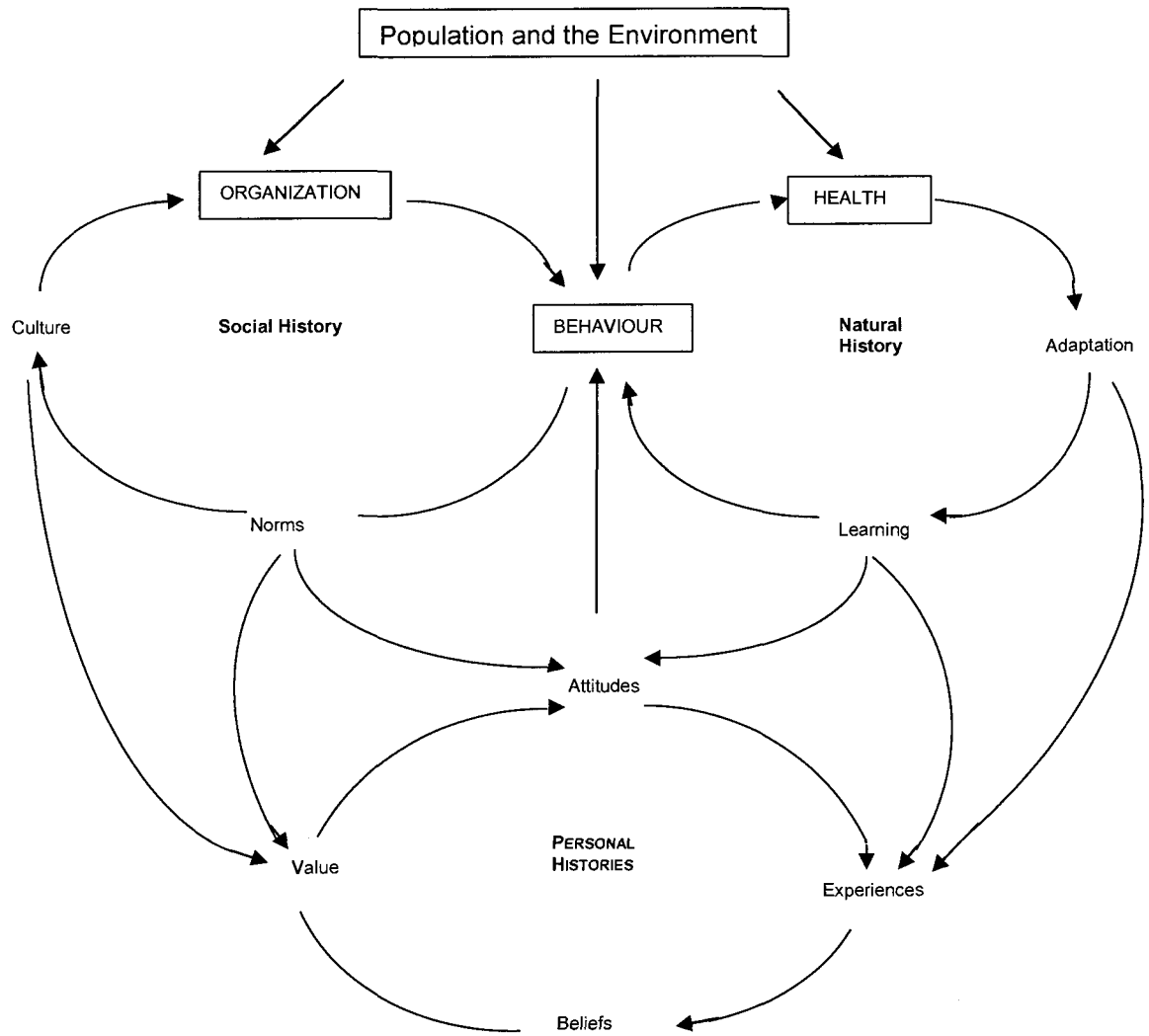
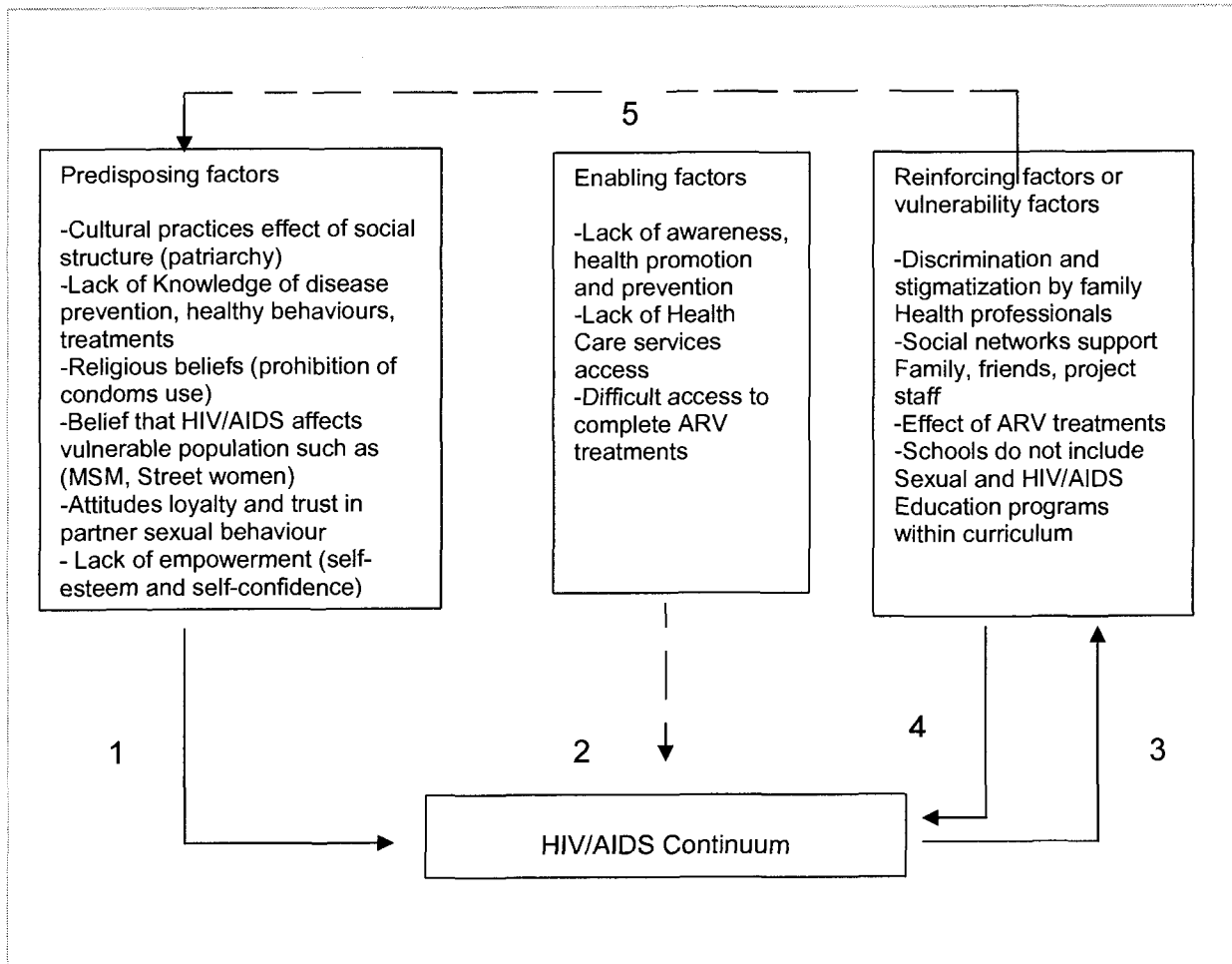


Figure 3 Factors influencing lifestyle and HIV/AIDS Continuum (adapted from Community and Population Health, Green and Ottoson, 1999).



The factors that contribute to health promotion are shown in Figure 2 and in Figure 3 are detailed the factors that predispose, enable and reinforce behaviours or make the population more vulnerable in the HIV/AIDS continuum.

Figure 4 Relationship between strategies in health services, health protection and health promotion.

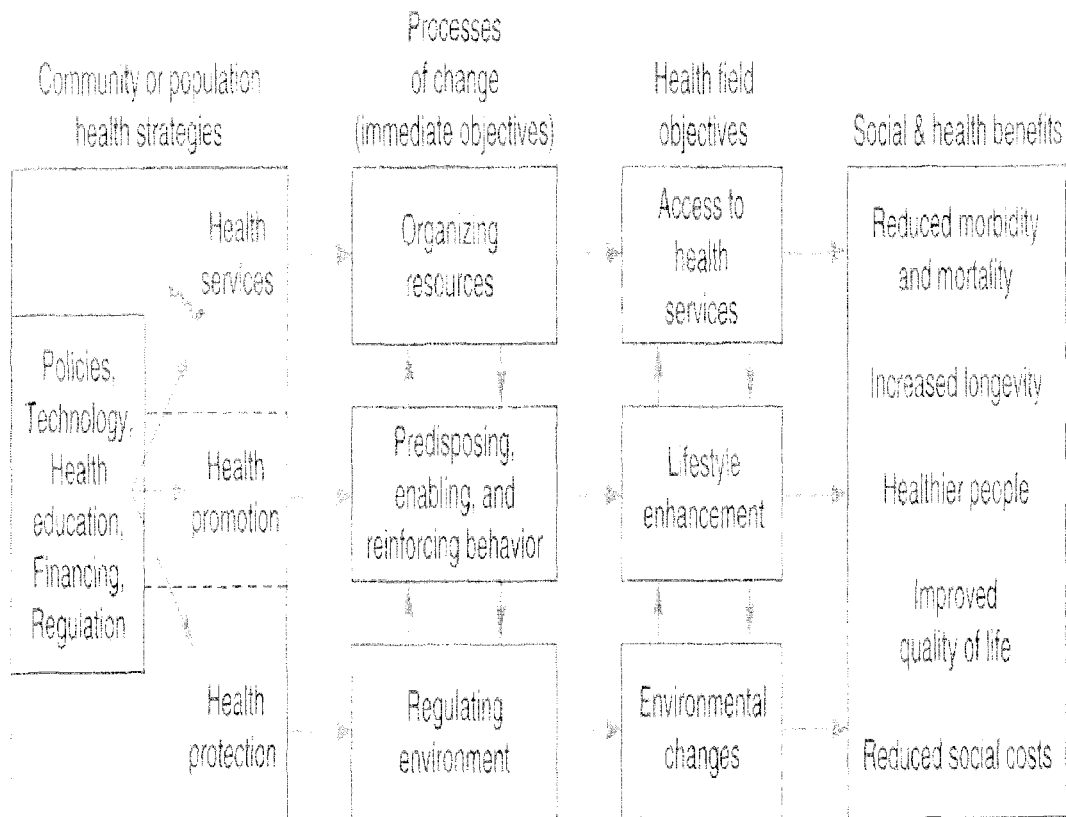


Figure 4 presents Health promotion located between health services and health protection, situating the factors that enhance lifestyle that situates and categorizes the research subjects of these two case studies. The red bolt indicates the possibility of disconnect between health policies and health services, promotion and protection.

Therefore, the questions asked to the study's participants examine individual attitudes, beliefs, and behavioral intentions (Theory of Reasoned Action). They also interrogate how beliefs influence decisions affecting health (Health Belief Model). Participants' responses to HIV/AIDS demonstrate changes in attitudes, behaviors they perceived (Stages of Change Model), the phases of pre-contemplation (impact of test results), the contemplation (knowledge about HIV/AIDS, existing ARV treatments), the preparation (understanding of their situation as HIV-positive and steps toward improving their lives through empowerment), and means to modify behaviors (adoption of healthy behaviors related to diet, ARV treatments and to help others in similar situation). In his Social Learning Theory, Bandura argues that individual behaviors can be modified by observation and imitation and that expectation can be affected by motivational processes such social environment meaning social and cultural factors within the existing structures. The actions of a person are related to the social structure. Wilkinson states 'that the roots for socialization and agreement makes a person be compliant to the way he/she appears to others, his/her capacity for shame and embarrassment making everyone more sensitive to eyes of others that pride and shame, acceptance and rejection, social inclusion or exclusion making us more or less vulnerable'.

While there are only few behaviours capable of transmitting HIV, there are a myriad of factors which determine whether and how these behaviours occur.

Tim Rhodes⁸

Although, change of behaviours depends on the individual and as product of its cognitive decision-making, social structure and cultural practice also exercise strong pressure towards the individual; risk behaviour can not be simply the product of individual actions but is usually the outcome of negotiated actions between two people.

Other theories applicable to health communication include the Diffusion of Innovations Theory, which advocates the use of media and celebrity to promote products or ideas within target population. The MTCT has used celebrities such as Miss Colombia pageant participants as motivational figures and role models. According to Community Organization Theory, community groups create social networks emphasizing community participation and involving locality development, social planning and social action. The community groups follow health processes and strategies to adopt organizational changes according to government policies and national programs adopted by formal organizations. Finally, Social Marketing Theory imports theories of consumer behavior into communication using the “four Ps” (product, price, place and promotion) in order, for instance, to promote condom use.

I have focused on the women who have received support services; the health promotion predisposing factors, enabling factors and reinforcing factors

are used as variables for the research, as they describe the experiences of women living with HIV/AIDS, and they permitted me to understand the two selected case studies. Therefore, through questions focused specifically on the three categories of factors influencing way of living and quality of life, I show their relationship to HIV/AIDS. Based on the Precede-Proceed Model, the sequence in which factors are presented is numbered in order to demonstrate how predisposing factors (attitudes, beliefs and values), enabling factors (skills, availability and accessibility) and poor reinforcing factors that can be more vulnerability factors such as lack of support from family, peers, teachers, employers, and health providers predispose people towards risk and therefore increasing HIV infections.

Women's knowledge (information and education) of HIV/AIDS, their behaviors prior to diagnosis, their sense of empowerment, available social support, and the difficulties in accessing health care delivery and medicine treatment were used as variables for showing the. Inadequate government response to the needs of all population that has moved the community to establish health promotion projects, such as the Sunflower Project. The above variables involve individual (Health Belief Model and the Stages of Change Model), interpersonal (Social Learning Theory) and community behaviors (Community Organization, Organizational Change Theory, and Diffusion of Innovations Theory). Community projects are important for Colombia because

⁸ Rhodes, T (1997) Risk Theory in epidemic times: sex, drugs, and the social organization of 'risk behaviour' in *Sociology of Health and Illness* Vol.19 No. 2 pp 208-27. Blackwell Publishers Ltd. Editorial Board 1997. USA.

national promotion and prevention responsibilities were transferred after the health reform from the Ministry of Social Protection to the EPS (Health Promoters Entities) and IPS (Health Lending Entities). Community initiatives are also essential because there is a high turnover rate in the government; membership in community organizations is often more long standing. HIV/AIDS infections in women have continued to increase, especially among those groups not considered vulnerable, such as women with a permanent partner and children. Still, education programs are nearly absent; sometimes they were initiated but they did not endure; the community has relied only on information and education available through NGOs that have developed promotion and prevention strategies; as well the community has independently established its own support network.

Interview responses will provide the information on motivation; facilitation and reinforcement activities carried out by the projects and will help us to understand how the two initiatives have improved the quality of life of women with HIV/AIDS.

Description of the Research Process and Methodology

In order to understand the epidemic in Colombia, I began at the macro level and honed in to the micro level, working my way from the global to the local context. To understand the proportion of women affected and at risk, it was necessary to research some demographic aspects of Colombia. It was also necessary to evaluate the legal framework of Colombia, which has a direct

impact on the rendering of health care services. The health reform and the corresponding legal framework have determined the amount of attention and protection given to people living with HIV/AIDS. It was important to explore the structure imposed by the health reform of 1993 and its impact on the health care system in order to understand the loss of leadership in combating HIV/AIDS and to understand how patients with HIV/AIDS have been affected. New laws have been written and approved to protect fundamental human rights and to demand treatment and services for the population living with HIV/AIDS.

As HIV/AIDS has evolved in Colombia, community organizations have played a significant role: they fight to obtain treatments and services for regular patients, and they work to produce legislation changes. Additionally, community groups and foundations, many of which are part of the HIV/AIDS Working Group, offer services such as pre- and post-test counselling. The sense of connectedness that these projects offer is deliberate: in the Sunflower Project - Case Study , a grassroots experience, - the women interviewed expressed gratitude particularly for the support offered by this project. The Mother-to-Child-Transmission initiative - is institutional and preventive, and its use of official channels to serve women also forms a valuable experience. Social support for these women, however, is offered primarily by the Sunflower project.

In Latin America, most of the existing studies on women with HIV/AIDS focus on street women and IV drug users, who are considered high-risk populations within urban areas. Literature on other types of women at risk,

however, is incipient for the area. Multiple scholars recognize the higher social and biological vulnerability of women, generally speaking, to HIV infection due to the efficient transmission through heterosexual contact (Bury 1995, Corea 1992, Rodriguez-Trias and Marte 1995), but this fact has not been publicized.

Therefore, the fact that the increasing infection rate over the last five years among women with a permanent partner has come as a shock. In spite of the epidemic's growth among them, these women are silenced by the social structure of marriage; a patriarchal structure that is socially disadvantageous for women with HIV/AIDS. Married women are especially vulnerable to infection due to their husbands' behavior (Cohen & Durham 1993). They are dependent and powerless, making it much difficult to ask husbands or partners for safe sex (Crystal and Sambamoorthi 1996). As Wilkinson states: "Social status and health are linked by effect of living conditions, and position within the social hierarchy and experience of superior, dominant status versus inferior, subordinate status, tied with processes of stigmatisation and exclusion of those nearer the bottom of the hierarchy."⁹

I focused on the recollection on the voices of "housewives," or women with one permanent partner. By the time they were diagnosed, 78% of the women included in my research were living with a permanent partner after the death of their first partner, and had established new relationships. The other 22% were widowed, separated or divorced. They were afraid of establishing new

⁹ Wilkinson, R.G., in Marmot & Wilkinson, (2006) *Social Determinants of Health*, Second Ed., page 341. Oxford Press, New York.

relationships, and they ranked from 1 to 4 on Colombia's socio-economic scale. As explained in Chapter Two, Colombia's socio-economic continuum ranges from 1-6, where 1 represents the very low-income and 6 the population with the highest income. As Cohen & Durham (1993) argue, in Latin America sexual transmission is both homosexual and heterosexual, with transmission from bisexual males acting as an important source of HIV infection for women.

Twelve women were infected through heterosexual contact, and two were infected through blood transfusion. Responses present different aspects of their journey from the time of diagnosis, including how HIV/AIDS has changed their lives and their religious and cultural beliefs. The responses also present women's perceptions on existing projects addressing HIV/AIDS, and how these projects have improved their lives.

Reality is constructed by the individual and varies from one individual to another due to varying experiences, perspectives and perceptions (Creswell 1994). In depth, semi-structured and open-ended questions were used in the attempt to capture these women's experiences. Interviews were prepared to last approximately 40-80 minutes, and they intended to explore many aspects of the lives of these women in order to understand better their experiences and the complexity of the social environment, social support and networks, behavioral, and health issues that surround living with HIV/AIDS. A semi-structured, open-ended interview format was also used for interviews with the project staff in order to understand the different levels of interaction between government institutions,

agencies and women living with HIV/AIDS. Though HIV/AIDS does not discriminate based on educational background, it is apparent that the disease has hit the low-income population the hardest.

The interviews were taped using a digital recorder. On a daily basis I saved the files. Each file was named with the interviewee name using a voice program. After each interview I reviewed and completed notes taken during each interview pointing at surroundings, family members around the interviewee and any other detail I found to be important or interesting regarding each interview as well as detailing the place where the interview took place and reactions of my interviewee when she was talking (sadness, anguish, despair, tears, uncomfortable moments and words highlighting the interview). The research interviews are in Spanish, as Spanish is the language spoken in Colombia but for the purpose of this work the words have been translated to English. I transcribed the interviews myself; it was a lengthy process as in some interviews the surrounding noise was very strong that made the process difficult but my notes were a great support for the process. The notes for each interview were attached to the transcribed interview to have consistency in the process and to keep all the information together. I have been the only interpreter of the stories. The excerpts included in this work were selected at my own discretion to present in the women's words, feelings, and experiences regarding the topic selected for this research. When the transcription was finished, I sorted the information by the topics selected at all times; I kept the privacy of my interviewees in respect to my compromise and as part of my responsibility to their contribution to my study.

As part of the attachments I have included the English version of the questions in Appendix Three, and translated questions are in Appendix Four. As HIV/AIDS involves very sensitive issues, I explained to the women my motivation for my research, which had been previously explained by the Sunflower Project coordinator. I deemed it important, however, to do it again, and I asked for their consent to respond to my questions and to sign the consent form. The option of providing information off-the-record (no taping) was available, as was the choice to end the interview at any moment if they felt uncomfortable or if they did not want to answer any further questions. They were assured that all information would be used only for research purposes and that their names would not be used. I taped and transcribed the interviews. The women's participation was voluntary; there was nothing offered in compensation for their participation. However, there were two specific cases - Isabella and Marcela - in which the economic situation and emotional distress of my interviewees and their families at the time of the interview were such that they moved me to provide some cash for food and vitamins at the end of the interview (Chapter four).

Even though I had my questionnaire pre-sorted into topics that I wanted to investigate, the interviews rarely followed the predetermined order and format. After introducing myself and having participants sign the form, we started the interview with a simple question about how the woman had met the project coordinator. The coordinator is someone the women respect for her strength and the support she provides at crucial moments. For most of them, she is the equivalent to "an angel" whom they meet at the hospital during an AIDS crisis.

Often, women would freely delve into the telling of their stories; otherwise I asked about what I wanted to hear. Women were asked what they knew about HIV/AIDS before they were diagnosed. Why did they take the test? Was counselling offered before or after the test? Also, they were asked about available support, approaches to treatment, efforts of health care staff, stigma, and discriminating experiences after diagnosis, and how they have faced their situation. Their stories, in the end, provided very valuable information about changes in their life, their behaviors, and their attitudes. For instance, their need for involvement with community groups, for a sense of community participation, and individual empowerment tended to start after they are diagnosed. They shared the common goal of wanting to eliminate discrimination and rejection faced by women after diagnosis.

The knowledge of the national language, culture, the community's previous health activities, its involvement with international organizations working in Colombia, and contacts within the health sector were advantageous to my research. I also asked for background information, and I approached other staff within the UN agencies to ask about their views on the projects selected. Being a woman and a mother helped me to relate with the women participating in the research. Being a witness, however, to the disrupted and sometimes hopeless lives lived by these women made me an engaged observer and is difficult to detach from the women's situation. For this reason, one of the participants and active members of the network and I participated in an HIV/AIDS sensitivity workshop organized for the employees and families of my family business.

Methodology

Multiple methods were used in this research. It was important for me to document and to present carefully women's experiences using narratives that capture the complexity of events and situations in their daily lives. Sharing their own and hearing others' experiences of exclusion and oppression contributed to a better sense of self-awareness and a drive for more education, an important step toward achieving women's rights¹⁰. Women's narratives express an abundance of suffering and healing, of disenfranchisement and empowerment,¹¹ and illness narratives explore the way people handle illness that disrupts their everyday lives and their suffering, leading to transformations in identity, cultural values and personal and interpersonal experience (Bury 2003, 1982, Kleinman 1988). As Kleinman has expressed, illness has four meanings: the first is the standard scientific meaning, physiological symptoms. The second meaning is the cultural significance associated with post-industrial capitalist societies' moral hypocrisy, as was made evident when venereal diseases brought about stigmatization and discrimination. The third meaning is the impact that the illness has on the patient. The fourth meaning is explanation and emotion, which relates the patient's struggles with their social network and health professionals. AIDS means the loss of health, confidence, and hope. Patients and families face events that disrupt their lives. Also, illness narratives describe patients' circumstances as they come to terms with their illness. Stories told by patients

and their families use explanatory models that illustrate the case studies. The case study methodology, however, was used to review the project framework.

Purpose of the Study and Summary of Findings

It can be said that being a woman with AIDS implies numerous confrontations related to self-esteem, human rights, health, and gender just to be alive, take care of the children, face professional challenges and develop ourselves.

Sunflower Project Coordinator¹²

The purpose of my study was to learn about the experiences of Colombian women living with HIV/AIDS¹³ and to explore whether projects designed for women living with HIV/AIDS have improved their quality of life. Female narratives situated me in the women's lives, illness narratives permitted me to understand the illness process, and the population health approach helped me to understand the disadvantageous situation of women and how health determinants frame their situation. This research presents edited excerpts of the journeys of fourteen women¹⁴ dealing with HIV/AIDS. The impact of the diagnosis, the challenges they have faced within their social network, their interactions with health services, various experiences of stigmatization and

¹⁰ Campbell, M. (2003) Dorothy Smith and Knowing the World We Live In. in *Journal of Sociology & Social Welfare*. March, Vol. 30, Issue 1, p3 p20.

¹¹ Ciambone, D, (2003) *Women's experiences with HIV/AIDS: mending fractured selves*, NY: Haworth Press, 2003.

¹² During the whole document quotations have been used to illustrate chapters where the quotation is used. The quotations are presented in bold Book Antigua to differentiate them from voices and testimonies from interviewees.

¹³ Names of participating women have been changed, to avoid possible identification. Even though, all the participants signed the participant's agreement form I promised them to protect their testimonies by changing their names.

¹⁴ The voices and testimonies are used in *Arial Narrow italic*, however I have only selected fragments from the about two hour interviews, they have been edited to avoid personal responses that might be identifiable and only information related to the pre-selected topics is printed here.

discrimination, and the perceptions of their lives now are the subjects of these excerpts. Also, as each woman is linked to one of the projects, each expresses her feelings toward the project and what she has received from it. Furthermore, they express from their own perspective what they see missing from health and preventative education.

In Colombia the first case of HIV/AIDS was detected in a female sex worker who died in Cartagena in 1983. Colombia is now the country with the second highest infection rate in South America, preceded by Brazil and followed by Argentina. The HIV/AIDS epidemic is considered concentrated within men having sex with men (MHM) and sex workers, though an increase in infection rate is evident among women with one permanent partner. In 2002, the ratio of infected men to infected women was 7:1. All the women interviewed had one permanent partner at the time they were diagnosed, and since then, some have lost their partners or been divorced. All the women have children; some of the children were born HIV-positive. Women have received social support from the Sunflower Project.

As previously mentioned, literature on women living with HIV/AIDS has been more widely available in recent years, yet the majority of published work focuses on street workers and drug users, their struggles and social conflicts. Consequently, women who were not street workers or drug users reported feeling safe as they were married (love, social commitment), or had one permanent partner (trust) and thought that love and trust would preclude them

from being infected and affected by HIV/AIDS. Once infected, they were silenced, ashamed, and rejected. As Kleinman¹⁵ describes, “the response to this disease suggests that the dominant, commercialized sexual image of post-industrial capitalist society hides a double standard of amoral promiscuity on behalf of individual rights and consumer values and a highly moral if knowingly hypocritical, condemnation of the venereal results.”

Results show that women feel shame not for having HIV/AIDS but for the stigma they confront from family and health professionals. Women’s responses not only indicate but insist on the need for education and information for women with HIV/AIDS in order to prevent complications related to AIDS and as well to make women aware of HIV/AIDS and to prevent new infections. Empowerment, on the other hand, allows women living with HIV/AIDS to face their struggles. Implementation of sexual and reproductive education permits women to take action in order to protect their rights and lives. Also, there is a need for skills training in order to develop economic subsistence projects that allow women to earn an income, to improve their lives, to support their families, and to overcome poverty. The majority of infected women are single mothers, who have lost their partners, or who have had others leave them behind.

¹⁵ Kleinman, A., (1988) *The Illness Narratives: Suffering, Healing, and the Human Condition*. Basic Books, Inc., Publishers, NY. P.22

...The goal to fight HIV/AIDS by NGOs is unachievable if there are no government policies, no national leadership and insufficient resources along with strong social and cultural values of the population to fight stigmatization and discrimination...

A. Garcia Abreu¹⁶

It was shocking to me to learn about the infrastructure of the Ministry of Social Protection team working on HIV/AIDS: a team of only forty people is responsible for all transmissible and chronic diseases in a country with a population of almost 46 million people. After the health reform, leadership for the HIV/AIDS epidemic was lost, and the budget set aside specifically for HIV/AIDS was integrated with the budget for all transmissible diseases. Interviewees questioned the low supply of and the quality control for essential medicines for standardized antiretroviral therapy used by the EPS and ARS. Interviewees also expressed concern over the existence of the black market's exchanging leftover medicines. As it stands, the EPS and IPS are not complying with the law, and there are no health promotion and prevention activities. Sexual education and HIV/AIDS awareness, including self-esteem, self-respect and respect for others – teachings that would target discrimination, stigmatization and homophobia - are not included in school curriculum. The capacity of the community to deal with HIV/AIDS needs to be strengthened by its partnership with women living HIV/AIDS, families, and NGOs. As well, there is a need for female empowerment and a need to find economic alternatives that would allow women to feel financially productive and have an income that would support themselves

and their children. Community work has to emphasize the legal support required by those not linked to any regime. HIV/AIDS and other sexual diseases projects should focus on gender, vulnerability, community awareness, education, and empowerment.

The Sunflower Project, as a woman to woman intervention, is the only project working at a national level on women's HIV/AIDS prevention. Still, there are deficiencies in the program, such as a database yet to be created of women served and needing follow-up. A new space for delivery services is also needed. Additionally, there is a need for a direct and permanent link between the Sunflower Project and the Mother-to-Child-Transmission initiative so that follow-up on each project's successes may occur. The establishment and sustainability of a 1-800 number to offer immediate support for women would be greatly beneficial.

The Mother-to-Child Transmission project has been a successful initiative from the point of view of the few children born positive of all women tested and who were treated by the project and thanks to the European Union, funding coverage was extended. By mid-2006, the project will be incorporated into the Reproductive Health Regular Program within national health strategies. Even though the project offers information their focus is more services oriented.

¹⁶ Garcia Abreu, A. Moguer, I and Cowgill, K., (2003) *HIV/AIDS in Latin American Countries –The Challenges Ahead*. The World Bank

Description of Chapters

In Chapter Two, I provide a description of the growth of the HIV/AIDS epidemic in Colombia, providing a chronology of the progression of infection within different population groups. The role of UNAIDS is described as the international agency that coordinates various international funds. Also described in the second chapter is the history of health communication and health promotion projects in Colombia. In order to research the decision-making bodies, I had to refer to the health reform of 1993 so that I could foreground current processes, effects on existing programs such as the projects targeting HIV/AIDS, and the delivery of health care services. Colombia has determined a legal framework to protect health as a fundamental human right; the country has special decrees protecting the rights of people living HIV/AIDS. In the appendices, I have included the most relevant decrees relating to the rights of people living with HIV/AIDS. The tutela has been used to enforce health promotion and prevention and to prevent the violation of human rights. Also, I review the work of organizations and community groups in Colombia and present the Mother to Child Transimission Project.

In Chapter Three, I introduce the Sunflower Project, my key Case Study. In Chapter Four, the women's responses to knowledge about HIV/AIDS, discrimination and stigmatization, behaviors and attitudes, and social networks are presented. Women's voices have been transcribed and translated only; no editorial changes have been made, which is to say that their meaning remains intact. Women's names have been changed, and their children's names are

withheld as agreed upon during the interview process. Finally, I offer a synthesis of findings and conclusions with implications for future research.

Chapter Two. AIDS in Colombia

Description of Colombia

In the northwest corner of Latin America, Colombia is the oldest democracy in Latin America. The government is divided into three branches: the head of the executive branch - the president - is elected by popular vote for a four-year term. The legislative branch is comprised of Congress and the House of Representatives, and the judicial branch is rooted in the Supreme Court of Justice. The official and most common language is Spanish; some Indigenous communities, however, continue to use their native language.

In 2005, there were approximately 45,600,000 people, 77.4% living in urban areas and 22.6% in rural areas. Women accounted for 48.5% (22,107,229) of the population, with 27% (11,860,497) in their reproductive years and 6,175,968 having a permanent partner. There were 1,166,847 pregnancies, and the fertility rate was 1.5 children per woman. That year, 966,800 children were born, and the average life span at birth was 72.9 years (75.9 for women and 69.9 for men). The DANE (Colombia's National Administrative Department of Statistics) reported 682,400 deaths from all causes from 2000-2005. The female mortality rate was calculated to be 5.44 for every 1000 inhabitants, and the infant mortality rate was estimated at 18.0 for every 1000 live births.

Colombia has a mixed population, including 81 indigenous groups that comprise 1.7% of the overall population. The demographics also categorize the population into the following groups: 58% mestizo, 20% white, 14% mulatto, 4% black, and 3% mixed black-Amerindian. On the Pacific Coast, the majority of the population is of African ancestry. The literacy rate in 2005 was 92.9% (93.1% women and 92.8% men), and there was an unemployment rate of 13.6%. High unemployment rates and internal displacement, however, have incited the population to migrate from rural to urban areas, increasing the number of slum areas in big cities, worsening problems in health care accessibility, and creating new avenues for the transmission of HIV/AIDS and other infectious diseases within the low-income population. However, public expenditure from GDP has increased over the years to 10.6% in 2005 from 3.9% in 2003. By 2002, only 8.2% of the total population was living below the international poverty line, whereas 22% were living in dire poverty in 2000.

Chronology of AIDS in Colombia

In 1983, Colombia faced the first clinical case of AIDS; since then, the epidemic has only worsened. Heterosexual relations between women and their permanent male partners have greatly increased the number of HIV/AIDS infections. The first vertical HIV/AIDS case was detected in 1987. In 1986, the SISBEN, System for Selecting Beneficiaries of Social Spending, and an Action Alert System were established. The Action Alert System estimated the number of people living with HIV/AIDS to be ten times higher than the number shown in the register due to the under-reporting of cases. The health reform in 1993

created a “Functional Working Group” to deal with all communicable diseases and HIV/AIDS. Health promotion, prevention, information and education responsibilities were assigned to the new system of Health Promoters Entities (EPS), but their focus was on decreasing health care costs and increasing profit; epidemiological trends, promotion, and prevention activities were not foremost on their agenda. Furthermore, the Subsidized Regime Administrators (ARS) did not have at their disposal specific resources for health promotion or health prevention. Minimal resources, as a result, have made it nearly impossible to achieve universal health coverage for the entire population.

By 1995, Colombia ranked third among Latin American countries in terms of HIV/AIDS epidemics, with a total of 14,000 reported cases. Statistics show that in 1996, the ratio of male-to-female infections was 47:1. By 1997, 589 new cases were reported with an estimated of 82% male and 18% female cases. Staggeringly, in 2002 the ratio of male-to-female infections was 7:1 (numbers from Ministry of Health)¹⁷. In the same year, there were 1095 new HIV/AIDS cases reported, with 33.9% reported from heterosexual transmission, 46.5% from homosexual and/or bisexual transmission, and 0.1% from transmission by Intravenous Drug Usage (IDU).

International funding provided to combat Colombia’s HIV/AIDS epidemic in 1997 was equivalent to only 1% of the total national funding set aside for HIV/AIDS (a percentage that still holds today). As such, in 1997, the government

regulated comprehensive care and non-discriminatory policies for people living with HIV/AIDS (PLWHA). By 1998, AIDS was the 29th leading cause of death, while in 1991 it held the 97th position (INS). In 1999, approximately 71,000 Colombians were living with HIV/AIDS, 70,000 of which were adults between 15 and 49 years of age, including 10,000 women (Garcia, 1999). By 2000, 27% of the total numbers of reported cases were being treated under the compulsory health plan, 2% of the total numbers of cases were under-subsidized, 66% were linked and, information about the remaining 5% was unknown. Amendments to the laws surrounding MSM contributed to the creation of the National Medicine Fund for High Social Impact Diseases, which was mandated to offer treatment to HIV/AIDS, cancer and homophile patients. ARV treatments were included in the health benefit package (POS). From the existing twenty-five drug treatments to combat HIV/AIDS, only twelve were included in the POS due to lobbying and pressure from community groups.

In 2001, with a total of 19,063 new cases reported. Out of 6,500 people living with HIV/AIDS, 6,150 were covered by Social Security (UNAIDS 2001). The majority of infected women were between 15 and 49 years of age; a total of 52,000 infections in women were reported, and among these women the MTCT rate was 35-40%; that is, 2,000 new neonatal infections per year were occurring. By the end of 2003, the Ministry of Health reported that approximately 220,000 people were living with HIV/AIDS including adults and children. Prevalence was

¹⁷Ministerio de Salud/ONUSIDA Infeccion por vih y sida en Colombia. Estado del arte 2000-2005 HIV AIDS infection in Colombia. State of the Art

estimated at 0.7% in population between 15-49 years of age. The incidence rate was 13.2/1million, and the death male: female ratio was 6:2, with 3,600 total deaths. Out of the total number of adults diagnosed with HIV/AIDS, 30% were women who had no access to adequate health services, despite the fact that information for mothers had been available during the eight prenatal controls. In 2003, of the total reported cases 77% were caused by sexual transmission, and this increasing trend was evident especially in the Atlantic Coast region (north), in the Orinoquia region (mid-southeast) and the Amazonia region (south border with Brazil); 2%, in turn, were caused by mother-to-child transmission, 1% by blood transfusion, and 20% by unknown causes. Since 1998, the number of infected women has increased considerably with an annual percentage of 20% to 29.85% in 2004. The year ended with a male: female ration of 4:1. 96% of total infections between 1983 and 2005 were through sexual intercourse, 55.9% heterosexual, 28.25% homosexual and 15.79% bisexual. The remaining 4% were perinatal, transfusion, IVUs, labour accidents, tattoos.¹⁸

In 2005, 72% of women who tested HIV-positive reported being in stable relationships. Even though the majority of infections were acquired due to risky behaviors (unprotected sex, needle-sharing) there was a lack of information, health promotion, prevention, and education. Consequently, local organizations have taken an active role in the wake of the epidemic. Providing information and health promotion and fighting for ARV treatment access, they have been working

¹⁸ Ministerio de Protección Social & ONUSIDA (2006) Infección por VIH y SIDA en Colombia. Estado del arte 2000-2005, Pro-offset Editorial Ltda. Colombia Pro-offset Editorial Ltda. Colombia

with the population to learn about their specific needs and their cultural practices related to healthy behaviors. They have also been offering social, legal and moral support, and they have helped to improve the lives of the HIV/AIDS afflicted.

Currently, there is the possibility of having medicines donated from Brazil, and a joint price negotiation within the Andean Community is expected to reduce treatments costs for those living with HIV/AIDS¹⁹. These two events would certainly be beneficial, as some Colombians are struggling to obtain complete ARV treatment; they also have difficulties in accessing services. CD4 viral count tests are supposed to be taken every four months, but presently there is a waiting time of two months for appointments. Patients reported delays of up to six months in receiving treatments, and they reported low quality in ARV treatments offered by some EPS.

...Besides, the EPS are not handling medicine treatments; they provide partial treatments, and you know, ARV treatments should not be stopped. As a consequence, patients get sicker, plus the psychological pressure motivates patients to look for alternatives, which have defaulted into a black market of medicines. As well when there is not enough money to buy missing medicines, they're moved to buy leftover medicines. Nonetheless, there is a fight between multinational and generics medicines. The EPS puts pressure on doctors to only formulate generics. (Other patients mentioned that using generics over regular medicines reverses the course of treatment.) Therefore, health professionals can do very little, as much as they want to do and have good attitudes toward patients, time restrains their services; they are forced administratively to cover more patients. They are paid by the hour, and they are paid the minimum, and then there is no quality in health care services offered. The only thing that matters is how many patients they cover and how

¹⁹ Evaluación del Plan Estratégico Nacional ante el VIH/SIDA 2000-2003 – Informe Preliminar May 2003 p.4

many can they invoice. It is just a matter of numbers. In Colombia, everything is being reduced to numbers; there is no human quality in treatment, and that is very, very sad....

Florina is 27 years old.

She lost her husband five years ago, her baby boy six years ago, and her baby girl five years ago.

Both babies were about 4 months old.

ARV prices now make the treatment more accessible, and efforts have been made to extend services. New legislation, Law 972 approved in 2005, which demanded that EPS comply with health promotion and prevention responsibilities, is expected to provide information and education to contain the spread of HIV. Yet there is a need to challenge social attitudes and to work on vulnerability issues. The advancement of these processes requires political will in order to catalyze social change and to bring about an improvement in the lives of those living with HIV/AIDS.

Figure 5 Colombian Map showing the spread of HIV/AIDS by departments by 2005



AIDS in Colombia and International cooperation

International cooperation in fighting AIDS in the 1980s was received via the PAHO/WHO Special Program. The joint efforts of the UNDP, UNICEF and UNFPA resulted in the creation of UNAIDS. Nationally, there were specific funds budgeted for work on HIV/AIDS that were delivered through the Ministry of Health and through other external sources such as private organizations or NGOs. International cooperation included technical advisory and talks encouraging Colombia to cement its national HIV/AIDS policy. Colombia receives very little external financing to combat HIV/AIDS and other related infections. Social Security funds have covered 67% of total national expenditures on HIV/AIDS since the health reform was passed.

International cooperation has been welcomed in the form of technical assistance supporting local initiatives undertaken by public institutions and community groups. The support offered by UNAIDS, for one, has focused on technical assistance, strategic planning, information sharing, strengthening information, education, and communication (IEC), promoting social participation, and building the capacity for partnership with civil society. Furthermore, UNAIDS has worked closely with NGOs with the objective of strengthening management capacity, reinforcing regional networks by promoting empowerment of leadership and self-care training, promoting greater involvement of people living with HIV/AIDS, and mobilizing resources. UNAIDS took part in the revision of the National Strategic Plan for 2000-2003, helping to redesign it for implementation for 2004 to 2007. Also, UNAIDS is largely responsible for calling the

government's attention to AIDS as a priority of the public agenda. UNAIDS has mobilized funds to produce PLWHA human rights television messages, to develop ethnographic research on socio-cultural family aspects of PLWHA and MTCT, to achieve project-financing extensions, and to work on the implementation of prevention projects for the highly vulnerable population. Special support for proposal writing is offered on their behalf to local organizations. The United Nations agencies work cooperatively to support national initiatives that respond to the epidemic. Based on the report from the Resident Coordinator in 2004, the UN supports a number of initiatives, including the UNFPA's charting factors of mortality associated with maternity; promoting effective strategies of action to support the HIV/AIDS vertical transmission project in cooperation with WHO/PAHO, UNICEF, WB, UNAIDS. UNICEF is mobilizing support to people living with HIV and AIDS and providing gender-focused interventions through mass awareness campaigns; in coordination with other agencies (UNDP, WHO/PAHO, UNFPA, UNODC, UNHCR/OCHA, IOM, ILO, and WB) and public institutions (the Ministry of Social Protection, the Ministry of Education, and the Red Cross). With the Global Fund project; the Intersectoral National Plan against HIV/AIDS; the strengthening of the PLWA organizations and inclusion of HIV/AIDS as part of the Humanitarian Action Plan II; and the development of the "HIV/AIDS" Strategy in UN work stations a strong UN presence is, thus, critical to Colombia's fight against HIV/AIDS. The UNAIDS staff consists of an Epidemiologist Advisor, an Administrative Assistant and an

Administrative Clerk, whose office space is moved every two years between the UN agencies' offices in Bogotá who share the administrative costs.

Although I have focused on the UN's support to Colombia via their specialized agencies, there are many other international financing sources and support resources being donated from worldwide recognized NGOs such as World Vision, Oxfam, and CIDA, but their financial contributions are difficult to monitor.

Health Care Delivery and Regulatory Framework of HIV/AIDS in Colombia

Public Institutions delivering health care and dealing with AIDS

...HIV/AIDS is on the rise due to the change in social and cultural factors that are closely related to the depressed socio-economical and those socio-cultural macho conceptions and religious beliefs that influence cultural traditions and practices plus the lack of strategies of self-prevention...

*Juan Gonzalo Lopez,
Vice-Minister of Health Protection, 2004*

The Ministry of Social Protection (renamed in 2003 after the fusion of the Ministry of Health and Ministry of Labour and Social Security) has remained the policy-making institution responsible for formulating, monitoring and evaluating the regimes and for supervising the activities related to disease control programs. The National Program for HIV/AIDS was, formerly, the governing body within the Ministry, but it was segmented by the reform. HIV/AIDS was included in the

communicable diseases portfolio, and this portfolio is overseen by a ministerial staff of 40 who also deal with chronic diseases. Yet although policies exist, there are not enough mechanisms in place to force EPS and IPS to comply with the law.

Coordinating and supervising laboratory tests such as ELISA and Westernblod, the National Health Institute (INS) has played an important role in controlling HIV/AIDS. It has also been responsible for the quality control of national work initiatives and for reconfirmation results. Furthermore, the INS has trained municipal and departmental lab technicians as well as staff in the EPS, IPS, and ARS.

Regulatory Framework for HIV/AIDS

...We must stop dehumanizing physicians if we are to stop their usually inadvertent dehumanization of patients. Each time the cycle of symptoms begins; the sufferer loses faith in the dependability and adaptability of basic bodily processes that the rest of us rely on as part of our general sense of well-being. This loss of confidence becomes grim expectation of the worst and, in some, demoralization and hopelessness...
Arthur Kleinman²⁰

It is important to describe the legal process followed in Colombia in relation to HIV/AIDS since the first case in 1983, and it is equally important to highlight the role played by community groups in support of PLWA and in demand for a consistent legal structure. In 1987, the National HIV/AIDS Program was established as the governing body of the Ministry of Health for HIV/AIDS. In

1991, the new political constitution created the *tutela*, a legal instrument against which individuals could claim violation of their human rights. The National HIV/AIDS Council, sanctioned by Decree 1559 (in 1991) and Decree 1543 (in 1997), determined that the Ministry of Health would be in charge of the regulation and management of HIV/AIDS and other STI. The Council was made responsible for the development, promotion and support of national projects and proposals that focused on prevention and control of HIV/AIDS and other STIs. Under its jurisdiction also fell the establishment of committees conjoining municipal and federal representatives as well as the approval of the treatment guidelines for HIV/AIDS. At the same time, Decree 1543 prohibited HIV testing as a requisite for insurance coverage and prohibited considering HIV a pre-existing pathological condition for insurance coverage purposes.

In 1993, the health reform, entitled Law 100, abolished the public Social Security System and established in its place the General Social Security Health System (SGSSS), which was characterized by the inclusion of both the contributory regime and the subsidized regime²¹. The health reform is based on the principles of equity, quality, efficiency, solidarity and community participation, the framework for this social health insurance system was built around universal coverage, a comprehensive pension plan, coverage for work-related risks, and supplementary social services. The Ministry of Health, as aforementioned, remained the institution responsible for formulating, monitoring and evaluating

²⁰ Kleinman, A., (1988) *Illness Narratives: Suffering, Healing, and the Human Condition*. New York. Basic Books, Inc., Publishers

²¹ El Congreso de Colombia. Ley 100 de 1993 100/Art.162, 1993

the regimes and maintained control of activities related to disease control programs and health delivery to the “*vinculados*”: those without health coverage. The Ministry also managed the competition between private and public health care providers. The decentralization process saw the transference of control over secondary and tertiary health facilities to the health secretariats at the local and regional levels. Decentralizing also meant teaching personnel at the local and regional levels new skills, as major public health campaigns were transferred to 32 departments in 1070 municipalities. Furthermore, health prevention and promotion responsibilities and the administration of primary care facilities were also transferred to local organizations.

The contributory regime offers the Basic Health Plan (PAB) through the Health Promoters Entities (Entidades Promotoras de Salud, EPS), which receives a premium per capita according to age, sex and geographical location of each participant (capitation fee). The EPS are responsible for health promotion, prevention, education and information activities of their affiliates, and they administer the Compulsory Health Plan (also known as the Plan Obligatorio de Salud, POS). The plan includes health intervention services rendered by the health care delivery institutions (IPS). Prior to the health reform, these institutions were public hospitals, health centres or national institutions. The ESSE (Empresas Sociales Solidarias del Estado) are similar to the EPS but instead of being privately operated, they are community operated. The IPS and ESSE are contracted by the EPS and the subsidized regime Administrators (ARS) that administer the subsidized regime.

...Salud Coop (EPS) offers the test. Sporadically the "Seguro Social," Cajasalud, Colsanitas offer the test under the service package but they do not offer health prevention. In Bogota and Bucaramanga (capital of Santander, Dept) the linked population only receive the service; they do not have follow-up tests or treatment. The Ardila Lulle Foundation offers support. On the Atlantic coast basically the community groups provide support while the municipal and department response is totally disordered and some of the economic support is addressed to sex street workers as HIV is related to such punitive activities as street work. In Barranquilla the Francois-Xavier Bagnoud Foundation, in Cordoba the Funguia Foundation and others in other cities help patients to survive...

Manager of MTCT Project

The EPS focus on offering basic services at the lowest cost; they also have an interest in increasing their profits by devoting only minimal attention to epidemiological trends. The value of the subsidized POS regime is 50% of the POS in the contributory regime, and recipients of the POS regime are entitled only to essential clinical services, some surgical interventions, and treatment of catastrophic diseases, but they are not entitled to hospitalization in an internal medicine ward nor to follow-up for chronic diseases (e.g. diabetes, cardiovascular diseases other than hypertension). Preference of enrolment in the subsidized regime is given to children, single mothers, the elderly, the handicapped, and the chronically ill.

Delays in the decentralization process have created problems in the delivery of POS services in hospitals and in local organizations. Wealthier municipalities have been able to gather more resources than poorer municipalities, leading, over time, to greater inequalities between municipalities. Surveillance and reporting systems, for instance, do not function in rural areas as they do in big cities where deaths are certified.

The systems offer the flexibility to the insured population within the contributory regime to choose their insurer, but sometimes, as is often the case with HIV/AIDS patients, claims are rejected and patients are forced to present a tutela and have the courts force the EPS to comply with the law. In order to access services, the insured must have contributed payment to the EPS for at least 100 days. In case, the job is lost the insured person is left without an insurer (meaning no EPS and no health service), and she faces significant challenges to service accessibility. When registering with another EPS, her pre-existing seniority in the program may or may not be recognized.

The subsidized regime is designed to protect that segment of the population that falls between 1 and 3 on Colombia's socio-economic scale (Colombia uses a scale numbered 1 to 6, where 1 represents the lowest-income and 6 the highest income). Those people whose socio-economic status ranks between 1 and 3 are to register in the SISBEN (System for Selecting Beneficiaries of Social Spending). However, the lack of government funding prevents qualified people from registering. Although health coverage has been extended to rural areas, one-third of the population is still without access to health care. Prior to the reform, low-income population, or "vinculados," not insured or linked to the subsidized regime were allowed access to services through public hospitals only after a payment of one-third of the total cost of the medical procedure (supply-oriented model). Public institutions satisfy the demand for services for the insured population in rural and poor urban areas. The health reform divided among treatment centres the tasks of diagnosis,

treatment, patient follow-up and contacts and segmented the National HIV-AIDS Program, which was replaced in 2000 with a “Functional Working Group” dealing with all communicable and chronic diseases. The inspection, monitoring and regulation of the health system (juridical, contractual, administrative, and financial aspects) were delegated to the National Health Superintendence. However, uninsured patients still had to pay for services (debts), expenses that are not easily recoverable. The same year, the Ministry of Health contracted to CINSSA (International Consultants in Social Security and Health) the task of carrying out a socio-economic assessment of the impact of HIV/AIDS on social development in Colombia. In 2000, Resolution 412 defined the guidelines for integrated management of HIV/AIDS, the syndrome approach to STI and congenital syphilis.

Law 715, passed in 2002 regarding administrative decentralization, budget allocation, territorial competencies and responsibilities, determined that while policies and norms are defined at the national level, technical assistance should be offered at the regional level. In accordance with Agreement 226 of 2002, national policy and controls approved the Drug Manual for the Compulsory Health Plan and determined that EPS and ARS are responsible for executing actions related to treatment provision.

In 2003, the fusion of the Ministries of Health and Labour and Social Protection adopted the name of the Ministry of Social Protection, and in December of the same year, made the commitment to reactivate the Council, which had not been operating in recent years. In February 2003, the list of drugs

for the Compulsory Health Plan was updated as well the *National Policy on Sexual and Reproductive Health*, covering 2002 to 2006, which was adopted in February 2003. The Policy reviews the topics of sexual and reproductive health, identifying priority areas such as safe motherhood, family planning, adolescent sexual and reproductive health, uterine cancer, sexually transmitted infections, HIV/AIDS, and domestic and sexual violence. Emphasizing, among other things, gender equality and women's empowerment, with a focus on education and outreach activities, the policy recognizes sexual and reproductive rights as human rights and states that health protection is the government's responsibility. The policy's main objective is to improve people's sexual and reproductive health and enjoyment of sexual and reproductive rights, emphasizing a reduction in vulnerability and risk while promoting safer practices and assisting groups with special needs by the following measures: strengthening health services, health promotion and prevention using information, education, and communication strategies; strengthening the involvement of public and private institutions; bettering health information systems; and research²². In July 2004, the HIV/AIDS Intersectorial Responses Plan for 2004-2007 was presented. The plan was prepared by the HIV/AIDS Working Group (representatives from several ministries and national, departmental and municipal institutions, NGOs, international organizations, and public and private institutions); it is based on intersectorial and institutional coordination, monitoring and evaluation, promotion

²² Ministry of Social Protection. (2003) *National Policy on Sexual and Reproductive Health*, Bogota, D.C.

and prevention, and supporting the integration of HIV and AIDS within the framework of the National Policy on Sex and Reproductive Health.

Even though Law 100 clearly assigned responsibilities to the health providers, there was no mechanism in place to enforce compliance by the EPS, IPS and ARS regarding health promotion and prevention. A new decree was thus approved to enforce compliance with the law. ARV treatments have been included in the Compulsory Health Plan (POS). Out of fifteen existing drugs prescribed to combat HIV/AIDS, eight are included in the POS, and the establishment of the Medicine Fund has also been considered an achievement. Also, the possibility of having treatments donated by Brazil and the joint price negotiations within the Andean Community are expected to reduce treatment costs for those living with HIV/AIDS²³. However, people living with HIV/AIDS are still facing inaccessibility to complete treatment plans, delay in CD4 tests, and they are voicing complaints about the low quality in treatment offered by some EPS, despite the fact that the Compulsory Health Plan includes ARV treatments; still, treatments are not always available for each reported case.

There is also a need to disseminate information about the prevention of other STI, such as syphilis, to increase awareness of other opportunistic infections, and to increase the availability of treatment especially for women with HIV/AIDS in order to prevent further complications. There is, furthermore, a definite need for more education to help women avoid stigma and discrimination, which would improve not only their social networks but also their lives.

...The system itself, what was Law 100, the health reform, has forced health professionals to default in the same thing. Even though service was not perfect it was much better five years ago. The team was strongest; it included a Psychologist, a Nutritionist, and a dentist along with nurses. Just today, I saw there were about 2000 patients (men and women) like me attending the health service and there are only two doctors. The estimated consultation time is 10 minutes, on average...

Florina, 27 years old, lost her husband and babies (two), each at 4 months of age.

With few resources, public services have found endurance very difficult. Five of the largest national public hospitals have closed, and ten more are in liquidation (Paredes, 2004), reducing service accessibility for the low-income population. For the same people, this limited accessibility means increased treatment cost due to their having to travel to distant treatment centres outside of their neighbourhoods.

Table 1 presents the government activities that have been carried out since the first case of AIDS was reported in Colombia: it shows how actions organized by public institutions were developed with the support of community groups. At the time, community groups were working with homosexual population and street workers women and men.

²³ Evaluación del Plan Estratégico Nacional ante el VIH/SIDA 2000-,2003 – Informe Preliminar May 2003 p.4

Table 1 Government and Public actions towards fighting HIV/AIDS

History of Action of Public Institutions toward HIV/AIDS

Year	Program/ Project	Government institutions	Community Groups	Activities
1985	Education, Prevention, & AIDS Advisory Comm. (CEPAS)	Health Secretariat Bogotá Simon Bolivar Hospital	GAI	Develop prevention and information programs. Homosexual college /university students prisoners & health.
1986	1 st National program to fight AIDS	Ministry of Health Epidemiology Direction		
1987	Experts Committee	Ministry of Health – Epidemiology Direction and Rep National institutions	Existing Organizations. & Community. Representation	
1987	Distrital Program for AIDS			
1988	CEPAS			Edition of HIV/AIDS Infection case management protocol.
	Regional and local HIV/AIDS programs	Antioquia, Valle and Bogotá Health Secretariats		
1989	1 st mid-term National Plan	Ministry of Health, PAHO, WHO under Global Program		
1990 1993	Hiring of national advisors (epidemiologist and health educator)	PAHO/WHO	Participation in delivery actions	Technical support to national STI and HIV/AIDS program.
1991	Regional HIV/AIDS	In 23 Departments		
1993	Adoption intersectorial focus to the epidemic	Ministry of health and national institutions	With community. Representation	Delivery action to control the epidemic
1994 1996	Prevention and control of STI and HIV/AIDS Program	Ministry of Health + 14 government institutions	Organize	Implementation. Including intersectorial coordination. Communication, participation and decentralization
1995	Financing of the Intersectorial mid-term plan	CONPES SOCIAL 2756		Training activities in -Sexual Health Prevention, blood & hemorrhages. During invasive procedure transfusion- Epidemiologic surveillance. & Research -Socioeconomic Impact reduction, -Monitoring & Evaluation
1996 1997	Financing through individual project design	Regional and municipal programs		Continue with activities in the plan

History of Action of Public Institutions toward HIV/AIDS

Year	Program/ Project	Government institutions	Community Groups	Activities
1997	Reduce national resources, problems with registry/ notification systems	Ministry of Health –Effects of the Health Reform to SGSSS.		Promotion/prevention assigned to contributory and subsidized regime entities, departments & municipalities
1997 1998	Cont. work of Plan IMP, less financial Resources, & administrative Structure No National HIV/AIDS Program			
1997	National HIV/AIDS Council within the Ministry of Health	Representatives from Ministry Health, Education, Communications, Labour & Social Security, ICBF, Ombudsman, INS, INVIMA, National Sexual, Education Coordination, UNAIDS, EPS, National TV Committee, Blood Bank National. Network, department & municipal Committees	National Coordination. NGOs working on AIDS, PLWA,	Promote actions of the National Program of STI and HIV/AIDS. Present policy proposals to develop actions in HIV/AIDS promotion and prevention
1997	Decree 1543	President of Colombia		Assign rights and obligations of people with HIV/AIDS. Promotion and Prevention, care and infection control of HIV/AIDS
2000	Agreement 117 defined HIV/AIDS to be an illness of public interest	Ministry of Health		Determine those illnesses with high impact on collective health and required special attention and follow-up.
2000	National AIDS Programme replaced by a "Functional Working Group", which deals with all communicable diseases			
2000	Resolution 412	Ministry of Social Protection		Regulate promotion and prevention by EPS.
2004	Agreement 282	Ministry of Social Protection		Determination of viral charge to be included in subsidized POS and the corresponding increment in the capitation unit and included antiretroviral medicines

History of Action of Public Institutions toward HIV/AIDS

Year	Program/ Project	Government institutions	Community Groups	Activities
2004	Intersectorial Plan for National response for 2004-2007	Ministry of Social Protection and Multisectoral working group		Replacing previous strategic plan the new Intersectorial Plan within the Nat. Policy on Sex and Reproductive Health. Institutional/intersectorial coordination, monitoring and evaluation. Creation of National Monitoring Facility on HIV/AIDS. Promotion and Prevention, Social support and Care
2004	National Policy of Sex and Reproductive Health			National framework determining priorities for the government.
2004	Instruction 018	Ministry of Social Protection		Establish goals, activities and indicators to be accomplished within PAB according to 2004-2007 national plan
2005	Law 972			Mandatory for EPS to carry out health promotion and prevention, and provide information about availability of services and health education

Health Promotion and Communication in Colombia

Colombia was a pioneer in the establishment of health promotion and communication projects. In 1947, a young priest, José Joaquín Salcedo, was transferred to a small town named Sutatenza. Upon his arrival, he found a largely illiterate and alcohol-afflicted community, and proposed the construction of a theatre for entertainment and educational activities. The theatre was built with the help and participation of the community. With a homemade 90-watt transmitter, he began to broadcast radio programs. "Radio Sutatenza" was born, with one program encompassing entertainment, sports and educational

instruction; another focused solely on instruction, airing and re-airing lessons for the benefit of students. This station became the first, worldwide, used for educational purposes, particularly among the rural population. Father Salcedo believed that education was needed to empower people and to inspire a democratic society founded on equality. It was the beginning of what we now call distance education. Relocated to Bogotá, Radio Sutatenza became part of Cultural Popular Action radio station to expand distant education activities and to provide education to eight million rural adults, helping them assume responsibility for their own development. Program topics included hygiene and basic health care, reading and writing, arithmetic, increasing productivity and recognizing personal dignity. In time, family health improvements, farming techniques, environment, economic skills, and consciousness to social issues, community participation, human rights, ethics, and religious principles were also discussed. To broaden the station's availability and to assist in accomplishing its goals, printed materials and records were produced. However, this grassroots and community-based organization faced financial hardship and lacked government support. In the end, all technical equipment was sold to one of the biggest radio broadcasting companies in Colombia. However, the experience was inspiring, and it has been replicated in Asia, Africa, and other countries in Latin America such as Brazil, Peru and Chile.

The National Federation of Coffee Growers of Colombia established the Primary Health Department, which organized women's programs to be implemented with the help of regional committees. Following in the footsteps of

Radio Sutatenza, the Primary Health Department established a radio program, a television program and complementary printed materials that were distributed with the help of regional committees. Services were provided to coffee growers and their families, helping them to achieve a very high level of health care. As a by-product, hardship on the international coffee trade was reduced. Projects used information, education and communication strategies to educate the community and to promote healthy behaviors within the community.

Prior to the health reform, the Ministry of Health facilitated the community's participation in the preparation, testing, and production of education materials. The ministry also provided staff training at the national level. Materials were prepared with the input of departmental health secretariats; they were locally tested for language and accuracy and then approved and printed. Most national campaigns materials (television ads, radio announcements, and posters) were developed under the umbrella of the Ministry of Communication (responsible for National Broadcasting TV and radio), which distributed to elementary and high schools the campaign materials in an effort to broaden the campaign's effect. Building on the "Radio Sutatenza" concept of distance education and educational programs for children, the Ministry of Communication created an educational channel. The Health Promotion strategy encouraged municipalities to work toward the Healthy Municipalities initiative, which encouraged close contact between regional governments, health sector officials, the community and local media. The educational benefits of the channel were evident when, for instance, cholera appeared in Latin America. By means of the

radio, the community was taught safe cooking practices and healthy behaviors such as hand-washing, living in clean spaces, recognizing the basic symptoms of the most common infectious and transmissible diseases, and understanding the importance of vaccines. Vaccination campaigns were successful in reaching approximately 95% of children under one year of age. The Ministries of Education, Communications and Health worked in partnership with the support of international organizations and the community in order to obtain that coverage. To date, the Ministry of Communications and INRAVISION have donated the show time for teleconferences related to HIV/AIDS and the World AIDS Day, and for HIV/AIDS commercials. The donated show time for these broadcasts is after 10 p.m.; when the family band changes to adult band the messages do not have significant cachet

Before the health reform, coordination existed between the following organizations: the former National HIV/AIDS Program, the Public Relations and Media Office of the Ministry of Health, and officers from the PAHO/WHO, UNICEF, UNIC, and UNDP. With the advent of the health reform, the landscape changed completely: the Community Participation Committee was dismantled, departments were downsized, and responsibilities were shifted. Furthermore, the National HIV/AIDS Program was segmented. In the early stages of the decentralization process, the Ministry ran timely information campaigns, but these did not endure. The Ministry of Social Protection remained the policy-making institution responsible for formulating; monitoring and evaluating the regimes and maintained control over the activities related to disease control

programs. The Functional HIV/AIDS Working Group replaced the National HIV/AIDS Program, and the former has been dealing with all communicable diseases; promotion and prevention, however are not their responsibility. Law 100 assigned promotion and prevention responsibilities to the EPS and the IPS. Local organizations developed promotion and prevention activities for the community.

...The Bogotá Health Secretariat has implemented counseling services within health institutions (health centers and hospitals) through community organizations, such as the SIDA Foundation, that trained 300 people, even though the program was financed and is considered one of the invoice-able services. "MEDICO EN SU CASA," a service for people living in distant areas from the city, has faced fierce opposition from the Ministry...

Manager MTCT Project

During the period of this research, the only TV and radio commercials related to HIV/AIDS were those produced by the MTCT, and financed by international funds. The interviewees were asked about messages seen on TV and their responses pointed that the showing time was after 10 p.m., and that the time was not optimal for capturing the attention of the general population.

...Educational strategies are short-lived; there are some processes in some departments. International agencies favor the process when there is a change in government. .. What existed before does not exist anymore and many good strategies that worked have tools that don't last in time. There are very few that are kept, as was the case of "Listening to HIV Proposals," a strategy for working with youth, so they will propose what they need, and what they will need to do, producing communication and education strategies by them...

Manager MTCT Project

In the quote above, the Manager of the MTCT expresses the challenge to continuity faced by many educational campaigns, which, at best, function for two years; if there is a change in government; however, a program's shelf life is even shorter. Education, for the most part, is left to the discretion of the schools, though the Ministry of Education reproduces and distributes at the national level materials produced by the Global Fund.

...Educational processes in health died in Colombia in 1997, even though the Sex Education Law of 1993 is still valid, and there are not enough human resources available to execute this task. However, the government has created a new project of competence of the citizens –addressed to a democratic defense of the citizens. The argument is that you can defend yourself not only with arms but also with education (and education is meant to have sexual education included) – which can be interpreted to mean that if you want to have a healthy and responsible sexuality you have to be a competent citizen. This is a disadvantage because sexual education and prevention are not focused on HIV/AIDS
UNAIDS Advisor

The Catholic Church is opposed not only to condom use but also to other forms of contraception, and the Church holds that providing this type of information to youth will only promote sexual activity. There are public schools less reluctant to provide sex education, but most of the schools are private and Catholic, and education is in hands of the school administrators. International agencies, on the other hand, have been supporting information, education and communication processes, including providing printed materials. Sometimes, these materials are welcome, however, population don't take ownership of the information presented. New legislation would make EPS and IPS work on health promotion compulsory as well as health prevention and education as

determined by Law 100, and would help to develop health communication strategies to motivate behavior change. Piltrow (2002) states that measures leading to disease prevention and health promotion strengthen the capacity of both the individual and the community to take responsibility for their own development, creating positive effects on both levels. If municipalities, regions, and departments do not work in cooperation with each other toward this goal, each works independently, and city mayors become individually responsible for assigning financial resources to promotion and prevention activities. Yet often it seems that those funds are dedicated to organizations with little to no experience in working with HIV/AIDS.

Even though HIV/AIDS has its own legal framework, it is executed differently in each municipality, and each department has its own schedule of development. In Norte de Santander the hospital has a strong HIV program; although it operates according to its own policies and not the departmental policies, it is being used as a departmental referral program. Santander has a new institution, Ardila Lulle, for working with HIV. In contrast, the Atlantic coast is much disorganized, as are other parts of the country. On the coast, university hospitals have closed, and there are no tertiary hospitals available. There are only clinics. These problems translate into a heavy workload for community groups.

In 2005, an intersectorial framework plan for sexual and reproductive health was presented. Yet in spite of the plan's conceptualization, there were not

enough financial resources approved for its implementation. HIV/AIDS must be demarcated as a government priority, as sufficient financial resources are currently impossible to amass.

Non-profit Organizations and community groups in Colombia

...Community work is focused on internal development and external challenge; creating ideas enabling people to think about change. Community work is a constant struggle, and it consists of everything that people do to address oppression in their own lives, suffering in the lives of others, and their sense of solidarity or group kinships...

Cheryl Townsend Gilkes²⁴

Community groups and foundations have existed in Colombia for 40 to 50 years, addressing, among other things, social issues, women and children's issues, and sexual education. Several organizations, foundations and community groups working on HIV/AIDS were created after the first case was detected in a female street worker in Cartagena in 1983; some organizations, for instance, who concentrated formerly in family planning expanded their scope, and have been working with HIV/AIDS since that decade. As the epidemic, at the outset, was concentrated in the gay population, male groups formed and developed awareness and prevention. Women, at first, were invisible; services were not customized to their needs, and there was a definite lack of information available to them. Women were treated especially badly when their diagnoses

²⁴ Gilkes, Cheryl Townsend (1994). "If It Wasn't for the Women...': African-American Women, Community work, and Social Change" In *Women of Color in U.S. Society*, edited by Maxine Baca Zinn and Bonnie Thornton Dill. Philadelphia: Temple University Press.

were disclosed: they faced immediate stigmatization. However, HIV/AIDS, as many other diseases, needs to be seen through the gender perspective, and community work highlights the ways in which women can mitigate the discrimination they experience in their own communities.

Community organizations have supported people living with HIV/AIDS by looking for government responses to information, education, and treatments and by developing health communication programs for the community. Not all of the HIV/AIDS awareness organizations have survived over time, however, due to limited economic resources, internal discrepancies, individual interests, religious beliefs, difference in socio-economic background, politics, sexism, stigma and discrimination between members, all of which create power struggles and internal conflicts. Some organizations were closed in order to open new ones. Others shut down due to competition and struggle between organizations: grassroots and community-based organizations sometimes feel overly protective of the work they do, and they withhold research or study findings. This only results in the unnecessary duplication of efforts and the waste of invested resources. Sometimes, the research carried out by one organization cannot be used for project proposals because previously collected information is incomplete or the research methods are not compatible with those required by international donors. The following table 2 presents community organizations existing since 1980, including their work, population served, and location. Seeing that there was no official record for this information and that I have compiled the list myself,

there may be omissions from this list. Additionally, some of them might not exist anymore for the reason stated above.

Table 2 Community Groups and organizations in Colombia

Community Groups and Organizations in Colombia

Year	Name	Location	Target Population	Type of work
1984	Support and Information Group GAI	Bogotá	Homosexual	Information and communication through gay bars
1986			Nursing Students National University	
1987	Fundación EUDES	Several locations around the country	PLWHA	Living home assistance to low-income population. People rejected by their families with no place to live. Street workers, boys and girls
1988	Liga Colombiana de Lucha Contra el SIDA LCLCS	Bogotá and some cities around the country	MSM	Ambulatory integral health services to PLWA Bogotá. Medicine Bank and Lab services. Individual Counseling at national. Level. Family/couple counselling. STI, HIV/AIDS, HR. Pre/Post Counseling
1989	GAI –FIASAR (Corporation for Research and Social risk anticipation	Bogotá	People living with HIV/AIDS	Project homosexuals & street workers. Training HIV/AIDS prevision for Government officials, NGOs & community leaders
1990	La Casa Programme Universidad de los Andes	Bogotá	General population	Info line HIV/AIDS. Drug addiction. Help line. Pre/Post counselling
	-Social duties & h. rights respect Association ASOBHUM- Colombian Association for Prevention-Health Prevention Association for youth- OMEGA Foundation (Loss & grieve)- FUNDEMI (Development industrial health Foundation).-La Casa-Liga Colombiana de lucha contra el SIDA-Dialogo Mujer	Bogotá	Responsible for the Colombian Congress on Sexual and reproductive youth health. Women for Women 1994	1 st instance of an NGO working on HIV/AIDS at national level.

Community Groups and Organizations in Colombia

Year	Name	Location	Target Population	Type of work
1992	Apoyemonos (Colombian Foundation for AIDS, Hepatitis and STI Support)	Bogotá	MSM Street Workers	Sex Infection Counseling Strategic Plan. Human sexual rights, communication materials based on qualitative & ethnographic research. Help line. Pre/Post counselling
	Positives for LifeCovidGenesis Program	Medellin, Antioquia	PLWHA	1 st National Encounter of support groups working on HIV/AIDS. Pre/Post counselling
1993	-VIHDA Project-Fundamor-The right to be happy gr.-Strength self support groups Committees	Cali, Valle	PLWHAChildren with HIV/AIDS	2 nd National Encounter of self support and other support groups working with HIV/AIDS
1995	Corporation against AIDS	Bogotá	Children with HIV/AIDS	Integral Seminar on HIV/AIDS
	Francois-Xavier Bagnoud Foundation	Barranquilla, Atlantico	Children with HIV/AIDS	
1996	Better Life Foundation	Cali	PLWHAStreet workers	Better Life Encounter. Family & group support. National Encounter. Help line. Pre/Post counselling
1997	Apoyemonos and Liga Colombiana contra el SIDA		MSM	Review Decree. 559/91, Decree 1543/97. Active NGO participation in the National HIV/AIDS Council
	Indetectables Magazine	Bogotá	PLWHA	Pre/Post counselling
	Liga Colombiana de lucha contra el SIDA Maria Fortaleza	Pasto, Nariño	Women Living with HIV/AIDS	1 st National Encounter Women with HIV/AIDS. Pre/Post Counseling
	RECOGAP (Support groups National Network)		General population	Determine access of self-support groups in hospitals, secondary & tertiary level hospitals
1998	Liga Colombiana de Lucha contra el SIDA		Women with HIV/AIDS	1 st Latin American Seminar WLA
1999	GAMI (Support group for women & child)	Cali, Valle	Women with HIV/AIDS	3 rd Encounter of NGOs.
	Premedical	Bogotá	General population	Workshops behavior/attitudes on sexual/reproduction. Education for school children.
	Common Cause	Cali, Valle	General population	
	Happiness Club	Bogotá	General population	

Community Groups and Organizations in Colombia

Year	Name	Location	Target Population	Type of work
	Exist	Bogotá	General population	
	Dialogo Mujer	Bogotá	Women to Women	
	Darse	Cali, Valle	PLWA	
	Amor y Vida	Bogotá	PLWA	Pre/Post counselling.
	Caminos de Esperanza	Bogotá	PLWA	
	Ecolibertad	Bogotá	PLWA	Counseling HIV/AIDS. Drug addicts.
	Patients with HIV Foundation	Manizales Caldas	PLWA	
	The Good Samaritan Foundation	Bogotá	PLWA	Pre/Post counselling.
	Cormujer	Bogotá	Street workers	
	San Antonio de Padua	Villavicencio, Meta	PLWA	Social/legal support. Pre/Post counselling.
	Ardila Lulle Foundation	Bucaramanga, Santander	PLWA	
	SIDA Foundation	Bogotá	PLWA	Pre/Post counselling
	Foundation Funguia	Montería, Cordoba	PLWA	
	Sunflower - WLHA Network	Bogotá	Women with HIV/AIDS	Pre/ Post counselling. Social support workshops. Advocacy workshops

The-Mother-to-Child-Transmission Project

The MTCT as a governmental project initiated in August 2003 focuses in serving low-income pregnant women who do not have access to health services and babies born from HIV infected females of reproductive age. The objectives of the project are:

- Promote the acceptance, responsibility and self-consciousness of women within reproductive ageInitiated in August 2003 in seven cities, the program was designed to offer:
 - Free and early HIV testing as part of prenatal care;
 - Alternative antiretroviral treatments;
 - Cæsarean operations;
 - Follow-up and psychosocial support to pregnant women and their families;
 - Policies for maintaining a low risk of vertical transmission;
 - Education about nutrition and breast milk substitutes.

Produced with the financial support of the European Union, the project has created a media campaign, including television and radio commercials and an information booklet to publicize their initiatives. The information booklet is distributed in Colombia by health secretariats at the municipal level.

Tests provided to women include the CD (Eliza Test) for diagnosis as well as other tests at 36 weeks in order to re-count lymphocytes in pregnant women during the prenatal control (there should be 8 prenatal controls) within the health care system. Diagnosis follow-up and ARV treatments are provided through the health care system. One month after birth the babies are tested and six months' supply of milk substitutes for HIV-positive babies is included in the control and development. Mothers receive education and complimentary nutrition for nine months as they learn in health education sessions about healthy sizes and weights for their babies. Women from ARS and EPS requesting services from the project receive tests and milk formula but are sent back to the ARS and EPS

systems to continue with the regular services for them and their babies. In some places, the Western Blot is used for confirmation of diagnosis, specifically in Cali, Antioquia and Capital District. The target population is estimated to be approximately 316,670 pregnant women in low-income areas in Colombia who do not have access to health services.

The project develops activities that aim to empower women through health awareness, increasing women's self-knowledge and, thus, increasing their protection against HIV transmission by means of heterosexual contact. For those who are infected, the project aims to provide training about how best to minimize the impact of the infection on the fetus. The MTCT database includes information about the number of women approached and the type of service requested. Testing and controls are offered through health secretariats as part of the regular pregnancy services as the MTCT, and they rely on municipal health secretariat staff to render services including tests and milk substitute provision. The MTCT project is administered by REDSALUD (the Colombian Network of Hospital Cooperatives), which also administers the National Medicine Fund for High Social Impact Diseases (HIV/AIDS, cancer and hæmophilia). REDSALUD covers 80% of the costs incurred by public hospitals around the country. The National Medicine Fund, which subsidizes 60% of the total cost of drugs and regulates drug market prices, was created to ensure that poor patients not affiliated with either of the two tiers receive an adequate supply of drugs. The patients have to be linked to a program administered by a public hospital or a private institution that covers the remaining 40% of the drug treatment. As the

Fund is the country's largest purchaser of HIV/AIDS drugs, it has the strongest negotiating power with the pharmaceutical industry. However, cultural objections prompted health projects to arrive late in Colombian society; barriers include the economy and aggressive health staff.

The project has designed a database that includes all the women contacted, type of service rendered to each woman, dates of childbirth, follow-up and treatment administered. The project offers two viral counts, one at the time of diagnosis and the second at week 36, before the baby is born and before the lymphocytes are counted. Services start with diagnosis until one month after birth, when they receive prophylactic treatment, and when they reach six months. Then they are linked to the health system and receive a six months' milk substitute supply. Following that, they are included in the National Program of Control, Development and Education. At nine months, the babies receive complimentary nutrition, and the mothers are trained to measure the weight and size of their babies. Tests offered are the Eliza test for diagnosis and the Western Blot for confirmation of diagnosis. Also, home visits are offered to provide more education, vaccination, prenatal control, family planning, infections and self-care.

There should be eight prenatal medical controls, but women often undergo only one: in 2004, 59% of women were diagnosed between weeks 15 and 32, 17% have been diagnosed between weeks 33 and 37, and 13% of women between weeks 38 and 70, meaning that 30% of women are diagnosed late. The number of tests rendered is 368,873, with presumably 1284 positive results.

Nine hundred and forty women were diagnosed with 21 babies born positive. HIV was detected late in fifteen of the pregnancies; only six babies had project intervention and received ARV treatment. There have been induced abortions, although they are not registered in the medical histories as such; they are registered, rather, as spontaneous abortions.

...During my last pregnancy, I had many problems with my bronchial tube. I couldn't breathe, and I was sent to the health center... then they sent me to another health center... then, back to the first health center, where they took blood samples for several lab tests. They didn't tell me what tests they were doing... not even the doctor mentioned anything to me... I was very sick; they ran more tests. I was sent to the hospital... I think ... there was something wrong with my lung ... there were several complications. I couldn't sleep; if I laid on the bed, couldn't breathe ... if I was seated still couldn't breathe ... and everybody kept telling me that there was another lab test pending that I needed to go again to the health center. I didn't know what they talking about. Finally I went and they took more blood. When I went, a month after, the doctor and the staff told me that I was HIV-positive, but nobody told me anything, or gave advice before the test... At the beginning, I was fine, I was not scared or anything, but suddenly, my mind started to ask questions. The baby wasn't born yet, so they gave me the medicines, after Catalina (from the organization) helped her get the ARV treatment. I didn't have health coverage ... my husband hadn't included me or the children...

OMAIRA, 24 years old,

Has been living with HIV/AIDS for two and a half years.

She has a son, nine and a half, a daughter, three, and a one and a half year old child born HIV-positive.

Around 68% of the total number of infected women is between 20 and 30 years old, and approximately 18% are between 15 and 19 years old. This is to say that a total of 86% of women are in their reproductive years when they are affected by HIV/AIDS. The other 14% correspond to women older than 31 years of age. Marital status of women within the project is as follows: 62% are involved

in a free union, 27% are single, 27% are married, 1% is divorced, and 2% are widowed. There have been fewer induced abortions, but this information is not registered in medical histories: abortions are reported as spontaneous. The cities with the highest incidence of HIV/AIDS are Cali, with .20% HIV-positive, Bogotá, with .16% HIV-positive, and Barranquilla, with .14% HIV-positive. With the European Union's second phase of financing, Bogotá joined the project in October 2004, thirteen months after both Cali and Barranquilla. Bogotá has administered eighteen thousand tests, equivalent to 10-15% of the total number of tests administered nationally.

...Bogotá has a different health care system than the rest of the country. The health reform and the restructuring of the Ministry of Health, suffering a loss in the direction of health promotion and prevention and in staff numbers, have created policies that are not clear depending on the Ministry's staff. Functionaries that were working in a determined program were transferred to other departments; the strong teams of promotion and prevention were totally diluted. The Bogotá health secretariat has strengthened its physical structures and health processes (that are more advanced than the rest of the country), and has adopted measures and defined its mission according to what it considers important. However, public health goes one-way, health insurance another way and surveillance and control go a different way. The secretariat works three fronts: one to develop policies, a second to set policies in place, and the third one exercises surveillance and control...

Director MTCT Project

Bogotá is home to one-sixth of the country's total HIV infected population. Local hospitals work in partnership with the project. The Simon Bolivar Hospital, one of the biggest public hospitals in Bogotá, has since August 2003 served 29 mothers between the ages of 15 and 27 and one who was 38. From these 29 mothers, 27 living babies were born. Eleven have received CD tests at one

month of age; and at six months of age, all of these eleven babies were HIV-negative. Tests on the other sixteen babies, however, have not been done. Out of all the mothers asked, none believed that this would happen to them but rather that HIV affected other people (such as prostitutes or homosexuals). However, all of the infected women said that they had a previous partner who infected them. Their current partners are negative.

“...It is easier to infect women as there are more tissues exposed during a sexual encounter...”

*Betty Ruth, Nurse at the SB Hospital
Responsible for HIV/AIDS hospitalized patients*

The MTCT Project considers its strengths the prenatal controls and the offering of education, nutritional support and psychological support to the patients. Nonetheless, the project staff believes that there is still more room for work with youth on issues related to self-esteem and education to eradicate taboos and to promote condom use.

The project has been praised both nationally and internationally. However, staff turnover has been one of the project's biggest challenges, forcing the project to reinitiate activities and retrain staff every time new staff is hired. Recently, MTCT has been integrated within the sexual reproductive health and the mother and child program within each municipal health secretariat. However, three departments took full responsibility for the project in 2005, including budget and wages for assigned staff. It is expected that the project will continue with its successful activities and that the budget will cover the project's costs.

In sum, I can conclude that the MTCT has achieved its proposed goals overcoming challenges and supporting public institutions benefiting women by providing HIV testing, offering education to pregnant women and offering milk substitutes for babies. Project staff interviewed expressed that women felt grateful for the services received. However, as mentioned before only 21% received the diagnosis and confirmation tests through the MTCT and the after birth services follow-up and for the purpose of social support women were referred to the Sunflower Project. Though I tried to make a comparison between the two projects, the information harvested from the MTCT project staff only permitted me to present what looks more a project report than an ethnography of the MTCT where the relationship with women served was just reported instead of spoken from themselves. I hope, therefore, that once the project is administered directly by municipal and departmental staff, the project's service standards will be sustained in order to prevent future vertical transmission.

Chapter Three. Description of the Case Study Project

The Sunflower Project



...The day a woman can love with her strength and not with her weakness, not to hide but to encounter herself, not to admit defeat but to confirm herself; then, love will be for her and for him a fountain of life and not a deadly jeopardy....

Simone de Beauvoir

The project was named in honour of a woman who died of AIDS. In the words of the national coordinator:

...My friend died from AIDS six years ago; she had a professional title, a good socio-economic status. She had a good life, but her family was very negative, her self-esteem was very weak and her mental health very fragile. She wanted us to get organized into a

support group so we could work for other women. She said we would name it SUNFLOWER. The seeds in the center are the women getting together because they need help, and the yellow petals are the projects and dreams that we could develop. The name is masculine because she did not want it to be a closed feminist group and a masculine name will tie many things and project is a dynamic word...

Sunflower Project - National Coordinator

The Sunflower Project is a woman-to-women, grassroots organization, born out of a need for knowledge and a demand for the existence of educational programs that would help women face the struggles inherent in battling HIV/AIDS.

The purpose of the project is to break the existing silence experienced by and forced on women living with HIV/AIDS in Colombia. Its objectives are health promotion, prevention, education, peer support, social network support, empowerment, and advocacy at the national level.

The project solicits the participation of HIV-positive women in decisions about their sexual and reproductive rights, and it asks women's input in regard to prevention and health care services at the local, regional, and national levels. Coordinators work to create and support initiatives that will improve the quality of life of women living with HIV/AIDS as well as initiatives that might reduce women's vulnerability toward HIV/AIDS. As such, essential to the project's success is an environment wherein open communication can occur between women, and support networks can exist for women dealing with HIV/AIDS. The environment must be inclusive not only in the way it reaches out to women but

also in the way it includes women, asking them to take an active role in designing and evaluating sexual education programs, in promoting the sharing of experience, and in creating an information feedback system within the network, where information is shared between organizations at both the national and the international level.

The project's greatest goal is the development and the sustainability of an economic project to allow the network to repeat activities, and to teach women the skills to generate income for their families.

Figure 6 First Encounter of Women Living with HIV/AIDS in Bogotá, 2004



First group of positive women, by permission

Colombia's mountain range outlines the natural geographic regions that were used to configure the network's regional headquarters: Costa Atlantica (North), Santanderes (East), Region Andina (Center), Llanos Orientales (Center East), Valle and Cauca (South West), Amazonía (South East), Eje Cafetero (Center West), Pasto (South) and Medellín (North West). Each regional office has a member coordinator, either working solely for the women's network or for the network in partnership with another organization, or for another organization that is the regional connector to the network.

In May 1997, the Liga Colombiana de Lucha Contra el SIDA, with the sponsorship of UNAIDS and UNFPA, staged the First National Encounter of Women living with HIV/AIDS. The participants reviewed the status of women living with HIV/AIDS as well as their rights and responsibilities. As a result of the event, seven women committed to working toward guidelines and strategies that would establish the National Network of WLWHA, whose objective was to identify women's needs and to give them a voice. Also to search for more education, health services, legal advice, social support, and fight against discrimination.

The Sunflower Project received help in its initial stages from Maria Fortaleza Foundation in the department of Nariño, which is located on Colombia's border with Ecuador. But when the group obtained their government incorporation as the National Network of Women Living with HIV/AIDS, the national coordinator was relocated to Bogotá, where it was more convenient to facilitate contacts with national authorities and international organizations located in the capital city of Bogotá, DC (Capital District). In 1999, The Sunflower Project

represented Colombian women in the 1st Regional Seminar of Women Living with HIV/AIDS in Latin America and the Caribbean, financed by UNAIDS along with other eighteen countries. The exchange of experiences and notes on various topics helped the women in the development of the national network.

By the year 2000, and with the support of UNAIDS, women in seven Colombian cities touching the most populated regions of the country - Barranquilla (North Coast), Bogotá (Center), Cali (South West), Cúcuta (East), Medellín (North West), Pasto (South) and Pereira (Center West) - received training in the following areas: HIV vulnerability, empowerment, human rights, sexual and reproductive health, HIV/AIDS information, and ARV treatment access. The formation of the National Network of Positive Women was the product of the training sessions in which they participated. The training was to be replicated, and eventually 197 women around the country would participate in the sessions. With the support of the regional coordinators, experts presented the issues. The sessions included theory and practice centred on gender. Themes were developed according to participants' interests in each region, allowing exercises to be modified locally. In Medellín, sexuality and reproductive rights were the topics chosen, while women in Cali worked on empowerment. A very open methodology guaranteed active participation, an open space for reflection, sharing of diagnosis, personal growth, self-esteem, and empowerment.

In 2001, the participants' responses in the Medellín training sessions defaulted in the creation of a women's support group for prevention and

information. In Cali, GAMI Foundation provided support and pre- and post-counselling to women living with HIV/AIDS. In Cúcuta, women renewed their commitment to the network. Requests to develop more training workshops in Cartago (Valle), Armenia (Quindio), Manizales (Caldas), Tunja (Boyacá) and Villavicencio (Meta) were the indicators of the workshops' success. UNAIDS financed the purchase of computers and the printing of posters to promote the network.

In November 2002, the project was officially approved as "Fundación Nacional de Mujeres Positivas – Proyecto Girasol". Since then, the foundation has participated in the creation of national policy and the analysis of national and regional HIV/AIDS expenditures. Successful activities have been presented internationally at the 2000 Forum in Rio de Janeiro, Brazil. The Brazilian Women with HIV/AIDS Network, for one, has adopted the Sunflower Project as a model to develop their Positive Citizens Project. Also, the model was presented at the National HIV/AIDS Symposium in Costa Rica and at the 2003 Forum in Cuba, and it has been promoted at a number of national events. With financing from UNAIDS and UNFPA, the Sunflower Project carried out the GAUI initiative - the word GAUI hails from the Kogi language (Kogies – Indigenous group of the North Coast of Colombia), meaning creating, producing, and making something. The project was to train women from the network with skills to produce wax candles and sunflowers, miniature balconies in wood, HIV/AIDS symbols, decorated pencils with porcelanicron and bookmarks. Products were sold through educational and cultural institutions and international agencies. Then, members

of the network decided to replicate the experience and to train with these skills as many women in the regions as possible. In June of the same year, UNAIDS financed a special training program to develop the organizational development project, “Desarrollo Organizacional,” which was a “training the trainee” project to develop a strategy for organizational development. There were coordinators in Pasto, Medellín, Cali, Pereira and Bogotá trained to replicate the project at a national level. A total of 180 women (10 in Bogotá, 28 in Cali, 63 in Pasto, 31 in Medellín and 48 in Pereira) from different organizations were trained. Also, 12 male community leaders requested information. Participants were people with HIV/AIDS and/or living with someone with HIV/AIDS, mothers of infected people, girlfriends, and other relatives. The literacy level varied from illiterate to university-educated. All from housewives to university students to handcrafters to micro-entrepreneurs were on hand, and ranged from 18 to 55 years of age. They were single, married, partnered and/or divorced.

The purpose of the organizational development program was to provide tools to obtain technical, human and economic resources in order to develop more sustainable economic projects for the growth of the project. Training sessions opened up for women the possibility of being self-sustainable, of creating micro-enterprises, and of leading productive projects:

- In Cúcuta, a group of women created a micro-enterprise to support their families.
- In Medellín, women became specialized in handcrafts and are working on HIV/AIDS prevention in conflict areas.

- In Pasto, women participated in occupational therapy workshops and have manifested the intent to create micro-enterprises, to establish HIV/AIDS prevention workshops with local authorities, and to provide support to the uninsured population so that they might obtain integral health care and achieve inclusion in the SISBEN.
- In Cali and Pereira women are supporting government-initiated prevention activities.

Evidently, women needed motivation to participate in educational processes: in December 2004, the second training program recruited 295 women nationally.

Fundamentally, the Sunflower Project functions in such a way that it plays into women's natural social roles: traditionally, women as mothers, supports and communicators are associative, and they enjoy social contact. The Sunflower Project provides a forum in which they can share their everyday experiences and struggles and in which they can develop awareness and activism. This community organization offers them the opportunity to recover values including solidarity, autonomy, human rights respect, dignity, and the right to intimacy, self-esteem, and choice. The network is the only community organization dedicated to educating women. Its mandate is to increase women's empowerment by furthering their knowledge of HIV/AIDS.

Little research, thus far, has addressed community work with stigmatized women; Berger (1994) suggests that community work should be incorporated into traditional inquiries of gender and political participation in order to understand how HIV-positive women can become politically active and empowered.

Born in a small town distant from Colombia's capital city, Mireya has been living with HIV for 10 years. At the time of her diagnosis, she was 19 years old, caring for a 2-year old son and grieving the death of her son's father, who had died two months earlier. "Everything was so sudden," she said. "I was volunteering at the local hospital when I offered to donate blood and was told that all tests would be run on the blood, including HIV." Neither counselling nor information was provided before the test. She is one of the original members of the Sunflower Project.

Evaluation during different training sessions around Colombia confirmed that many women share a desire for more information, sexual education, and better reproductive health practices in order to face their fears about infecting others, to learn the facts about sexual abstinence, and to deal with rejection, low self-esteem and social stigmatization.

...I was very, very sick, and my sister called the Ministry of Health looking for guidance and support. She was redirected to the Sunflower Project. She came to see me with a doctor; they have given the best gift ever. I call her 'my guardian angel'; they took me to the hospital. I was there for five months as a terminal patient. I weighed 80 lbs, I lost my hair, and I was given few days to live... The coordinator of the Sunflower Project helped me go through this hard time. Thanks to her and God I'm alive now...

Dalia, 46 years old, has been living with HIV for 5 years. She has two daughters (24 and 7 years of age) and a son (13).

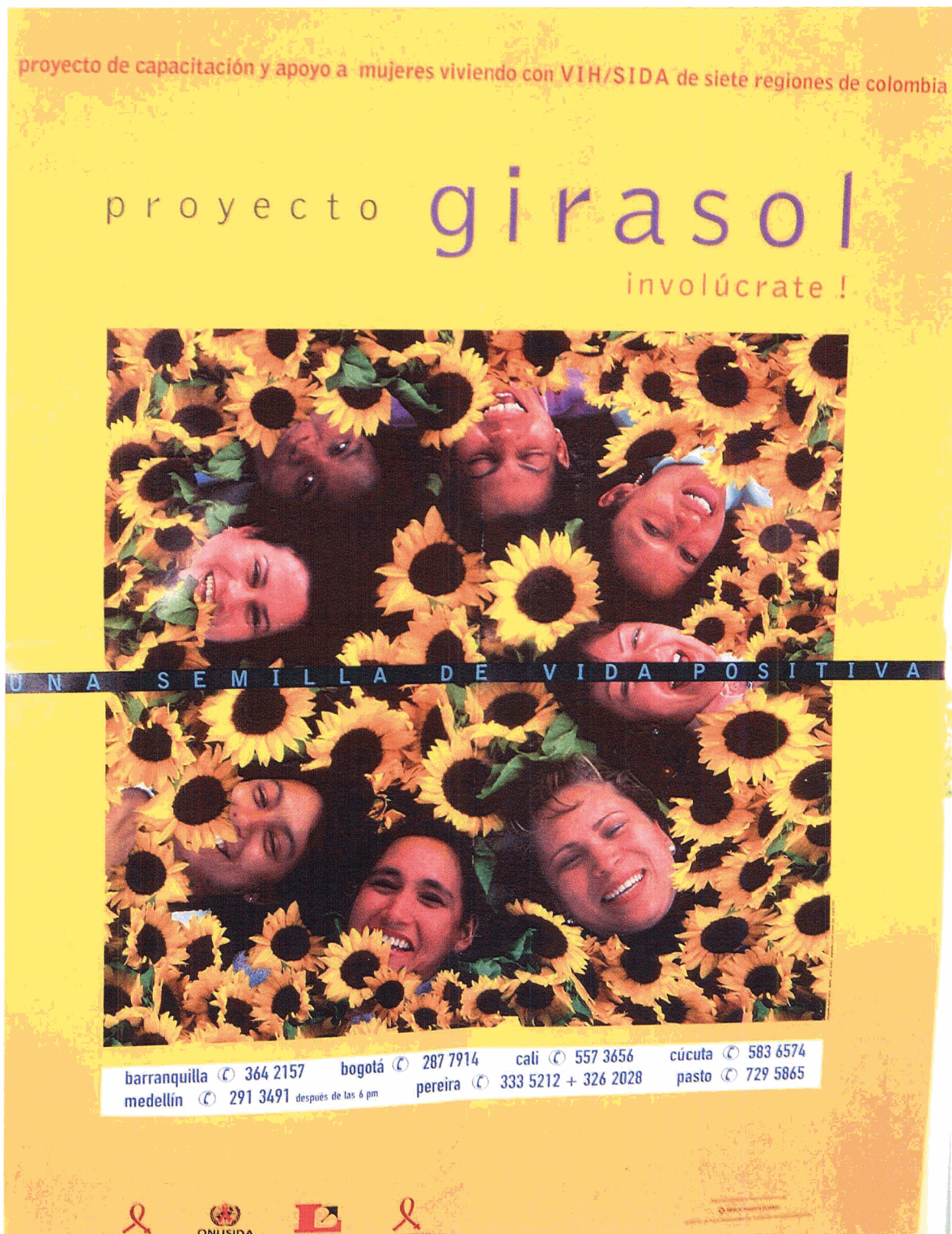
In sum, the women I interviewed felt extremely attached to the organization. They were grateful to the staff for the support they received, for the staff's devotion in visiting HIV/AIDS patients in hospitals, especially the women,

and for the foundation's willingness to confront both media and society, expressing the fact that HIV/AIDS does not discriminate: anyone could be living with the disease. They were grateful for the gathering of women from a variety of socio-economic backgrounds, recognizing that the stronger they are in numbers, the stronger they will be in protecting and promoting their rights and her life stories, in achieving a better educated and healthier society, and in building self-confidence and life-enjoyment and improving their quality of life.

...The Sunflower project has given me information, and support backed up by institutions and people. It helped my decision to live, and search for more information. You have to make up your mind... ask myself what can I do with this... and I found the tool that helped me to open the door to hope...

MIREYA

Figure 3-2 Poster promoting services and showing the seven initial members of the National network of Women' living with HIV/AIDS.



The Sunflower Project Positive women poster, by permission

Chapter Four.

Findings of The Case Study: Women Voice Their Experiences and Perceptions of AIDS Projects

.... The same week I was told that 80% of women who tested positive at the Simon Bolivar Hospital were wives infected by their husbands, who have had bisexual relations....

Silvana Paternostro²⁵

Overview

My purpose was to learn from the experiences and perceptions of women living with HIV/AIDS. I am grateful for having had the opportunity to meet fourteen HIV-positive women who were willing to share their experiences and other personal and private information with me. In Colombia as well as other Latin American countries, women live within a patriarchal society. Colombian women, in turn, take on the role of protectors; they assume the major responsibility of supporting their children while culturally they are often dichotomized into “good” mothers and “bad” promiscuous women (Cohen & Durham, 1993).

Colombia, like most Latin American countries, is founded on a patriarchal structure that favors strong men and submissive women. These attitudes are difficult to change due, in part, to strong Catholic beliefs that interfere in women’s

²⁵ Paternostro, S. (2001) *En La Tierra De Dios y Del Hombre – Hablan las mujeres de AmericaLatina*. Editorial Suramericana, Buenos Aires

health education, specifically in regard to the use of contraceptives. Condoms are perceived in a negative light because they ostensibly promote youth sexuality and freedom. Representatives of the Catholic Church condemn the use of condoms, arguing that condoms are not effective in the fight against HIV/AIDS. As such, the Church has been undermining the aim of prevention and education campaigns.

Although HIV/AIDS has been present in Colombia since the 1980s, the issue is still hard to manage. For most women, disclosing information about their own infections is perceived as betraying intensely personal information, information that might be misinterpreted, wrongly judged, or worse, used as the basis for discrimination. Women living with HIV typically bear the responsibility for child-care, housekeeping, and health and social work in addition to their own illness and the illness of their partners, or someone else in the family. Most of the time women's own needs are the least well met (Barlow 1992). The majority of the women living with HIV/AIDS are diagnosed after their partners, husbands, or children have died. As a general rule, women look after their own health needs only after their family's health needs are taken care of, and if there are still resources available. Women, especially within the low-income population, work outside the home for little money. This is to say that women carry the burden of work and family subsistence, a two-fold role that is rooted in the patriarchal structures of the low-income population. The topic of my research highlights aspects of the women's lives that they felt affected them the most.

...In many cultures, individual behavior yields to community or collective behavior, while in others instances; it is argued that certain behaviors, such as sexual behaviors, are closely linked to cultural practices that demand additional attention to community and cultural values and practices...

*Thomas Tufte,
Dept. of Film and Media Studies
University of Copenhagen²⁶*

The excerpts I present here highlight women's feelings, their experiences, and the challenges they have faced during their struggle with HIV/AIDS. I wanted to ascertain whether or not the projects reviewed in the previous two chapters of this thesis have improved their quality of life. The predisposing factors, enabling factors and reinforcing factors of the Precede-Proceed Model of health promotion are used to situate women's responses and are presented using the Stages of Change Model. I also explore how the Health Belief Model and the Theory of Reasoned Action examine individual attitudes, beliefs, and intentions to modify behaviors. The health belief model can support the approach to personal vulnerability, "so long as one's audience perceives itself to be vulnerable"²⁷ In an attempt to explore the correlation between socio-economic status and the level of health promotion and education coordinated by the EPS, insurers, and ARS, questions were asked about women's knowledge of HIV/AIDS prior to their diagnosis.

...I saw HIV as very, very distant; I never even thought about it, it never crossed my mind...I had heard about AIDS but you never even

²⁶ Tufte, T. (2000) HIV/AIDS Communication and Prevention: A Health Communication Research Project, 2001-2003. University of Copenhagen

²⁷ Wight, D (1993) page 478

imagine that you are going to have it, that you're going to have face it... I heard that it was a male sickness and that everything was outside my life.... but you never think that you're going to have it at home...

YOLANDA, 28 years of age, has lived with HIV for 5.5 years. She has 12 & 13 years old daughters from a previous marriage, and a 4 1/2 years old boy born HIV-positive.

...I didn't know anything. There were some TV commercials but I always ignored them; I never saw them as something that ever hit close to home....

AMPARO, 50 years old

Women provided similar answers to my questions. For the most part, women trust their partners, and they think that having a stable relationship precludes them from contracting HIV. When they do contract the infection, the severity of HIV/AIDS affects their social network and support. Women often stick by their men through HIV infection, illness and death, but men often abandon their women when they become HIV-infected or ill (Springer 1992). Cultural beliefs and traditions compel them to act according to what they have seen and learned, and, as a result, the women try always to please their partners; they do not want to disappoint them as matter of social hierarchy superior and dominant versus inferior and subordinate and following Catholic principles entrenched within the culture: submission, and obedience are interpreted as respect for the chief of the household. Men are the ones with knowledge; women follow their desires and requests, which means that health requests made by women, such as condom usage, are not acknowledged. Furthermore, the Church prohibits some the use of contraception methods that would prove more safe sex for women, such as practicing regular condom usage. These beliefs influence

decisions affecting their health (Health Belief Model) within the predisposing factors.

Women's reactions to HIV/AIDS demonstrate that knowledge (health education) changes attitudes, beliefs, and values leading to modified behavior, as well as modified perception of behavior. Education should be included within health promotion in order to catalyze a change in the social environment and in order to alter behaviors by modifying cognitive and affective mediators that control programs, policies and practices. I use the Stages of Change Model, also called the Transtheoretical Model, to situate responses in order to understand the impact of HIV/AIDS, women's knowledge, the changes they perceived throughout their struggle with HIV/AIDS, and what information they perceive is still missing for others vulnerable groups. In the pre-contemplation phase, as Prochaska suggests, a person has no intention of modifying her behavior within six months (of receiving the test results, for instance). She does not fully realize the impact of the diagnosis, and she does not develop the motivation to change.

...First, it was very painful, and I was in denial... I could not see a possible way out because of the little information and education that I had at the time... My son was 2 years old. I knew I had to take him to be tested, but just thinking that he could be HIV-positive... My partner also needed to be tested...could he be HIV-positive? The emotional weight that you feel is so hard that you don't even imagine, even just thinking about the possible result of the test, the impact is too much... Nobody wants to hear that you are sick with the virus and that it will turn into a fatal disease... especially when the person who has given you the test result is trying to do his best but does not have more information than you do... The only thing everybody knew was that it was deadly. I was afraid for my son; I was afraid of dying. When you're young you think that you own your life and you can master your life better than anybody else... Time helped me understand little by little, but the question keep coming up...why me? If this could happen to any human being, woman or man, then there

is no difference...it is just a matter of working it out or sexual orientation... This is a process for you to realize... however, this is a lengthy process.... because it is your skin, your life, your own process...
MIREYA

The first test brings about feelings of uncertainty and disbelief; then, when the diagnosis is confirmed, women confront a new crisis. Family dynamics are disrupted in coping with loss and grief, impacting their psychosocial adjustments to managing stress, self-esteem, social isolation, decision-making and disclosure. Feelings of fear are overwhelming for some people. Emotional distress, suicidal urges, and feelings of uncertainty are some of the challenges posed by psychological distress. Further distress is caused by the disease's impact on relationships. Especially for many of the female patients, having a good friend is a key element in this scenario (Bury 1982) and because social support it is influenced by social structural imperatives becoming more than individual links of networks in terms of social cohesion which at the society level have powerful effects on health strengthening social relationships and improving the health of communities (Stansfeld)²⁸.

*...It was overwhelming, when I found out that I was HIV- positive; it was very hard for me to accept and to take as a reality. I was a housewife and had an accounting job in an Ophthalmologist's office and was about to give birth to my third child. As it was a private doctor, he ordered some lab tests. It was very hard for me; the person who gave the results thought I knew about my status, which I did not. It was difficult to handle especially because my husband was negative and I was positive. Then he left me with the kids. .
MELINDA, 31 years old, has been living with HIV for 10 years.*

²⁸ Stanfeld, S. in (2006) *Social Health Determinants*, Second Ed. Oxform Press, New York

In the second phase of the Stages of Change Model, the contemplation stage, a person intends to take action within the next six months (knowledge about HIV/AIDS and existing ARV treatments).

...After I was diagnosed, my life was the same. I was a symptomatic; I had no visible problems; I had my career, and was economically stable. My husband was not a saint - he was unfaithful to me. He questioned how I got infected, and my marriage ended. We were separated eight months after I was diagnosed...I was afraid, and so I focused on my work... that was my life. I didn't want to take the medicines until I got sick and realized that I was missing my children, tried to get myself and the kids organized, and look for another partner. Then everything was organized, but I lost my job. Without health services I saw myself in a tough situation and became very sick, lost weight, had diarrhea, sweatiness, and lost my hair. It was hard but thanks to God I had the unconditional support of my new husband at the time...
MELINDA, 31 years old

A period of denial occurs before a patient accepts what an HIV diagnosis means to her: the risk of job loss and social rejection by family, friends, and relatives. For many, denial is a familiar coping mechanism: many patients have no experience working through difficult and painful feelings, and so the process of denial continues for a long time (Bisset and Gray 1992), as is evident in Mireya and Melinda's voices in their precontemplation phases. Knowledge and information modify their cognitive domain and their emotions, feelings, and attitudes in response to behavioral change. These are included in the predisposing factors according to the Precede-Proceed Model.

In the third phase of the Stages of Change Model, preparation, a patient intends to take action within a short period of time, and she takes some behavioral steps in the direction of improving her life (understanding her situation as HIV-positive). Realizing that contracting HIV was not her fault and

that it could happen to any woman (beliefs) are significant behavioral modifications. Feeling empowered gives the women the opportunity to take responsibility for their lives and their futures and to be advocates for women in similar circumstances. Acts of advocacy include offering social and moral support to other women and telling them not to feel ashamed, that they, too, can live with dignity and develop self-esteem.

...A myriad of difficulties make life feel burdened, uncomfortable, and all too often desperate. It has always seemed that there is a kind of quiet heroism that comes from meeting these problems and sentiments they prologue, of getting through each day, of living through the long course with grace and spirit and even humour; sick persons and their families understand the courage, even if most others do not....
Arthur Kleinman²⁹

The fourth phase of the Stages of Change Model, maintenance, relates to the modification of behaviors (adoption of healthy behaviors related to diet, sexual practices and ARV treatments).

...I had my daughter (now she is 7 years old) even though I had HIV. We decided to have her; she was healthy because we took all the precautions. After my 7 year old was born, I was pregnant three years later. Another baby girl was born, but as I was not in the SISBEN, they did not do a Cesarean and she was not given the ARV treatment. I did not know of the Sunflower Project yet... it was terrible; she got sicker and sicker, and she died. Since then, we always use condoms. Many things I learned from the Sunflower Project; we learned how to use condoms, and they also taught me my rights and how to fight and claim those rights and how to have recognized my responsibilities and obligations. I know what I can ask from the EPS...
MELINDA

As Melinda's story demonstrates, time was required to heal her suffering over the death of her baby daughter, and education was required to shape her

²⁹ Ibid

future behavior and it seems also to learn about her rights. Thanks to the Sunflower Project, less risky behaviors came to be regularly practiced.

Mireya is an HIV/AIDS activist, and she is currently studying for her BA in Social Psychology. She has been a very active member of the Sunflower Project since 1997. She develops training workshops in schools and universities, and she has represented the project internationally. Also, Mireya feels that things happen for a reason. During her journey with HIV/AIDS, she has sought education and empowerment, and now she feels that the disease has brought opportunities and success to her life. When she shares her unique experience with other women, she provides them with a model for alternative ways to respond and to deal with their own circumstances.

The Social Learning Theory, or Bandura's Theory, holds that individual behaviors can be modified by observation, imitation and expectations affected by motivational processes such as environment. This is applicable largely in programs addressing youth, but the theory also works well in relation to the Sunflower Project, which is a forum in which women can witness other women experiencing similar phenomena. In this forum, women learn alongside one another better health and positive attitudes, and they are strengthened enough to face and share their own stories.

I have presented some excerpts that pertain to the health promotion theories introduced in Chapter One. In the next part, and as mentioned before, I have chosen to discuss predisposing factors. Most of the stories presented refer to cultural practices, the influence of patriarchal structures, a lack of knowledge

(in this case, the women have seen or heard about HIV/AIDS, but women never felt they were at risk), as Wight mentioned “a more obvious reason for people not to feel vulnerable is that AIDS is still largely associated with marginal, stigmatised groups from whom it is easy for most people to distance themselves³⁰. As well the influence of religious beliefs regarding their sexual practices. However, as Wight said “this perception that one is not personally at risk, has been termed ‘Aids invulnerability’ is explained as resulting from people’s beliefs that they, personally, behave responsibly about their health, in contrast to others who take great risks”.

Excerpts relate to enabling factors that can also be considered as the vulnerability factors in that they illustrate a lack of awareness, a lack of health promotion, and little prevention activity that might have prepared women for a possible positive result and the feelings of disbelief and hopelessness. Amparo’s story typifies the reaction of someone who is unprepared for diagnosis:

...When my partner got sick, they told him that he had to take the test, but he didn't take it... and he was told that we would die from AIDS. It didn't last too long; he died soon. When he was in the hospital he pulled out all the IV needles and everything, so he was sent home... but he used to get up and go outside with a shirt in the middle of the night. He was 50 years old, and wanted to die... After he died, I was diagnosed HIV-positive... I had nobody to talk to; I was alone... Throughout four years I had nobody to talk to...

As I interviewed Amparo she was very distressed; her story is one of disbelief and hopelessness. Amparo is 50 years old, and she has been living

³⁰ Wight, D. (1993) A re-assessment of health education on HIV/AIDS for young heterosexuals in *Health Education Research—Theory & Practice*, Oxford University Press, Vol.8 no.4 pages 473-483

with HIV since 2001, when she was diagnosed. She has a son 26 years of age and a daughter 20 years of age. After her first husband abandoned her some years ago, she met her second partner with whom she lived for three years until he died four years ago. The interview with her took place in my mother's office. Amparo was very scared that someone would see her. When we spoke on the phone before the interview, she agreed to take part in the research, but she asked me to wait for her outside the office. She gave me her physical description and described the clothes (color and type) she would be wearing. She works as seamstress in a factory 45 hours a week, Monday through Friday, with one break of 10 minutes in the morning, 35 minutes for lunch, and 10 minutes in the afternoon. The rest of the time she sits in front of the sewing machine.

...The only support that I have had is the Social Security health staff. After I was diagnosed that was the only place I went to. You don't sleep, you cry all the time. The Psychologist consoles you by saying that HIV is better than cancer or diabetes! I live with my children (son and daughter) but they don't know that I have this.... I haven't told them yet.... I don't want them to suffer... They only have me... if they find out they will die... A month ago, I told my daughter. She is going to the university, and she loves to go out partying; she has lots of male friends... So, I told her, not with the idea that she would understand me but for her... to realize that she has to be careful, and know whom she is going out with... I told her that anybody in the street could have the virus... So far, she has not recovered from the impact.... The other day, she came to me and told me that the worst thing I did to her was tell her that I am HIV-positive, that I had destroyed her life...that it would have been better for me not to tell her... that you have HIV...now I feel that I shouldn't have told her... Her answer was painful, it really hurt me, it gave me too much grief...So, I don't want to tell my son. If he finds out, I think he is going to die...

Amparo did not tell her son about the interview. She said that he is constantly worried about her: he regularly asks for her schedule, and he tries to

be at home whenever she is. As the interview ran over the scheduled time of one hour, she phoned home and told her son that she was accompanying a co-worker to buy something she needed. (Amparo kept checking the time during the whole interview). She worries about her son; he loves going out with women, and she frequently reminds him that he needs to take care of himself and know whom is he going out with. Because of AIDS, she recommends that he use condoms. He consoles her by saying that it was very sad that her partner died and that he understands how she must have felt. Amparo prefers not to talk about that, and when he starts talking about her former partner, she tells him that the conversation is over.

Regarding reinforcing factors or vulnerability factors, excerpts have been included on the topics of discrimination and stigmatization, health care service accessibility, ARV treatments, and social network support from family, friends and project staff. ARV treatment effects and the lack of educational programs (Sexual/HIV/AIDS) are used as variables to better understand the work carried out by the projects and the effects on the lives of women living with HIV/AIDS in Colombia.

...Women with HIV need good, informed, sympathetic doctors, social workers, drugs workers, researchers, lawyers and so on, but these professionals also need us and they need to listen to us and to value what people with HIV have to say, if they want to do their jobs effectively. We need to build up relationships of trust and partnership and co-operation...

Kate Thomson,

Being Positive Working with Women with AIDS, 1992

Women's testimonies underscored the prevalence of discrimination directed toward and the stigmatization experienced by women from their families and health institutions, that is, the EPS, ARS and IPS. Poor communication by doctors and inappropriate treatment or advice do not sensitively solicit the patient's nor the family's stories of illness (Kleinman, 1988). Isabela, a married, 28 year old woman with a seven year old daughter, and a five year old daughter HIV-positive. At the time of this interview she was dealing with painful AIDS symptoms. She was lying down on a rocking chair, tolerating a strong migraine episode that had already lasted three days. Along with her husband and daughters, she lives outside Villavicencio in an unfinished house (cemented floor, brick layered cement walls; half of the roof is finished; half of the kitchen has no roof) built by her husband and herself. The house has an area of approximately 320 square feet, and it is located on an unpaved and steep street. She was very emotional at the time of the interview due to a crisis of denial - she wished the whole process would end soon as she was tired of all the suffering she had endured. Her husband was diagnosed HIV-positive first. Diagnosis tests were done on Isabela after the baby was born. Isabela explained how hard it was to administer the medicines to her daughter (5 years old) and the struggles she has with her colds. It was a heart-wrenching interview. Her husband was just recovering from a serious toxoplasmosis that had almost completely immobilized him for several weeks until Catalina, the representative from the community organization, visited them and got him some support so he could move his limbs and get out of

bed. As her husband did not have any health insurance, Isabela was the only one sustaining her household. Isabela's family knows about her and her husband's diagnoses, and supports them. Her father moved in with them to help but as of late, he has also been sick.

...My husband is sick, and he hasn't been working regularly... We didn't have health care coverage... when my husband got sick... somebody offered to put him in the system as an employee of a company... but this person sold us forged documents... When we went looking for health ... we were told that the documents were false, and they didn't treat us. That was two years ago. Then we met Catalina from the organization and she helped us get our documents and put forward a TUTELA to access treatment... I'm the worker and my husband is my dependant. He just had toxoplasmosis, and was paralyzed completely... Catalina helped him with obtaining physiotherapy...that helped him get up from bed... But yesterday he fell down and broke his nose ... now we have to find a walker so that he can move around.

When I feel fine and we have some money, I get up and prepare "agua de panela" ... otherwise when I'm sick my 7 year old daughter gets up, boils water, adds brown sugar (AGUA DE PANELA) and with a piece of bread this is the food of the day. Before I got sick ... I worked in a store...washed clothes at nights ... I used to crochet and do paintings for sale ... I was very active and we needed to have a home. However, I don't have the strength anymore... I clean when I can... or do it slowly ... (she cries hard) I don't want this anymore; I'm tired ... I only pray to God that this will end soon. (She apologizes.) I don't like anyone to see me like this. (Isabela was coughing repeatedly.) Today (actual time 11:45) we haven't eaten anything... (Sobbing) ... because we have nothing to eat... besides my dad came to stay with us... and help...but he got the cold and fever.... I just can't stand this anymore.... (Crying) ... today... we have to beg for food to the neighbors... and we already owe \$200.000 ... to the convenient store three blocks away... but we have no money to pay...

ISABELA

Isabella's story illustrates a universal aspect of social vulnerability of those powerless in society, where not only the symptoms of the illness but the economic and social pressures increase their human suffering, creating distress and despair. This corroborating that to fight HIV/AIDS, health promotion and

prevention involving behaviors change (condom use), and availability of treatment are not enough when basic needs are not met and there is not even food in the table.

Piedad is 29 years old; she is married to a soldier. She has a 10 year old daughter and a 2 year old son. Her husband lives in the brigade where he was infected. But her oldest daughter does not know anything about her father's sickness; they have told her that he has leukemia so that she would not say anything at school and so that she would not be discriminated against.

...After my husband was diagnosed in the brigade, I received a phone call from the nurse and she told me that she was going to tell me something... she started saying that this did not mean that I was dying but ... she tried to alert me and told me that my husband's HIV test was positive and that I should have the test. She didn't give me any more information but ordered the test for the next day.... I didn't receive any more information after that. Catalina is the one who gets her the ARV treatment.... Right now... we're in a terrible economic situation; we don't have any income, and we don't have anything to eat. As my husband is not in the brigade anymore, he is not receiving any money.... the pension will start in three months.... so in the meantime, we work in whatever he can find...

As a soldier, Piedad's husband had health coverage, but Piedad and her children were not covered under his plan. Catalina (from the organization) advised Piedad in filling out, documenting and presenting the tutela (legal process to fight human rights abuses). The army accepted that her husband left the corps and granted him a disability pension so that he might receive HIV/AIDS coverage. However, out of the brigade, he has no income, and the pension process takes approximately six months before payments begin. He works in security whenever the company needs him. However, the security company gives him only short shifts that are not regular, which is to say

that health coverage is not included. Piedad and her husband do not want to fight with the army, and so they are waiting for the pension payments to begin and to request health coverage for Piedad. She has had several complications, such as toxoplasmosis, with nausea and diarrhea; she was in the hospital when Catalina met her. At the time, her weight was 30 kilos (roughly 80 lbs). Four months prior to this interview took place Piedad weighed 40 kilos. She showed emotional distress and cried during the interview. This story is another painful example of the consequences of human suffering caused by a combination of economic and social factors

Discrimination and Stigmatization

...Stigma often carries a religious significance – the afflicted person is viewed as sinful or evil-or a moral connotation of weakness and dishonour.

Arthur Kleinman³¹

HIV/AIDS is strongly associated with stigma, threatening women's status, promoting isolation, and erecting barriers to group interaction by damaging women's sense of identity. Incidences of stigma range from casual observations to direct comments about the respondents' HIV status (Berger, 2004). Therefore, discrimination against infected women and those perceived to be at high risk undermines the basic human rights of certain groups of people in society (Hope, 1999). Since the 1980s, when AIDS appeared in Colombia, hospital staff has received training, but response shows that more training is required. There are, for instance, physicians who refuse to do physical evaluations for their HIV/AIDS

patients, making patients feel rejected. Verbal rejection is also common: HIV/AIDS patients are often asked to leave health care areas for “regular” patients. Clinical histories of HIV-positive patients are marked in red ink with “PATIENT WITH HIV,” leading nurses to act discriminatingly. Health care services for HIV/AIDS patients within the subsidized regime are rendered in an old building with cracked walls and missing lights that strongly gesture toward societal isolation and abandonment. Still, women reported that staff is good and considerate, but that they fear turnover in medical staff. Some of the participants related a change in medical practitioner to starting something new and unknown. A new doctor means the need to build a new relationship.

... Well, let me tell you what I faced when I was diagnosed... The doctor who asked me to donate blood in the hospital was the director. He felt he didn't have enough training to hand me the test results, but he told the nurse... who told other hospital staff... Everyone in the hospital knew before I was informed... The doctor who finally told me has supported me all the way... It was a traumatic episode, because I got a cold and some lab tests were done, including a urine test... The cleaner had just cleaned the counter and left it wet. However, when I put the container over the counter, the lab technician screamed at me that the container was wet, that I should be more careful as this could infect people... Saturdays, when I was volunteering at the hospital my son was left in the hospital daycare. The director of the hospital also left his son at the daycare; he was my son's godfather... well the following Saturday when I was diagnosed, the doctor decided not to take his son anymore... It was very hard for me... I knew something was going on. I started feeling a heavy emotional weight... you feel as if you have a stamp in your forehead... You feel different... as if everyone were watching you... At home, when I went to the washroom I made sure I cleaned it perfectly; I didn't sleep with my son anymore... I was afraid he would be infected... Later on, some months after, my boyfriend and I decided to live together... but I didn't want to have sex; I was scared because he was negative... Today things sound different... it sounds

³¹ Kleinman, A., (1988) *Illness Narratives: Suffering, Healing, and the Human Condition*. New York. Basic Books, Inc., Publishers

very light... One thing is living it and it is totally different just telling the story. There is social weight, plus the weight of your own imagination

MIREYA

...When I go to the hospital for tests that the doctor has ordered and I don't have the money to pay for them, the clerk always argues that these people with HIV/AIDS never have the money, that it is a very small amount... there are no millions to pay...that I have to come back when I am ready and have the money with me...

PIEDAD

Social Support

When I asked about their social support, the women's responses were mixed. Immediately after they were diagnosed the women kept their results secret. This is not productive, as Hope, citing Martin (1996), argues that relatives, friends and the community at large have the capacity to change attitudes toward HIV/AIDS victims. Social support is necessary if the emotional side effects of an HIV/AIDS diagnosis are to be lessened. This support can be offered in different ways: child care, cooking, company, self-esteem, education, social interaction, and positive nurturing permit HIV/AIDS patients to recover confidence in themselves and to have a more positive and productive life.

...At the beginning, I didn't tell my family, not even my mom. I told nobody; I was ashamed and I didn't know how to tell them. I was afraid that my mom would ask me what I had done... who I thought I was... because I had little information. The first person I told was my boyfriend... so he would take the test, and then a friend - she was my best friend in my town... The real support came from the health secretariat, the doctor who gave me the test results and the hospital epidemiologist... Then some months after, I told my sister. Two years later, I told my mom... Let's say that at the time I was diagnosed HIV-positive the doctor was willing to help, as were the epidemiologist and my boyfriend; XXX, he was my strongest support, and from the perspective of spirituality faith in God, gave me hope... I had support from my boyfriend, later my husband... He never discriminated me, never made reference to the virus, but I had to live

with other things. He was unstable, had more women, and he knew I found out...I never saw him, but I knew it and I didn't say anything. I felt it was justified. My self-esteem was very fragile and poor that I thought that was the reason why he accepted me. Now I think that it was really sad to think that way because there is a huge process to understand... The person that loves me has to love me for who I am, and how I am.... Otherwise, what happens to the women with cancer? Leukemia? Or to the ones who have lost a leg, are crippled, so many things...This is why I say it is a very painful and lengthy process. By looking at my friends, I can see that they are having sexual relations, but they try to protect their partners by not telling them anything. They are afraid of pain... they think that the diagnostic weighs more than their self-esteem and is more important than having their partners love them for who they are ...and that is very difficult, but unfortunately, we have to go through all this

MIREYA

A powerful reflection!

...My family doesn't know anything, only my mom... she didn't know what to do... they gave her information, and now she understands better.... From my husband's family nobody knows, and I hope they'll never find out... I really hope that his family never finds out... Only my mom and that is enough... Here, in the neighborhood, nobody knows. Catalina comes but nobody knows who she is... Her visits are short...she never stays long...Besides, Catalina's moral and social support. My only support at home is my oldest son; he is my right hand, when I feel sick and I can't get up from bed... he takes care of the girls... and cooks for all of us... OMAIRA

...My support is my mom and brothers... fortunately; they have not turned their backs on me. My family lives very close. My mom lives 10 minutes from here, my sister just three blocks away, but my mom is now worried about my grandmother, who is old and very sick. My sister comes by... frequently.... and cheers me up... She tells me that things are to change and everything is going to be fine again... My husband's family lives in a city in the North Coast. But one of his brothers came here two months ago...he came to help us...He works here... PIEDAD ...

These women words show that even though they do not disclose their situation to everybody it is important for them to feel supported but not to be

judged and questioned for something in most cases they have not been responsible, they have trust their partners and follow their cultural beliefs.

Spirituality is another form of psychological support. Based on their testimonies, all of the women interviewed have religious beliefs; they pray for the strength to continue their journeys and to be able to support their children. As Kleinman suggests, in "traditional societies, shared moral and religious perspectives on the experience of life crises anchor anxieties in established social institutions of control, binding thread in webs of ultimate meaning"³².

Mireya reported that at the time of her diagnosis, the only church she knew was the Catholic Church. Still, she was not familiar with priests or nuns but rather with prayers; she knew and relied only on prayer. She asked God for strength and support.

Piedad prayed to God every day, and as often as she could, and probably more when she felt tired. Sometimes, she said, she blamed God for what she was going through. She said she knew that she was putting too much pressure on him and that she should not be doing it, but it was very hard for her. She only asked God to give her the chance to live and to be able to take care of her children.

Yolanda said that she did not go to church during the day but rather she went in the evening, when she was coming home. She read the Bible after

everyone was asleep. However, when she came home early or got up early, she would go to the Trinitarian Church to hear something that would give her hope.

Education

Education is without a doubt the most important component of health promotion. As many of the interviewees reported, had they known more about HIV/AIDS and the risks involved, they would probably not have become pregnant. Still, not all women infected by heterosexual contact and now living with HIV/AIDS can accept that their husbands had sex with other men. They believe that a female street worker infected them. As Paternostro comments in her book, Latin American men have sporadic sexual encounters with men without considering themselves homosexual. These affairs are not shared with their wives or permanent partners, as it is not considered appropriate to inform the women who carry their names and their children.

Marcela is 51 years old. Some time after her separation from her first husband, she found a good man whom she dated and then moved in with. He was the love of her life; however, he infected her, and he died three years ago. She still loves him, and she continues to wear black to honour the love she felt for him.

More education, love within the family and solidarity are needed. I think that my family would have been different with more education and family support. I did not know how to teach my children; I taught them the way I learned, through verbal abuse and physical abuse. I never had a sense of the best way to do things, or how to dialogue, and I never showed them love. I did not have a happy childhood; all I remember is I worked as a maid from the time I was seven years

old to support our household, and my father was always drunk or with prostitutes. I got married to escape from home, looking for a better life, but he was like me: no education. He hit me during our honeymoon. I stayed with him for 23 years; he never talked or guided our son. He was drunk all the time, sleeping, abusing them verbally or physically. But he put his hands over my daughter and that was wrong, so I was protecting her all the time, or who else would? He tried to touch her several times, but I did not allow it. Education would prevent discrimination and would have people understand that this could happen to anybody

MARCELA

Amparo mentioned that she wished she had had more knowledge about HIV/AIDS so that she could have better managed her sexual life and been able to avoid HIV or at least been aware of the risk she was taking with her partner, whom she trusted completely.

...There is a need for more education, through conferences targeting both the HIV-affected and the non-HIV-infected populations. Published information, or print materials, is also important as they complement information offered in training sessions. Also, The Detectable Group Magazine (publication with national distribution produced by the Detectable group a NGO addressing topics related to HIV, legal aspects, education and support) should have a broader distribution. The Sunflower Project distributes materials during training sessions, which are very useful for people to keep at home and refer to whenever it may be required. These should be distributed door-to-door. Information should be presented in clear, simple language so as to be accessible to a large number of people. For some time, I volunteered at the Sunflower Project and had to disclose my personal history to other women: this put a real face to HIV.... I think this is key...

*NELLY, at 31 years of age, has two years living with HIV.
She has three daughters, ages 2, 6, and 8.*

Also, women considered important the training they received on economically sustainable initiatives that would give them the opportunity to earn an income, which, in turn, would allow them to look after their households.

Mireya always looks for opportunities to share her experience with others. She was a mother very early in life, and she thinks that hearing about her experience can be useful to other people. For example, the topic of children is one that she likes to speak about. She loves her son, but she thinks that she could have waited longer before having children, and she could have thought more of the responsibilities attached to childbearing.

...As a woman you have to be ready to take care of the children with or without a partner; even though you might be married it doesn't warrant you anything. We have to tell girls to wait, get educated first... because the more you are informed; your self-esteem grows, without any cultural and economic bias. The use is not material or physical, sometimes people are confused. Self-esteem and other things come within the family... I think that a woman who loves herself is not going to hurt herself. She says, "yes, I did it for curiosity and lack of information".MIREYA

... I would like to have more information about HIV/AIDS ... I think it is important to know about this disease. Also, If it were possible for me to get out with the children... I would like to paint... take-painting classes... OMAIRA.

...I don't have much information, or education... .I would like to study or work to help my husband. I wish we could have some money to have our own business, like a convenience store...I'm looking forward to when we receive the money from the brigade. We could do something, or do something from home...PIEDAD

... I wish I could have had information about AIDS when I was pregnant and that the test would have been compulsory because if I would have done it, my daughter would have been born healthy... At the hospital I met other moms with HIV-positive babies, but there was one friend who had the same problem but her baby was born healthy. Also, there should be more information on complications and risks of other things that could happen.... YOLANDA

Women living with HIV/AIDS face inequality and powerlessness. They are challenged by and subject to discrimination and stigmatization. Therefore, empowerment is needed to permit women living with HIV to manage their

situations and to help those not living with HIV to prevent infection. The testimonies presented in the last three pages speak of how these women were self-empowered by actively engaged with discrimination and stigmatization and have turned to educate others, participate and be self aware of their strength.

...Empowerment begins when women change their ideas about the causes of their powerlessness; when they recognize the systemic forces that oppress them, and when they act to change the conditions of their lives....

Ann Bookman and Sandra Morgen, 1988

Women expressed their gratitude toward the Sunflower Project's activities and toward all the women involved in the network. The women I interviewed feel that they were offered support when it was most needed in their lives. They feel that they have been empowered and that they are now helping the community on multiple levels. A remarkable outcome, perhaps most importantly, they feel that they are able to go on with their lives and their families. Empowerment practices employ generalist problem-solving models with a focus on issues of power and strengths in transactions, at the micro, mezzo and macro levels (Mancoske, R & Smith, and J.D. 2004). Therefore, women benefit at all levels, as does the community as a whole.

Florina is, at 27 years of age, an AIDS widow who has also buried two babies who died from AIDS. She has been living with HIV for 5 years.

...I took part in a second training session for women living with HIV/AIDS organized by the Liga Colombiana de Lucha Contra el Sida, when I realized that women's needs are different than men's needs and that all the work being done at the time addressed MSM and very little work addressed women. Women have been affected more as there is no based research on women; initially ARV treatments were designed for men. I felt that I wanted to do

something, being a woman living with HIV, especially after I lost my children and my husband to AIDS. At this point I'm about to graduate as a Social Psychologist. I need to empower myself and take charge of my own life. It is only I, and nobody will do it for me, what I want to do. This has been my internal strength...FLORINA

... I think that when doing health promotion in sexual and reproductive health, we have to teach the kids from the time they are in kindergarten... You don't have to talk about condoms or sexual relations, which is for different levels, but just teach them that their bodies are sacred. We have to work on their self-esteem, and provide information.... The world is like a wheel of fortune, with risks, but they need to be prepared to respond to those risks and not try to live their lives in a day... There is something to learn at each age. I'm separated from my husband; it was a very dysfunctional relationship... He is a good guy - he supported me - but I felt there was too much weight from the past, remembering his infidelities, more and more, until one day when he lost his job... then, I met the real XXX. You know when both of us were working, the short time we shared was wonderful, but [being with my husband] full time was a shock, especially with my son. Well he has grown, and he is not a little kid anymore, that was used to seeing his mom cry all the time. When he turned 8 he started asking me questions... what was going on between us, why were people calling saying things to me... Then, he started confronting him, and defending me... He made me realize that I shouldn't be staying in this relationship any longer... I made up my mind, and we are separated. We're friends, even though he says he has changed, that he wants to come back...and that he is keeping hope that maybe someday we will be together again... But for me it is over, my feelings have changed...I have gratitude for him as someone who gave great support...now, I'm thinking for myself and for him... I have to forget, well not forget... forgive and remember the good things we had together.

Now, I feel that I'm a normal person... and as such everybody has to accept me... I had looked at my life with him and that was something that wasn't worth it for me; it was really affecting me. I think that I have tried my best in fighting for things but if there is too much trouble... I spent too much time acting like I was under anæsthetic, justifying everything by the support he gave me. Yes it was my son who took the anæsthetic from my life... now in my life there is only space for my son and for myself. Sometimes you put a mask to things thinking that they are love, but they are not. That is what happened with XXXX.

MIREYA

Mireya's life changed when she decided to speak up and publicize her story. When she announced that she was HIV-positive, she felt that it was time the public see a face attached to HIV. She was confident that she had the support of other women. In Mireya, Florina, Nelly, Delia, and Melinda's stories, and as Gilkes (1994) has argued, women built professional careers by means of community work, fighting for women's rights to education and empowerment and fighting against discrimination.

In conclusion, women interviewed are willing to continue supporting other women by means of the Sunflower Project, as they believe that maintaining contact with the network will strengthen both themselves and other women. Also, they look forward to having a safe place where they can meet and share stories and struggles with their peers. Most importantly, the Project offers them the possibility of building an economically sustainable project from which all of the women can benefit.

Table 3 Women interviewed in the two selected sites

<i>Participant women and family Characteristics</i>											
NAME	LOCATION	AGE	YEARS WITH HIV/AIDS	PARTNER	CHILDREN		AGES		BORN+	ALIVE OR DEAD	NEGATIVE
					< 18	> 18	F	M			
Mireya	Bogotá	28	9	No	1			11	No	A	Yes
Florina	Bogotá	27	5	Yes	2		4m	4m	*	D	
Nelly	Villavicencio	31	2	Yes	3		8, 6 2		No No Yes	A A A	Yes
Piedad	Villavicencio	29	1.5	Yes	2		9.5	2	No	A	Yes
Isabela	Villavicencio	28	4.5	Yes	2		7 4.5		Yes	A A	Yes
Omaira	Villavicencio	24	1.5	Yes	3		3 1.5	10	No No Yes	A A A	Yes
Yolanda	Villavicencio	28	4.5	Yes	3		13 12 4.5		No No Yes	A A A	Yes Yes
Carolina	Villavicencio	27	2	Yes	4		6 5	4 2	No No No Yes	A A A A	Yes Yes Yes
Delia	Bogotá	46	4	No	2		24 7	13	No No No	A A A	Yes Yes Yes
Melinda	Bogotá	31	10	Yes	5		6 3m	12 11 10	No No No No *	A A A A D	Yes Yes Yes Yes
Amparo	Bogotá	52	6	No	2		20	26	No No	A A	Yes Yes
Diana	Bogotá	55	10	Yes	1		25		No	A	Yes
Camila	Bogotá	61	12	No	2		28	30	No No	A A	Yes Yes
Marcela	Bogotá	51	4	No			31	34 29	No No No	A A A	Yes Yes Yes

*Babies tested after suffering pneumonia in hospital

Synthesis of Findings, Conclusions, and Implications for Future Research

...We need to build on these successes, learn from our experiences, and determine what has worked and what is missing in order to respond with added effect in the future"...
Calderon, 1997

Responses from interviewees have provided me with sufficient information to conclude that the - Sunflower Project and the MTCT Project - have successfully achieved their goals. I have also determined, based on the Precede-Proceed Model, that there is a need on multiple levels for more information, education, and awareness strategies to complement the work carried out by the EPS, IPS and ARS. I reviewed documents provided by each project to learn about their objectives and conducted interviews with project staff that confirmed that the projects have met these objectives. I have learned, consequently, more about what these organizations envision for the future. As government communication strategies have, for the most part, been temporary, and as the "Adam Syndrome" – the need for staff to relearn and redo when there is a government turnover - has been common, stability is incredibly important to both projects. Interviews with international organization staff reaffirm both projects' successes and reiterate that awareness and education are needed to reduce future infections.

Results show feelings of shame not for having HIV/AIDS but for the stigma women deal with after they are diagnosed. Initially from members of their own family or their partner's family, health care services staff. Stigma is extended to

their children having to keep silence to avoid children's rejection and discrimination or having to be force to leave school. Also, women isolate themselves to avoid questions and answers. Empowerment, on the other hand, allows women living with HIV/AIDS to face their struggles given them the opportunity to assume responsibility for their lives and futures. Majority of women living with HIV/AIDS have learned from adversity and become advocates for other women. The creation of social network allows them to find not only social and psychological support but also friendship and obtain legal advice whenever needed during their journey with HIV/AIDS and in the search for treatment.

Women responses on what they heard and knew before they were diagnosed, along with their cultural understanding and religious beliefs showed that most of the information broadcasted to them was seen as a risk for population with risk behaviors never related to having one permanent partner, being faithful, and respect their partner. This is conducive to the need for more education and information for women on risky behaviors awareness and for women with HIV/AIDS to prevent complications related to AIDS and to prevent new infections in other women. Implementation of sexual and reproductive education permits women to take action in order to protect their rights and lives. Sexual education and HIV/AIDS awareness should include self-esteem; self-respect and respect for others – teachings that would target discrimination, stigmatization and homophobia - are not included in school curriculum.

It was very harsh for me to interview a woman that at time the interview was made late morning the whole family have not eaten since the day before and with no food available to eat that day. At the same time, hearing the struggles of other women in similar situation determined that, there is a need for skills training in order to develop economic subsistence projects that allow women to earn an income, to improve their lives, to support their families, and to overcome poverty. The majority of infected women are single mothers, who have lost their partners, or who have had others leave them behind.

...The goal to fight HIV/AIDS by NGOs is unachievable if there are no government policies, no national leadership and insufficient resources along with strong social and cultural values of the population to fight stigmatization and discrimination...

A. Garcia Abreu³³

It was shocking to me to learn about the infrastructure of the Ministry of Social Protection team working on HIV/AIDS: a team of only forty people is responsible for all transmissible and chronic diseases in a country with a population of almost 45 million people and that the health reform, took away the leadership for the HIV/AIDS epidemic and that HIV/AIDS budget was integrated with the budget for all transmissible diseases.

The path Colombia has followed to implement the legal framework treating HIV/AIDS and the human rights of PLWHA is very interesting. I am including in the appendices the most relevant legislation regarding the rights of people living

³³ Garcia Abreu, A. Moguer, I and Cowgill, K., (2003) *HIV/AIDS in Latin American Countries –The Challenges Ahead*. The World Bank

with HIV/AIDS: Decree 1543/1997 Assign rights and obligations of people with HIV/AIDS and Promotion and Prevention, care and infection control of HIV/AIDS and Resolution 412 regulated the promotion and prevention responsibilities of the EPS regarding HIV/AIDS. However, as the EPS have not complied with the law, the Ministry of Social Protection approved Law 972 determined clarifications to Law 100 that reinforce the responsibility of the EPS and IPS in the health promotion delineated by Law 100 about availability of services and health education for all preventable diseases. The new National Policy on Sexual and Reproductive Health adopted in 2003 looks promising as it focuses on gender issues and the need to involve both genders in educational processes. The government has made a step toward the implementation of the National HIV/AIDS Plan with the creation of the center for coordination, which monitors and evaluates the state of Colombia's health care according to the framework defined in the National Policy. However, it is important that the current Ministry of Social Protection increase the staff of forty people responsible for all transmissible and chronic diseases. It is also crucial that the Ministry recover the leadership of the National HIV/AIDS Program, as the goal to fight HIV/AIDS is in vain if there are no government policies, national leadership or resources to support the country's fight against stigmatization and discrimination (Garcia Abreu, 2003).

There are still flaws in the system, and there is a definitive need for better quality control of antiretroviral medicines provided by EPS and ARS as Interviewees expressed. This control must exist to ensure the quality and

availability of treatments and to prevent the black market from firmly taking root. Leftover treatments are unusable. The quality of essential medicines has been questioned, and patients argue that as the EPS are responsible for buying the medicines, they are concerned only with the highest profit margin, not with the quality of treatment. As it stands, the EPS and IPS are not complying with the law, and there are no health promotion and prevention activities. The services within health care institutions I quote Zerubel (1981) quoted by Kleinman, "that the organization of time in the hospital, is order to fit the work hours and needs of hospital staff more than the needs of patients and their families".

I recognized my biases towards this research because of my personal working experience, knowledge of the Ministry of Health prior to the reform, family influence towards helping and supporting the community since a very young age and my understanding of the social and economic standards of the country. These biases made more sensitive to understand the interviewed women needs to overcome the lack of treatments, their difficulties approaching the health personnel and how hard it is for them to defeat sensitivity in relation to their social surroundings and avoid human interaction and disclose their situation. That is why questions were semi-structured and open ended so that women can freely express themselves without judgment or criticism.

According to the women themselves, participation in these programs have been crucial in their survival and for the creation of emotional, social and economic networks. Although, these projects have been successful, the MTCT

project is service oriented and women are linked to this project temporarily while during pregnancy or during controls at birth and six months after. The Sunflower Project as a grassroots' initiative offered support to women by the means of health promotion, education, as social support, active women participation, empowerment and the possibility of building an economically sustainable business from which women can benefit and have an income that will improve their lives and their families. Empowerment has allowed women to learn about their rights, to engage actively with discrimination and stigmatization and have turned to educate others and how participation and self-awareness have strengthened themselves and feel they are able to go on with their lives and their families.

Community work has emphasized the legal support required by those with not health accessed. Furthermore, community-building work needs to be expanded: health education activities (advocacy, education, self-care, and social action) involving health care institutions are essential to community health. A partnership between government and community should include women living with HIV/AIDS, their families, NGOs, and municipal and departmental health secretariats is tantamount to the development of awareness, responsibility, and, finally, effective prevention strategies. HIV/AIDS and other sexual diseases projects should focus on gender, vulnerability, community awareness, education, and empowerment.

I look forward to seeing self-respect and self-esteem built to have an adequate sexual, reproductive education where people are able to make individual decisions and avoid risky behaviors associated with HIV/AIDS that unfold taboos, making people compassionate to fight discrimination, avoid stigmatization, and homophobia might be eradicated. This type of education should be included in school curriculum at all levels alongside education on condom use and safe sexual behaviors. Educated, empowered women have a better understanding of women's rights and of the ways they can improve their socio-economic status and their health, both of which contribute to reducing their vulnerability to infections.

Implications for future research

This research is important because it took a different perspective towards HIV/AIDS by interviewing women infected mostly through sexual encounters that have affected children by the prenatal transmission and recovered experiences and perceptions towards health communication through interactions with health care staff. Their understandings of reproductive and sexual education and their rights have these women received and how they perceived their actual status and how much more education is needed to prevent future infections. The importance of social support in process of empowerment and the improvement of women's lives and strong network of legal and social support that confronting AIDS have brought to these women. Also, provide a compilation of community groups and their activities that would be subject of more research to compare the

type of services offered to determinate cooperative work within organizations or duplication of efforts.

There is need for national institutions from the Social and Health sectors to work in partnership with community groups in health promotion, prevention benefiting of all population to avoid risky behaviors and new infections. It is important to include persons living with HIV/AIDS in working with all population.

The relationships between the EPS, ARS and community groups, as well as education and prevention activities and if they are fulfilling the population needs. Evaluate women empowerment and how women within different age groups perceive empowerment and how are they practicing their reproduction rights.

The Sunflower Project requires more support with creation of the database and collecting the appropriate data for input. Once the MTCT is passed to the government a follow up surveys of services offerings should be carried to out to assure the project is still successful and quality persists. I suggest to contact the UNAIDS advisor, for an overview of the national situations and existing research involving government institutions or community groups. Even though, Colombian Institutions may be interested in participating in research sometimes they are not easy to approach especially at the central level. Therefore, contact should be made well in advance as staff mobility can delay the process. If possible obtain written confirmation of appointments or meetings prior arriving in Colombia. Community groups are more open to foreigners however, prior contact is important.

As a qualitative study, policy was examined for relevance but not deep document analysis or comparison with other legislation was done. However, I am convince that responses presented here cannot be of use by the Ministry of Social Protection to understand the life of those living with HIV/AIDS and how the changes since the 1990s have been affected or have benefited them and what the real situation with treatment availability and the legal processes they have gone through to access health services. Besides, as Kleinman³⁴ stated “the bureaucratization of care arguably has worsened the problems experienced by the chronically ill in negotiating health care, as bureaucratic efficiency becomes the enemy of high quality care”. Furthermore, more research for economic alternatives for women living with HIV/AIDS.

At the international level, a policy comparison between Colombia and other countries where the epidemic is concentrated would be interesting to make. Also to compare the situation about availability, distribution and access to ARV treatments with other countries to determine if standards in place are working or if there is some ways of improvement.

Recommendations

Immediate Actions to Be Taken By the Health Sector

- ✓ Retraining health services staff to avoid discrimination and stigmatization.

³⁴ Kleinman, A. (1988) *The Illness Narratives*, p.264

- ✓ Determining legal sanctions to health staff violating human rights or committing acts of discrimination and stigmatization such as:
 - Denial of services and lack of complete treatments to people living with HIV/AIDS.
 - Delaying appointments and control tests at any level in any public or private health institution.
 - Treating associated infections in HIV/AIDS patients in all health centers without isolating them to one old deteriorated building and to STOP the use of the red ink seal “PATIENT WITH HIV” in the first page of patients’ medical record.

- ✓ Establish fines to EPS that are not complying with the law in carrying out health promotion and prevention activities for insurers through health communication strategies and targeting issues pertinent to all populations.

...Working together and forming new alliances offers us the chance to look at old problems from different perspectives, to ask new solutions. Just as the AIDS pandemic has served to highlight many pre-existing inequalities in our societies, so through our individual and collective responses we can either challenge or perpetuate them. So whatever we're doing, whether it's planning or providing services, support or information, whether from a personal or professional perspective, it is all of our responsibility to get it right....

*Kate Thomson, Being Positive
Working with Women with AIDS, 1992*

Although the number of community groups presented in Chapter Two might seem to represent sufficient support for people living with HIV/AIDS, especially for women, NGOs are dissolved just as quickly as they are created.

Internal misunderstandings, discrepancies in interests and lack of resources make their work unsustainable. Rivalry and power struggles incite them to withhold information that could be useful to others. Selfish attitudes do not benefit them or the people receiving their services.

However, the work they do is important, especially the legal support they provide to those without access to health care. Social support was additionally recognized by the women to be one of the most valuable services received. The women manifested a desire for more frequent contact; they also expressed the desire to have a common place to meet. My view on HIV/AIDS and other sexual diseases prevention projects is that they should be gender focused. They should take into consideration women's vulnerability, for as long as women participate in heterosexual relationships in patriarchal societies, they are subject to the decisions of their husbands or partners in relation to condoms, safe sex, and even HIV/AIDS.

More prevention and education are needed to modify cultural beliefs, attitudes and risky behaviors. Women's empowerment emphasizing self-esteem, women's rights, and negotiation skills (particularly when it comes to sexual practices) needs to be added to education programs. Due to the high risk of infection from husbands or partners engaging in extra-marital sexual activity, a shift must occur in the cultural belief that males assert their masculinity through sex. Therefore, there is need to devote more effort towards the predisposing factors, enabling factors and reinforcing factors. They will, however, have to be

reviewed from time to time to maintain positive and successful strategies of health promotion and health prevention.

Sunflower Project

As the Sunflower Project is the only woman to woman project working at a national level on women's HIV/AIDS prevention. Still, there are deficiencies in the program. For the moment, there is a need for the creation of a database including all of the women served by the project in order for follow-up work to be carried out. Once the new office space is open, more leaders will be trained and will continue to work on prevention at all levels. Workshops and training efforts have been significant but not sufficient to reach the entire female population. Another planned activity for the network is support for the Mother-to-Child-Transmission Project, to follow up on their successes in the hope of a brighter future. The establishment and sustainability of a 1-800 number to offer immediate support for women would be greatly beneficial not only to the affected population but to the other searching information about HIV/AIDS, social support and existing services.

Mother-to-Child-Transmission

The Mother-to-Child-Transmission Project, has been a successful initiative, and thanks to the European Union, funding coverage was extended. By mid-2006, the project will be incorporated into the Reproductive Health Regular Program within national health strategies. However, once in the hands

of the Ministry and the health secretariats, it is important that this program be maintained. Funds should be allocated for its continuity, and it should be a permanent activity within the reproductive health program.

Final Word

It was a great honour for me to meet these wonderful women, who brightened and clarified my knowledge about women living with HIV/AIDS. As Juan Carlos Riascos asserts in his book³⁵, 'Ser positivo,' [being positive], teaches humanity the grace to learn the extent of the pandemic as well as the desire to help others accept and overcome life's challenges.

I hope that this compilation of women's voices and testimonies will contribute to a better understanding of women's strength and values and that all of us will be able to dedicate at least a small part of our lives to fighting for quality of life and hope around the globe.

³⁵ Riascos, J.C. (2002) *En el Laberinto de la Esperanza*, Editorial Norma, Bogotá.

Appendices

Appendix One– Consent Form

SIMON FRASER UNIVERSITY

Informed Consent By Participants In a Research Study

The University and those conducting this research study subscribe to the ethical conduct of research and to the protection at all times of the interests, comfort, and safety of participants. This research is being conducted under permission of the Simon Fraser Research Ethics Board. The chief concern of the Board is for the health, safety and psychological well-being of research participants.

Should you wish to obtain information about your rights as a participant in research, or about the responsibilities of researchers, or if you have any questions, concerns or complaints about the manner in which you were treated in this study, please contact the Director, Office of Research Ethics by email at hweinber@sfu.ca or phone at 604-268-6593.

Your signature on this form will signify that you have received a document which describes the procedures, possible risks, and benefits of this research study, that you have received an adequate opportunity to consider the information in the documents describing the study, and that you voluntarily agree to participate in the study.

Any information that is obtained during this study will be kept confidential to the full extent permitted by the law. Knowledge of your identity is not required. You will not be required to write your name or any other identifying information on research materials. Materials will be maintained in a secure location. Having been asked to participate in the research study named above, I certify that I have read the procedures specified in the Study Information Document describing the study. I understand the procedures to be used in this study and the personal risks to me in taking part in the study.

I have been informed that I may refuse to participate in this project and that if I do refuse to participate in this project that there will be no repercussions for such a refusal.

I have been informed that research material (answers to questions I have been asked and, in the event that I have consented to have photographs or videotapes taken of me, any photographs or videotapes taken of me) will be kept confidential by Ana Maria Bustamante and will be used only for this study and may be used to communicate results to scholarly audiences,

unless I indicate to the researcher after being photographed or videotaped that I do not want images of me used for the purposes of communication of research results.

I understand that I may withdraw my participation at any time.

I also understand that I may register any complaint with the Director of the Office of Research Ethics or Dr. Gerardo Otero, Director of the Latin American Programme at 8888 University Way, Simon Fraser University, Burnaby, British Columbia, V5A 1S6, Canada.

I may obtain copies of the results of this study, upon its completion by contacting:
Ana Maria Bustamante, MA SFU 604 983-0635

I have been informed that the research will be confidential.

I understand that my supervisor or employer may require me to obtain his or her permission prior to my participation in a study of this kind.

I understand the risks and contributions of my participation in this study and agree to participate:

Signature

Date

Name of participant

Appendix Two – Consent Form in Spanish

Experiencias de Mujeres Viviendo con VIH/SIDA en Colombia

El Propósito de este estudio tiene dos partes. El primer propósito es entender las experiencias de mujeres viviendo con VIH/SIDA. El segundo es entender los beneficios que estas mujeres han ganado por formar parte de programas educativos en salud.

Procedimiento del Estudio: Su participación en este estudio será en tres formas: a) una aceptar una entrevista de 90 minutos sobre su experiencia con VIH y el programa de Salud; b) La Sra. Bustamante le solicitara acompañarla en sus actividades normales por un día; y c) Usted será posiblemente invitada a participar en un grupo focal con duración de sesenta minutos con otras mujeres del programa. La entrevista y el grupo focal tendrán lugar en la sede del proyecto.

Confidencialidad: Yo, acepto responder preguntas sobre mi experiencia con VIH/SIDA y mi involucramiento con un proyecto comunitario. Yo acepto participar en la entrevista y en el grupo focal y que mi voz sea grabada. Yo entiendo que mis respuestas serán mantenidas confidenciales y que no seré identificada en ningún reporte.

Contacto para información sobre el estudio: Entiendo que si yo tengo alguna pregunta o necesito mayor información puedo contactar a Ana Maria Bustamante al numero (610-9603 en Bogota).

Contacto para aclaración sobre derechos de los sujetos de la investigación: Entiendo que si tengo alguna pregunta o cuestionamiento sobre el tratamiento a mis derechos puedo contactar a la Oficina de Ética de la Universidad de Simón Fraser o la Universidad de British Columbia.

Consentimiento: Yo entiendo que mi participación en este estudio es totalmente voluntaria y que yo puedo rehusarme a participar o retirarme del estudio en cualquier momento sin perjudicar mi participación en el proyecto comunitario o cualquier aspecto de mi tratamiento de VIH/SIDA.

Mi firma abajo indica que he recibido una copia de esta forma y que deseo participar en el estudio.

Firma

Fecha

Nombre de la participante

Appendix Three – UBC Consent Form

Consent Form – To Be Translated into Spanish



The University of British Columbia
Institute of Health Promotion Research
Room 425 , 2206 East Mall LPC Bldg.
Vancouver, BC V6T 1Z2
Phone: (604)_ 822-9205

Institute of Health Promotion Research

Experiences and perceptions of women living with HIV/AIDS in Colombia

Principal Investigator: Dr. Jim Frankish, Associate Director of Institute of Health Promotion and Research 604-822-9205

Co-Investigator(s): Ana Maria Bustamante, Latin American Studies, Simon Fraser University, 604-983-0635. The research is for a M.A. degree, and it is part of a thesis (public document).

Purpose: The purpose of the study is two-fold. The first purpose is to understand the experiences of women living with HIV and AIDS. The second purpose is to understand the benefits that women gain from taking part in community, health-education programs.

Study Procedures: Your participation in the study will involve three parts: you are asked to take part in an interview (90 minutes) regarding about your experience with HIV and the community program; b) you are asked to spend a day with Ms. Bustamante while you do your normal activities; and c) you may be asked to take part in a focus group (60 minutes) with other women from the program. The interview/ focus group will take place at the project site.

Confidentiality: I agree to answer questions about my experience with HIV/AIDS and involvement in the community project. I agree that my interview/focus group may be recorded. I understand that my responses will be confidential and that I will not be identified in any reports.

Contact for Information About the Study: I understand that if I have questions or want information, I can contact Jim Frankish or Ana Maria Bustamante at (number in Bogota)

Contact for Concerns about the Rights of Research Subjects: I understand that if I have any concerns about my treatment or rights, I can may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

Consent: I understand that my participation in this study is entirely voluntary and that I may refuse to participate or withdraw from the study at any time without jeopardy to my involvement with the community project or any other aspect of my HIV/AIDS treatment.

My signature below indicates that I have received a copy of this consent form and indicates my consent to participate in this study.

Subject Signature

Date

Printed Name of the Subject

Appendix Four – Interview Questions in Spanish

Preguntas de la entrevista a las mujeres viviendo con VIH/SIDA en Colombia

CONOCIMIENTO

- A.
1. Me puedes contar como llegaste al programa?
 2. Como te enteraste que eras positiva?
 3. Que sabias del SIDA en ese momento?
 4. Qué servicios o recursos te ha ofrecido el programa? Como te has sentido en el programa?

RELACIONES INTERPERSONALES Y APOYO

- B.
1. Desde que estas viviendo con VIH/SIDA, cuál fue la reacción de:
 - a) tu familia?
 - b) tus vecinos?
 - c) tus amigos?
- C.
2. Quien te brindan apoyo y/o te colaboran en tu vida diaria?
 - a) familia
 - b) vecinos
 - c) amigos
 - d) programa
 - e) iglesia
 3. Como te colaboran?
- D.
4. Que cosas te han ayudado a sobrellevar esta experiencia?
 - a) “el apoyo y cercanía de mi familia”
 - b) “conversar con mis amigos” etc
 - c) programa
- E.
5. Como te tratan cuando recibes tu tratamiento?
 - a) personal de salud
 - b) personal de apoyo
 - c) personal de servicio?
 6. Es la información que te dan es fácil entender lo que te dicen (o te hablan en un lenguaje complejo y difícil de entender?)

DESCRIPCION PERSONAL

- F.
1. Como te sientes hoy?
 2. Que cosas te preocupan?
 3. Podrías describirme un día cualquiera en tu vida?
 4. Por ejemplo cuéntame como fue el día de ayer, que cosas hiciste, a donde fuiste?

PROYECTO

- G.
1. Como ha sido tu participación con el proyecto?
 2. Que has hecho?
 3. Has recibido información? (si) (no)
 4. A través de folletos, talleres, consejería?
 5. Crees que los folletos fueron útiles e informativos?
 6. Fue la información fácil de entender? ¿te creo esta información nuevas inquietudes?
 5. Es la información o talleres extendida a tu familia (esposo, compañero, madre hermanas (os)?
 6. Crees que el programa te ha ayudado?
 7. Podrías describir como?

Appendix Five – Social Networks Form

SOCIAL CAPITAL AND SOCIAL NETWORKS: YOUR EGO-CENTRED EDUCATIONAL NETWORK

1. List people who you identify as important to you or significantly involved in your educational life in some way
2. Identify for each of these people what is your relationship to you:
 - Mother/father; sister/brother; child; grandparent; relative (aunt/uncle; cousin; grandchild); lover/boy-girl friend; friend; roommate, neighbour; “buddy”; co-worker; counsellor; elder; priest/pastor; supervisor, teacher; classmate, etc
3. What role do these people play in your education? What are your ties to this person?

People	Relationship	Role and involvement

4. Create a diagram that illustrates this network and the relationships among the actors in this network
5. Is social capital circulating here?

Ego-centred networks are the personal networks of individuals

Alters are those people whom individuals (egos) identify as members of their personal networks

Social bond refers to the type of relationship between ego and other members of the network

Social interactions refer to activities in which network members participate together

Ties are links between people that are measured by perceived intimacy and frequency of association

Connectedness is the extent of reciprocal relationships among individuals in a network

Power / influence is the degree to which a person in a network gives and receives information or other resources

Role relationships are those associated with a particular place or position in a social network

Source: Schensul J. et al., (1999) "Mapping social networks, spatial data and hidden populations" Walnut Creek: Altamira Press.

Appendix Six- Decree 1543



Libertad y Orden

MINISTERIO DE LA PROTECCION SOCIAL

DECRETO NUMERO 1543 DE 1997

(Junio 12)

Por el cual se reglamenta el manejo de la infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de la Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS)

EL PRESIDENTE DE LA REPUBLICA DE COLOMBIA

En ejercicio de sus facultades legales y en especial las conferidas en el numeral 11 del artículo 189 de la Constitución Política, y

CONSIDERANDO

Que de acuerdo con la Constitución Política de 1991, la Ley 100 de 1993 y la Ley 10 de 1990, la Seguridad Social es un servicio público obligatorio y es un derecho de todos los habitantes del territorio nacional.

Que la infección del Síndrome de Inmunodeficiencia Adquirida (SIDA) se ha incrementado considerablemente en los últimos años en la población colombiana, tanto en hombres como en mujeres y menores de edad, a pesar de los avances científicos, comportando una seria amenaza para la salud y la vida de todas las personas, por lo que se hace necesario expedir las normas correspondientes en desarrollo de la función de control y prevención.

Que por su naturaleza infecciosa, transmisible y mortal, tanto el Virus de Inmunodeficiencia Humana (VIH), como el Síndrome de Inmunodeficiencia Adquirida (SIDA), requieren de un esfuerzo a nivel intersectorial y de carácter multidisciplinario para combatirlos.

Que la vulneración de los derechos fundamentales de las personas portadoras del VIH y que padecen el SIDA son cada vez más frecuentes, debido al temor infundado hacia las formas de transmisión del virus, por lo cual se hace necesario determinar los derechos y deberes de dichas personas y de la comunidad en general.

Que por lo anteriormente expuesto se hace necesario regular las conductas, acciones, actividades y procedimientos para la promoción, prevención, asistencia y control de la infección por VIH/SIDA.

DECRETA:

CAPITULO I

CAMPO DE APLICACIÓN Y DEFINICIONES.

ARTÍCULO 1o.- **Ámbito de Aplicación.** Las disposiciones contempladas en el presente decreto se aplicarán en el territorio nacional, a todas las personas naturales, jurídicas, nacionales y extranjeras sin distinción alguna.

DECRETO NUMERO 1543 DE 1997

Por el cual se reglamenta el manejo de la infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de la Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS).

ARTÍCULO 2o.- Definiciones Técnicas. Para los efectos del presente decreto adoptanse las siguientes definiciones:

AISLAMIENTO: Medida de contención preventiva de bioseguridad mediante la cual una persona enferma es sometida, por parte del equipo de salud competente, a controles especiales destinados a evitar el agravamiento de su estado o a que pueda llegar a afectar la salud de los demás.

ATENCIÓN INTEGRAL: Conjunto de servicios de promoción, prevención y asistenciales (diagnóstico, tratamiento, rehabilitación y readaptación), incluidos los medicamentos requeridos, que se prestan a una persona o a un grupo de ellas en su entorno bio-psico-social, para garantizar la protección de la salud individual y colectiva.

AUTOCUIDADO: Observancia particular y determinada que una persona hace para sí misma de un conjunto de principios, recomendaciones y precauciones, destinadas a conservar la salud, incluyendo la promoción de la salud sexual, la prevención de la infección por VIH y la minimización de las repercusiones físicas, psicológicas y sociales que causa la misma.

BIOSEGURIDAD: Actividades, intervenciones y procedimientos de seguridad ambiental, ocupacional e individual para garantizar el control del riesgo biológico.

CASO DE SIDA: Persona infectada con el Virus de Inmunodeficiencia Humana (VIH) que presenta signos y síntomas asociados con cualquiera de las enfermedades concomitantes a la inmunosupresión que definen SIDA según la clasificación del CDC de Atlanta para niños o para personas adolescentes y adultas, o a que en su momento adopte el Ministerio de Salud en sus normas técnicas, incluyendo el respaldo de pruebas de laboratorio científicamente determinadas para tal efecto.

Donde no se disponga de pruebas de laboratorio especializadas para el estudio de la infección por VIH, una persona enferma se considerará caso de SIDA acorde con la clasificación de Caracas o sus actualizaciones posteriores, contenidas en normas técnicas del Ministerio de Salud.

CONDICIONES DE RIESGO: Serie de factores y cofactores del entorno bio-psico-social y cultural, que determinan o inciden en la vulnerabilidad de una persona para infectarse con el VIH.

CONDUCTAS CON RIESGO: Acción o conjunto de acciones y actividades que asumen las personas, exponiéndose directamente a la probabilidad de infectarse con el VIH.

CONFIDENCIALIDAD: Reserva que deben mantener todas y cada una de las personas integrantes del equipo de salud frente a la comunidad, respecto a la información del estado de salud y a la condición misma de una persona, con el fin de garantizarle su derecho fundamental a la intimidad.

CONSENTIMIENTO INFORMADO: Manifestación libre y voluntaria, que da una persona por escrito luego de la consejería preprueba, con el fin de realizarse el examen diagnóstico de laboratorio para detectar la infección por VIH, el cual deberá consignarse en la historia clínica.

CONSEJERÍA: Conjunto de actividades realizadas para preparar y confrontar a la persona con relación a sus conocimientos, sus prácticas y conductas, antes y después de la realización de las pruebas diagnósticas. Ésta se llevará a cabo por personal entrenado y calificado para dar información, educación, apoyo psicosocial y actividades de asesoría a las personas infectadas, a sus familiares y comunidad, en lo relacionado con las ETS, el VIH y el SIDA.

DECRETO NUMERO 1543 DE 1997

Por el cual se reglamentan el manejo de la infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de la Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS).

CONTAMINACIÓN: Presencia del VIH en objetos, productos y/o tejidos.

DISCRIMINACIÓN: Amenaza o vulneración del derecho a la igualdad mediante actitudes o prácticas individuales o sociales, que afecten el respeto y la dignidad de la persona o grupo de personas y el desarrollo de sus actividades, por la sospecha o confirmación de estar infectadas por VIH.

EQUIPO DE SALUD: Grupo interdisciplinario y multidisciplinario de personas que trabajan en salud, cuyas actividades están orientadas a la docencia, administración, investigación y atención integral de la salud individual y comunitaria.

ESTADO TERMINAL: Situación clínica con inminencia de muerte, no reversible en la cual, según criterio médico, una persona no tiene posibilidad de recuperar su estado de salud.

ESTUDIO CENTINELA: Investigación epidemiológica que mide la magnitud y la tendencia de la infección por VIH en grupos poblacionales específicos, utilizado para conocer indirectamente el comportamiento epidemiológico de la infección.

ETS (ENFERMEDADES DE TRANSMISIÓN SEXUAL): Enfermedades e infecciones producidas por determinados microorganismos, virus, hongos, bacterias y/o parásitos que se transmiten por vía sexual de una persona a otra.

INCIDENCIA: Número de casos nuevos en un tiempo, población y lugar determinados.

INFECCIÓN POR EL VIH: Presencia del Virus de la Inmunodeficiencia Humana (VIH) en el organismo de una persona, confirmada por prueba diagnóstica de laboratorio.

INMUNODEFICIENCIA: Falta, daño o disminución del sistema inmunológico de una persona para producir una respuesta ante la presencia de agentes o sustancias biológicas extrañas, por diferentes causas.

INTIMIDAD: Condición de la persona que le permite conservar su existencia con el mínimo de injerencia de los demás, para así lograr el libre y armónico desarrollo de su personalidad. Comprende tanto el respeto a la intimidad personal y familiar, como la facultad de defenderse de la divulgación de hechos privados, al permitir que la persona controle la información sobre sí misma.

MATERIAL BIOLÓGICO HUMANO: Toda sustancia de origen humano como órganos, tejidos, secreciones y/o células, que este libre o impregnada a otros materiales.

MEDIDAS UNIVERSALES DE BIOSEGURIDAD: Conjunto de normas, recomendaciones y precauciones, emitidas por entidades nacionales o internacionales de salud, adoptadas y/o expedidas por el Ministerio de Salud tendientes a evitar en las personas el riesgo de daño o infección causado por agentes biológicos contaminantes.

PERSONA ASINTOMÁTICA: Persona infectada por el Virus de Inmunodeficiencia Humana (VIH) que no presenta síntomas ni signos relacionados con el SIDA.

PERSONA INFECTADA: Persona en cuyo organismo está presente el Virus de Inmunodeficiencia Humana (VIH), confirmado por prueba diagnóstica de laboratorio, con o sin síntomas.

PERSONA SINTOMÁTICA: Persona con el Virus de Inmunodeficiencia Humana (VIH) que presenta manifestaciones clínicas propias del SIDA.

DECRETO NUMERO 1643 DE 1997

Por el cual se reglamenta el manejo de la infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de la Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS).

PREVALENCIA: Número de casos totales o acumulados durante el desarrollo de la epidemia en una población dada, en un tiempo determinado.

PREVENCIÓN EN EL SISTEMA INTEGRAL DE SEGURIDAD SOCIAL: Entiéndase por prevención de la enfermedad o el accidente, el conjunto de acciones que tienen por fin la identificación, control o reducción de los factores de riesgo biológicos, del ambiente y del comportamiento, para evitar que la enfermedad aparezca o se prolongue, ocasionen daños mayores o genere secuelas inevitables.

PROMOCIÓN EN EL SISTEMA INTEGRAL DE SEGURIDAD SOCIAL: Integración de las acciones realizadas por la población, los servicios de salud, las autoridades sanitarias, los sectores sociales y productivos, con el objeto de garantizar más allá de la ausencia de enfermedad, mejores condiciones de salud físicas, psíquicas y sociales individual y colectivamente.

PRUEBA DIAGNÓSTICA PRESUNTIVA: Examen de laboratorio que indica posible infección por el Virus de Inmunodeficiencia Humana (VIH) en una persona, y cuyo resultado en caso de ser reactivo, requiere confirmación por otro procedimiento de mayor especificidad.

PRUEBA DIAGNÓSTICA SUPLEMENTARIA: Examen de laboratorio de alta especificidad aceptado por la autoridad competente, mediante el cual se confirma la infección por el Virus de Inmunodeficiencia Humana (VIH).

SEROPOSITIVO: Resultado de una prueba diagnóstica reactiva o positiva para la infección por el Virus de Inmunodeficiencia Humana (VIH).

SERONEGATIVO: Resultado de una prueba diagnóstica no reactiva o negativa para la infección por el Virus de Inmunodeficiencia Humana (VIH).

SIDA (SÍNDROME DE INMUNODEFICIENCIA ADQUIRIDA): Conjunto de síntomas y signos generados por el compromiso del sistema inmunitario de una persona como consecuencia de la infección por el VIH.

VIH (VIRUS DE LA INMUNODEFICIENCIA HUMANA): Retrovirus que es el agente causal del SIDA.

CAPITULO II

DIAGNÓSTICO Y ATENCIÓN INTEGRAL

ARTÍCULO 3o.- Del Diagnóstico. Teniendo en cuenta los criterios clínicos, epidemiológicos y de laboratorio, el diagnóstico de la infección por el Virus de la Inmunodeficiencia Humana (VIH), el Síndrome de Inmunodeficiencia Adquirida (SIDA) y las Enfermedades de Transmisión Sexual (ETS) es un acto propio del ejercicio de la medicina.

ARTÍCULO 4o.- Indicación de las Pruebas Diagnósticas. Las pruebas de laboratorio para el apoyo diagnóstico de la infección por el Virus de la Inmunodeficiencia Humana (VIH) están indicadas por los siguientes propósitos:

- a. Confirmación de sospecha clínica de la infección por VIH por parte de un profesional de la medicina, con el consentimiento informado de la persona.
- b. Estudio de investigación del comportamiento epidemiológico de la infección por VIH.
- c. Para atender la solicitud individual de la persona interesada.
- d. Para descartar la presencia del VIH en material biológico humano.

DECRETO NUMERO 1543 DE 1987

Por el cual se reglamenta el manejo de la infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de la Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS).

PARÁGRAFO. Los estudios de investigación a que se refiere el literal 'o' del presente artículo, deberán ceñirse a lo estipulado en el capítulo IV del presente decreto.

ARTÍCULO 5o.- Realización de Pruebas Diagnósticas. Las pruebas presuntiva y suplementaria de infección por el Virus de Inmunodeficiencia Humana (VIH) previa consejería, se realizarán en laboratorios públicos o privados que cumplan los requisitos y normas de calidad establecidas por la Red Nacional de Laboratorios.

ARTÍCULO 6o.- Entrega de Resultados de las Pruebas. Los resultados de las pruebas para diagnóstico de la infección por el Virus de Inmunodeficiencia Humana (VIH) y los de diagnóstico para las Enfermedades de Transmisión Sexual (ETS) deberán ser entregados al paciente por un profesional de la medicina u otra persona del equipo de salud debidamente entrenada en consejería.

ARTÍCULO 7o.- Persona Infectada por el VIH. Para todos los fines legales consideráse que una persona infectada por el Virus de Inmunodeficiencia Humana (VIH), mientras permanezca asintomática no tiene la condición de enferma del Síndrome de Inmunodeficiencia Adquirida (SIDA).

ARTÍCULO 8o.- Obligación de la Atención. Ninguna persona que preste sus servicios en el área de la salud o institución de salud se podrá negar a prestar la atención que requiera una persona infectada por el Virus de Inmunodeficiencia Humana (VIH) asintomática o enferma del Síndrome de Inmunodeficiencia Adquirida (SIDA), según asignación de responsabilidades por niveles de atención, so pena de incurrir en una conducta sancionable de conformidad con las disposiciones legales; salvo las excepciones contempladas en la Ley 23 de 1981.

ARTÍCULO 9o.- Atención Integral de la Salud. La atención integral a las personas asintomáticas infectadas por el Virus de Inmunodeficiencia Humana (VIH) y enfermas del Síndrome de Inmunodeficiencia Adquirida (SIDA), de acuerdo con el criterio de equipo de salud y con sujeción a las normas técnico administrativas que exida el Ministerio de Salud, podrá ser de carácter ambulatorio, hospitalario, domiciliario o comunitario y tendrá su acción en las áreas de prevención, diagnóstico, tratamiento, rehabilitación y readaptación. Esta incluirá los medicamentos requeridos para controlar la infección por el VIH y SIDA, que en el momento se consideren eficaces, para mejorar la calidad de vida de la persona infectada.

PARÁGRAFO. La familia y el grupo social de referencia, participarán activamente en el mantenimiento de la salud de las personas asintomáticas infectadas por el Virus de Inmunodeficiencia Humana (VIH), en la recuperación de personas enfermas del Síndrome de Inmunodeficiencia Adquirida (SIDA), así como en el proceso de bienestar de las personas en estado terminal.

ARTÍCULO 10o.- Actualización de las Personas del Equipo de Salud. Las entidades de carácter público y privado que presten servicios de salud deben promover y ejecutar acciones de información, capacitación y educación continuada sobre ETS, VIH y SIDA a personal, con el fin de mantenerlos actualizados en conocimientos acordes con los avances científicos y tecnológicos al respecto, con la obligación de hacer aplicación, seguimiento y evaluación de las mismas.

ARTÍCULO 11o.- Preparación a la Familia o Responsables del Paciente. El equipo de salud capacitará a la persona responsable del paciente y a quienes conviven con éste para prestar la atención adecuada.

CAPITULO III

LA PROMOCIÓN, PREVENCIÓN, VIGILANCIA EPIDEMIOLÓGICA Y MEDIDAS DE BIOSEGURIDAD.

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ARTÍCULO 12o.- Promoción. La Promoción de la salud, en el caso específico de la infección por el Virus de Inmunodeficiencia Humana (VIH) y las otras Enfermedades de Transmisión Sexual (ETS), implicará el respeto por la autodeterminación de las personas en cuanto a sus hábitos y conductas sexuales.

ARTÍCULO 13o.- Prevención. La prevención en su más amplia acepción deberá garantizar:

- a. Procesos de educación e información.
- b. Servicios sociales y de salud.
- c. Un ambiente de apoyo y tolerancia social basado en el respeto a los derechos humanos.

ARTÍCULO 14o.- Intersectorialidad en Promoción y Prevención. La Promoción y la Prevención de la infección por el Virus de Inmunodeficiencia Humana (VIH) serán impulsadas por todos los sectores y organismos nacionales, y por las entidades de carácter privado que presten protección integral en salud.

ARTÍCULO 15o.- Protocolos de Atención Integral en VIH/SIDA. El Ministerio de Salud, teniendo en cuenta los principios científicos universalmente aceptados, expedirá las normas para la promoción, la prevención y asistencia de la infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de Inmunodeficiencia Adquirida (SIDA) y las Enfermedades de Transmisión Sexual (ETS).

ARTÍCULO 16o.- Educación para la Salud Sexual y Reproductiva. El Ministerio de Educación Nacional, a través de los Proyectos de Educación Sexual, en coordinación con el Ministerio de Salud, promoverá una sexualidad responsable, sana y ética en la niñez y la juventud. La educación sexual en las instituciones educativas se hará con la participación de toda la comunidad educativa haciendo énfasis en la promoción de actitudes y comportamientos responsables que permitan el desarrollo de la autonomía, la autoestima, los valores de convivencia y la preservación de la salud sexual; factores que contribuyen a la prevención de las Enfermedades de Transmisión Sexual (ETS) y al Síndrome de Inmunodeficiencia Adquirida (SIDA).

ARTÍCULO 17o - Difusión de Mensajes. El Ministerio de Comunicaciones, la Comisión Nacional de Televisión, y la Radiodifusora Nacional adoptarán los mecanismos necesarios para que a través de los medios masivos de comunicación se emitan mensajes de promoción focalizados a poblaciones específicas de la comunidad tendientes a la prevención de la infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS), los cuales podrán incluir el uso del condón, la educación en valores y la no discriminación hacia las personas que viven con el VIH y SIDA.

ARTÍCULO 18o.- Participación de las ONGs. El Ministerio de Salud, o la autoridad delegada, apoyará y coordinará la planeación y ejecución de acciones de las Organizaciones No Gubernamentales (ONGs) tendientes a la formación de líderes en grupos poblacionales específicos para la promoción y la prevención sobre los diferentes aspectos de la infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS).

ARTÍCULO 19o.- Obligaciones de las EPS. Las Entidades Promotoras de Salud (EPS) estarán en la obligación de realizar acciones de promoción, prevención y asistencia, de conformidad con el artículo 179 de la Ley 100 de 1993.

ARTÍCULO 20o.- Información de Casos. En desarrollo del sistema de información epidemiológico todas las personas naturales o jurídicas, públicas o privadas del sector

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salud, estarán obligadas a notificar los casos de infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de Inmunodeficiencia Adquirida (SIDA) y defunción a causa de esta enfermedad, así como de otras Enfermedades de Transmisión Sexual (ETS), a las Direcciones Territoriales de Salud, so pena de ser sancionadas de conformidad con las normas pertinentes y sin perjuicio de que puedan llegar a incurrir en el delito de violación de medidas sanitarias consagradas en el Código Penal. El secreto profesional no podrá ser invocado como impedimento para suministrar dicha información.

PARÁGRAFO PRIMERO. La información sobre el nombre de personas infectadas por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS), gozará del amparo de reserva, deberá hacerse con sujeción a las disposiciones contempladas en el presente decreto y a las normas sobre vigilancia y control epidemiológico que para tal efecto expida el Ministerio de Salud.

PARÁGRAFO SEGUNDO.- Para garantizar el derecho a la intimidad, la información epidemiológica es de carácter confidencial y se utilizará sólo con fines sanitarios.

ARTÍCULO 21o.- Prohibición para Realizar Pruebas. La exigencia de pruebas de laboratorio para determinar la infección por el Virus de Inmunodeficiencia Humana (VIH) queda prohibida como requisito obligatorio para:

- a. Admisión o permanencia en centros educativos, deportivos, sociales o de rehabilitación.
- b. Acceso a cualquier actividad laboral o permanencia en la misma.
- c. Ingresar o residenciarse en el país.
- d. Acceder a servicios de salud.
- e. Ingresar, permanecer o realizar cualquier tipo de actividad cultural, social, política, económica o religiosa.

ARTICULO 22o.- Realización de Pruebas en los Bancos de Sangre y Órganos. Los bancos de órganos, componentes anatómicos y líquidos orgánicos, así como las demás entidades médico-asistenciales que los reciban para fines de trasplantes, deberán realizar a sus donantes la prueba para detectar la presencia del Virus de Inmunodeficiencia Humana (VIH); igualmente los bancos de sangre y hemoderivados realizarán a las unidades de sangre donadas, las pruebas serológicas específicas para detectar la presencia del Virus de Inmunodeficiencia Humana (VIH).

PARÁGRAFO: En estos casos las pruebas que realice el Banco de Sangre se limitarán al tamizaje e informarán el resultado correspondiente a las autoridades sanitarias competentes, cuando el donante de manera previa así lo hubiere autorizado.

ARTÍCULO 23o.- Bioseguridad. Las entidades públicas y privadas asistenciales de salud, laboratorios, bancos de sangre, consultorios y otras que se relacionen con el diagnóstico, investigación y atención de personas, deberán:

- a. Acatar las recomendaciones que en materia de medidas universales de bioseguridad sean adoptadas e impartidas por el Ministerio de Salud.
- b. Capacitar a todo el personal vinculado en las medidas universales de bioseguridad.
- c. Velar por la conservación de la salud de sus trabajadores.
- d. Proporcionar a cada trabajador en forma gratuita y oportuna, elementos de barrera o contención para su protección personal, en cantidad y calidad acordes con los riesgos existentes en los lugares de trabajo sean estos reales o potenciales.

ARTICULO 24o. - Disponibilidad de Condones. Los establecimientos que ofrezcan facilidades para la realización de prácticas sexuales, así como las droguerías y farmacias o similares, deberán garantizar a sus usuarios la disponibilidad de condones como una medida de prevención.

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ARTÍCULO 25o.- Prohibición de la Referencia en Carnets. Sin perjuicio de las medidas sanitarias de carácter individual a que haya lugar y del derecho que toda persona tiene a obtener certificado de su estado de salud cuando lo considere conveniente, se prohíbe la exigencia de carnet o certificados con referencia a Enfermedades de Transmisión Sexual, incluida la Infección por el Virus de Inmunodeficiencia Humana (VIH).

ARTÍCULO 26o.- Vigilancia sobre las ONGs. Las Organizaciones No Gubernamentales que presten servicios de cuidado, atención o tratamiento a personas infectadas con el Virus de Inmunodeficiencia Humana (VIH) o enfermas del Síndrome de Inmunodeficiencia Adquirida (SIDA), estarán sometidas a la inspección, vigilancia, y control de las autoridades sanitarias de acuerdo con las disposiciones legales vigentes.

PARÁGRAFO. También estarán vigiladas las Organizaciones No Gubernamentales que presten estos servicios de Promoción y Prevención de Primer Nivel, a personas o grupos comunitarios.

CAPITULO IV

INVESTIGACIÓN

ARTÍCULO 27o.- Normas para la Investigación Terapéutica. En desarrollo del artículo 54 de la Ley 23 de 1991, la investigación terapéutica en humanos y en especial la aplicada a la Infección por el Virus de Inmunodeficiencia Humana (VIH) y el Síndrome de Inmunodeficiencia Adquirida (SIDA), se sujetará a la Declaración de Helsinki dictada por la Asociación Médica Mundial, hasta tanto se expidan disposiciones legales específicas sobre la materia.

PARÁGRAFO. En caso de conflicto entre los principios o recomendaciones adoptadas por la Asociación Médica Mundial, y las disposiciones legales internas vigentes, se aplicarán las de la Legislación Colombiana.

ARTÍCULO 28o.- Estímulo a la Investigación. El Ministerio de Salud a través de sus organismos o comisiones especializadas estimulará y apoyará la realización de investigaciones relacionadas directa o indirectamente con la Infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS).

PARÁGRAFO. Las investigaciones experimentales del Virus de Inmunodeficiencia Humana (VIH), el Síndrome de Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS) que involucren personas como sujetos directos de estudio, deberán ser aprobadas por el Ministerio de Salud o por las autoridades sanitarias delegadas; en los demás casos, el Ministerio de Salud podrá definir metodologías, evaluar y hacer el seguimiento de los proyectos científicos correspondientes.

ARTÍCULO 29o.- Investigación Epidemiológica. El procedimiento empleado en la investigación en Vigilancia Epidemiológica Centinela, encuestas de prevalencia, o en cualquier otro tipo de investigación, deberá garantizar el anonimato de las personas participantes.

CAPITULO V

EJERCICIO DE LOS DERECHOS Y CUMPLIMIENTO DE LOS DEBERES

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ARTÍCULO 30o.- Deberes de la Comunidad. Todas las personas de la comunidad tienen el deber de velar por la conservación de la salud personal, familiar y comunitaria a fin de evitar la infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS), poniendo en práctica las medidas de autocuidado y prevención.

ARTÍCULO 31o.- Deberes de las IPS y Personas del Equipo de Salud. Las personas y entidades de carácter público y privado que promuevan o presten servicios de salud, están obligadas a dar atención integral a las personas infectadas por el Virus de Inmunodeficiencia Humana (VIH) y a los enfermos de SIDA, o de alto riesgo, de acuerdo con los niveles de atención y grados de complejidad que les corresponda, en condiciones de respeto por su dignidad, sin discriminación y con sujeción a lo dispuesto en el presente decreto, y en las normas técnico administrativas y de vigilancia epidemiológica expedidas por el Ministerio de Salud.

ARTÍCULO 32o.- Deber de la Confidencialidad. Las personas integrantes del equipo de salud que conozcan o brinden atención en salud a una persona infectada por el Virus de Inmunodeficiencia Humana (VIH), asintomática o sintomática, están en la obligación de guardar sigilo de la consulta, diagnóstico, evolución de la enfermedad y de toda la información que pertenezca a su intimidad.

ARTÍCULO 33o.- Historia Clínica. La historia clínica es el registro o gaceta de las condiciones de salud de la persona; como tal es un documento privado sometido a reserva, por lo tanto únicamente puede ser conocido por terceros, previa autorización de su titular o en los casos previstos por la ley.

La historia pertenece a la persona y a institución cumple un deber de custodia y cuidado.

ARTÍCULO 34o.- Revelación del Secreto Profesional. Por razones de carácter sanitario, el médico tratante, teniendo en cuenta los consejos que dicta la prudencia, podrá hacer la revelación del secreto profesional a:

- a. La persona infectada, en aquel o que estrictamente le concierne y convenga.
- b. Los familiares de la persona infectada si la revelación es útil al tratamiento.
- c. Los responsables de la persona infectada, cuando se trate de menores de edad o de personas mentalmente incapaces.
- d. Los interesados por considerar que se encuentran en peligro de infección, al cónyuge, compañero permanente, pareja sexual o a su descendencia.
- e. Las autoridades judiciales o de salud competentes en los casos previstos por la Ley.

PARÁGRAFO PRIMERO.- El médico tratante podrá delegar en la persona encargada de la consejería, a interior del equipo de salud, la revelación del secreto profesional, la responsabilidad será solidaria.

PARÁGRAFO SEGUNDO.- En los casos contemplados en los literales a, b, c y d, del presente artículo, el secreto profesional se revelará a la persona interesada previa consejería.

ARTÍCULO 35o. - Situación Laboral. Los servidores públicos y trabajadores privados no están obligados a informar a sus empleadores su condición de infectados por el Virus de Inmunodeficiencia Humana (VIH). En todo caso se garantizarán los derechos de los trabajadores de acuerdo con las disposiciones legales de carácter laboral correspondientes.

PARÁGRAFO PRIMERO.- Quienes decidan voluntariamente comunicar su estado de infección a su empleador, éste deberá brindar las oportunidades y garantías laborales de acuerdo a su capacidad para recibirlos en caso de ser necesario, conservando su condición laboral.

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PARÁGRAFO SEGUNDO.- El hecho de que una persona esté infectada con el Virus de Inmunodeficiencia Humana (VIH) o haya desarrollado alguna enfermedad asociada al Síndrome de Inmunodeficiencia Adquirida (SIDA), no será causal de despido sin perjuicio de que conforme a vínculo laboral, se apliquen las disposiciones respectivas relacionadas al reconocimiento de la pensión de invalidez por pérdida de la capacidad laboral.

ARTÍCULO 36o.- Deber de Informar. Para poder garantizar el tratamiento adecuado y evitar la propagación de la epidemia, la persona infectada con el Virus de Inmunodeficiencia Humana (VIH) o que haya desarrollado el Síndrome de Inmunodeficiencia Adquirida (SIDA) y conozca tal situación está obligada a informar dicho evento, a su pareja sexual y al médico tratante o al equipo de salud ante el cual solicite algún servicio asistencial.

ARTÍCULO 37o.- Derecho al Consentimiento Informado. La práctica de pruebas de laboratorio para detectar la infección por el Virus de Inmunodeficiencia Humana (VIH) en el orden individual o encuestas de prevalencia, sólo podrá efectuarse previo consentimiento de la persona encuestada o cuando la autoridad sanitaria competente lo determine, de acuerdo con las previsiones del presente decreto.

ARTÍCULO 38o.- Personas Privadas de la Libertad. Las personas privadas de la libertad no podrán ser obligadas a someterse a pruebas de laboratorio para detectar infección por el Virus de Inmunodeficiencia Humana (VIH).

ARTÍCULO 39o.- La No Discriminación. A las personas infectadas por el Virus de Inmunodeficiencia Humana (VIH), a sus hijos y demás familiares, no podrá negárseles por tal causa su ingreso o permanencia a los centros educativos, públicos o privados, asistenciales o de rehabilitación, ni el acceso a cualquier actividad laboral o su permanencia en la misma, ni serán discriminados por ningún motivo.

ARTÍCULO 40o.- Prohibición de Pruebas Diagnósticas para la Cobertura de Servicios. Por ser la salud un bien de interés público y un derecho fundamental, las entidades de medicina prepagada, aseguradoras, promotoras o prestadoras de servicios de salud, sean públicas o privadas, no podrán exigir pruebas diagnósticas de laboratorio para el Virus de Inmunodeficiencia Humana (VIH) como requisito para acceder a la cobertura respectiva de protección. La condición de persona infectada por no corresponder a la noción de enferma, no podrá considerarse como una condición patológica preexistente, tampoco se podrán incluir cláusulas de exclusión.

ARTÍCULO 41o.- Deber de no Infectar. La persona informada de su condición de portadora del Virus de Inmunodeficiencia Humana (VIH) deberá abstenerse de donar sangre, semen, órganos o en general cualquier componente anatómico, así como de realizar actividades que conlleven riesgo de infectar a otras personas.

ARTÍCULO 42o.- Derecho a la Promoción, Prevención y Educación en Salud. Toda persona tiene derecho a obtener de los funcionarios competentes la debida información y las instrucciones adecuadas sobre asuntos, acciones y prácticas conducentes a la promoción, prevención y conservación de su salud personal y la de los miembros de su hogar, particularmente sobre higiene, dieta adecuada, orientación psicológica, salud mental, educación sexual, enfermedades transmisibles, especialmente las Enfermedades de Transmisión Sexual y el SIDA, planificación familiar, diagnóstico precoz de enfermedades y sobre prácticas y el uso de elementos técnicos especiales.

ARTÍCULO 43o.- Derecho a la Información Sobre el Estado de Salud. Toda persona tiene derecho a disfrutar de una comunicación plena y clara con el equipo de salud, acorde a sus condiciones psicológicas y culturales, que le permita obtener toda la información necesaria respecto a la enfermedad que padece, así como a los

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procedimientos y tratamientos que se le vayan a practicar, al pronóstico y riesgos que dicho tratamiento conlleva, y a que por sí misma, sus familiares o representantes, en caso de inconsciencia o disminución de la capacidad, acepten o rechacen estos procedimientos, dejando expresa constancia por escrito de su decisión.

ARTICULO 44o.- Derecho a Morir Dignamente. Toda persona tiene derecho a morir con dignidad y a que se le respete su voluntad de permitir que el proceso de la muerte siga su curso natural, en la fase terminal de la enfermedad; por lo tanto si el paciente lo permite el equipo de salud deberá otorgarle los cuidados paliativos que sean posibles hasta el último momento.

ARTICULO 45o.- Inhumación o Cremación. Las personas infectadas por el Virus de Inmunodeficiencia Humana (VIH), en cualquier momento de su infección, o los responsables de éstas después de su muerte, podrán decidir libremente la inhumación o cremación del cadáver, por no existir riesgo de orden sanitario que comporte situaciones de peligro para la salud comunitaria, en cualquiera de tales eventos.

CAPITULO VI

MECANISMOS DE ORGANIZACIÓN
Y COORDINACIÓN

ARTÍCULO 46o.- Estructura Organizacional. Para efectos de darle una estructura organizativa al Programa Nacional de Prevención y Control de las Enfermedades de Transmisión Sexual y el SIDA, se establecen instancias y mecanismos de coordinación, los cuales se señalan en los artículos siguientes.

ARTÍCULO 47o.- Consejo Nacional de SIDA. Créase con carácter permanente el Consejo Nacional de SIDA, como organismo adscrito al Ministerio de Salud, el cual se conformará así:

- a. El Ministro de Salud o su Viceministro, quien lo presidirá.
- b. El Ministro de Educación o su Viceministro.
- c. El Ministro de Comunicaciones o su Viceministro.
- d. El Ministro de Trabajo o su Viceministro.
- e. El Defensor del Pueblo o su delegado.
- f. El Director del Instituto Colombiano de Bienestar Familiar (ICBF) o su delegado.
- g. El Director del Instituto Nacional de Salud.
- h. El Director del Instituto Nacional de Vigilancia de Medicamentos y Alimentos (INVIMA).
- i. El Jefe del Programa Nacional de Prevención y Control de las ETS y SIDA.
- j. El Coordinador del Proyecto Nacional de Educación Sexual del Ministerio de Educación.
- k. Un Delegado del Grupo Temático ONU/SIDA para Colombia.
- l. Dos representantes de Organizaciones No Gubernamentales (ONGs) de lucha contra el SIDA, legalmente constituidas, nombradas por la Mesa Coordinadora Nacional de ONGs trabajando en SIDA.
- m. Un hombre y una mujer viviendo con el Virus de Inmunodeficiencia Humana, representantes de los Grupos de Apoyo y Autoapoyo, elegidos por el Ministerio de Salud.
- n. Un representante de las Entidades Promotoras de Salud (EPS).
- o. Un representante de la Comisión Nacional de Televisión.
- p. Un representante de la Red Nacional de Bancos de Sangre.
- q. Un Representante de los Comités Intersectoriales Departamentales y Municipales elegido por el Ministerio de Salud, de tema enviada por los mismos.

PARÁGRAFO PRIMERO.- El Jefe del Programa Nacional de Prevención y Control de las ETS y SIDA del Ministerio de Salud, ejercerá las funciones de Secretaría Ejecutiva.

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PARÁGRAFO SEGUNDO.- El Consejo podrá invitar a sus reuniones a representantes de otras entidades del sector público y privado y/o a expertos, asesores o consultores, cuando así lo estime necesario.

ARTÍCULO 48o.- Funciones. El Consejo Nacional de SIDA tendrá por objeto fomentar y respaldar las acciones que se lleven a cabo en el país para la promoción, prevención y control de la infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS); y asesorar al Ministerio de Salud en la toma de decisiones sobre la materia, para lo cual desarrollará las siguientes funciones:

- a. Proponer la política general para el desarrollo del Programa Nacional de promoción, prevención y asistencia de las ETS y el SIDA, en aspectos éticos, jurídicos, laborales, internacionales, financieros y de movilización social, información masiva y educación sexual.
- b. Recomendar los mecanismos para lograr la participación intersectorial en las actividades del programa.
- c. Evaluar el desarrollo del Programa Nacional de Prevención y Control de las ETS y el SIDA.
- d. Apoyar la consecución de fuentes de financiación nacional e internacional.
- e. Prestar la asesoría que se le solicite para la elaboración de Proyectos, Acuerdos o Convenios internacionales.
- f. Aprobar los mecanismos de coordinación necesarios con los Programas Nacionales de SIDA y ETS de otros países con los que Colombia tenga convenios o se suscriban posteriormente.
- g. Dictar su propio reglamento.
- h. Las demás que los sectores participantes consideren pertinentes en desarrollo de este decreto.

ARTICULO 49o.- Reuniones. El Consejo Nacional de SIDA se reunirá ordinariamente cada seis (6) meses y extraordinariamente a solicitud de su Presidente o de cualquiera de sus miembros cuando así lo considere necesario.

ARTÍCULO 50o.- Comité Ejecutivo. Créase con carácter permanente el Comité Ejecutivo de Promoción, Prevención, Asistencia y Control de las ETS y del SIDA, el cual estará integrado así:

- a. El Director General de Promoción y Prevención del Ministerio de Salud.
- b. El Jefe del Programa Nacional de Prevención y Control de las ETS y el SIDA, o quien haga sus veces, el cual deberá ejercer las funciones de Coordinador General del Comité.
- c. El Jefe de Educación en Salud del Ministerio de Salud.
- d. El Jefe de Salud Sexual y Reproductiva del programa de Desarrollo Humano del Ministerio de Salud.
- e. El Jefe de Acciones Prioritarias en Salud del Ministerio de Salud.

PARÁGRAFO. La Coordinación General del Comité Ejecutivo es responsabilidad del Jefe del Programa Nacional de Prevención y Control de las Enfermedades de Transmisión Sexual y el SIDA del Ministerio de Salud.

ARTÍCULO 51o.- Funciones. Son funciones del Comité Ejecutivo de Promoción, Prevención, Asistencia y Control de las ETS y del SIDA, las siguientes:

- a. Dirigir el desarrollo de las estrategias para la promoción, prevención, asistencia y control de la infección por el VIH y el SIDA, de acuerdo a la dinámica de la epidemia.

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Por el cual se reglamenta el manejo de la Infección por el Virus de Inmunodeficiencia Humana (VIH) o Síndrome de la Inmunodeficiencia Adquirida (SIDA) y de otras Enfermedades de Transmisión Sexual (ETS)

- b. Promover la participación de Organizaciones No Gubernamentales (ONGs), de personas viviendo con VIH y SIDA, de la empresa privada y otros sectores en las actividades de Programa.
- c. Adoptar con las modificaciones a que haya lugar las directrices y recomendaciones de ONUSIDA.
- d. Elaborar, dirigir y evaluar la ejecución del Programa Nacional de Prevención y Control de las ETS y SIDA.
- e. Presentar y entregar informes previos a las reuniones del Consejo Nacional de SIDA, para ello se entregarán previamente copias del mismo a sus integrantes.
- f. Reglamentar los Comités Intersectoriales del nivel Seccional, Distrital y Local de promoción y prevención de las ETS y SIDA.
- g. Dictar su propio reglamento.
- h. Las demás que se consideren pertinentes.

ARTICULO 52o.- Reuniones. El Comité Ejecutivo se reunirá ordinariamente cada dos (2) meses y de forma extraordinaria por solicitud de cualquiera de sus miembros.

ARTICULO 53o.- Funciones del Coordinador General. Son funciones del Coordinador General del Comité Ejecutivo de Promoción, Prevención, Asistencia y Control de las Enfermedades de Transmisión Sexual y el SIDA, las siguientes:

- a. Desempeñar la Secretaría Ejecutiva del Consejo Nacional de SIDA.
- b. Convocar y presidir el Comité Ejecutivo de Promoción, Prevención, Asistencia y Control de las ETS y SIDA.
- c. Coordinar acciones buscando unificar criterios entre el Consejo Nacional de SIDA y el Comité Ejecutivo de Prevención y Control de las ETS y SIDA.
- d. Conceptuar y tramitar los proyectos o iniciativas orientados a la promoción y prevención de las ETS y el SIDA.
- e. Presentar al Consejo Nacional de SIDA las propuestas sobre políticas y estrategias de promoción y prevención de las ETS y el SIDA, para su discusión y aprobación.
- f. Cumplir y hacer cumplir el reglamento interno.

ARTÍCULO 54o.- Creación de los Comités Territoriales. Créanse con carácter permanente los Comités Intersectoriales a nivel Seccional, Distrital y Local de promoción y prevención de las Enfermedades de Transmisión Sexual (ETS) y el Síndrome de Inmunodeficiencia Adquirida (SIDA).

CAPITULO VII

PROCEDIMIENTOS Y SANCIONES

ARTICULO 55o.- Propagación de la Epidemia. Las personas que incumplan los deberes consagrados en los Artículos 38 y 41 del Capítulo V del presente decreto, podrán ser denunciadas para que se investigue la posible existencia de delitos por propagación de epidemia, violación de medidas sanitarias y las señaladas en el Código Penal.

ARTICULO 56o.- Sanciones. El incumplimiento de las disposiciones del presente decreto por parte de las instituciones públicas, privadas o personas naturales o jurídicas, dará lugar a la aplicación de las sanciones establecidas en la Ley 10 de 1990, las cuales serán impuestas por las autoridades sanitarias en ejercicio de las funciones de inspección y vigilancia, de acuerdo a la gravedad de la falta, así:

- a. Multas en cuantía hasta de 200 salarios mínimos legales mensuales.
- b. Intervención de la gestión administrativa y/o técnica de las entidades que presten servicios de salud hasta por un término de seis (6) meses.
- c. Suspensión o pérdida definitiva de la personería jurídica de las personas privadas que presten servicios de salud.

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Por el cual se reglamenta el manejo de la infección por el Virus de Inmunodeficiencia Humana (VIH) o Síndrome de Inmunodeficiencia Adquirida (SIDA) y de otras Enfermedades de Transmisión Sexual (ETS)

descargos por escrito, aportar las pruebas y/o solicitar la práctica de las que considere pertinentes y de las que sean conducentes.

ARTICULO 66o.- Práctica de Pruebas. La autoridad competente decretará, a costa de la persona interesada, la práctica de las pruebas que considere conducentes, las que llevará a efecto dentro de un término máximo de treinta (30) días, el cual podrá prorrogarse hasta por un término igual al inicialmente fijado.

ARTICULO 67o.- Sanciones. Venido el término del artículo anterior y dentro de los diez (10) días siguientes al mismo, la autoridad sanitaria procederá a calificar la falta y a imponer la sanción que corresponda.

ARTICULO 68o.- Circunstancias Agravantes. Son circunstancias agravantes de una infracción las siguientes:

- a. Haber obrado por motivos invidiosos o fútiles.
- b. Realizar el hecho con la complicidad de personas subalternas o con su participación bajo indebida presión.
- c. Cometer la falta para ocultar otra.
- d. Rehuir la responsabilidad o atribuirse a la otra u otras personas.
- e. Ejecutar el hecho aprovechando calamidad, infortunio o peligro común.
- f. Preparar premeditadamente la infracción y sus modalidades.

ARTICULO 69o.- Circunstancias Atenuantes. Son circunstancias atenuantes de una infracción las siguientes:

- a. Los buenos antecedentes o conducta anterior.
- b. La indiferencia o la falta de ilustración cuando haya influido en la ejecución del hecho.
- c. Procurar por iniciativa propia resarcir el daño o compensar el perjuicio causado antes de la imposición de la sanción.

ARTICULO 70o.- Exoneración de Responsabilidad. Si se encuentra que no se ha incurrido en violación de las normas sanitarias, se expedirá resolución motivada, por la cual se declare al presunto infractor exonerado de responsabilidad y se ordenará archivar el expediente. Contra esta providencia procederán los recursos de ley de conformidad con el Decreto Ley 01 de 1994.

PARÁGRAFO. El funcionario competente que no defina la situación bajo su responsabilidad, dentro de los términos previstos en el mismo, incurrirá en causal de mala conducta.

ARTICULO 71o.- Notificación de las Sanciones. Las sanciones deberán imponerse mediante resolución motivada, expedida por la autoridad sanitaria y deberá notificarse personalmente al afectado dentro de los cinco (5) días siguientes a la fecha de su expedición. Contra esta providencia procederán los recursos de reposición y apelación según el caso, dentro de los cinco (5) días siguientes a su notificación. Si no pudiere hacerse la notificación personal, se hará por edicto de conformidad con lo dispuesto en el Código Contencioso Administrativo.

El recurso de reposición se interpondrá ante la misma autoridad que expidió dicho acto y el de apelación ante su inmediato superior.

PARÁGRAFO. El recurso de apelación se concederá sólo en el efecto devolutivo de conformidad con lo previsto en el artículo 4o. de la Ley 45 de 1948.

ARTÍCULO 72o.- Autoridad Sancionatoria. Cuando sea el caso iniciar o adelantar procedimiento sancionatorio, práctica de pruebas o investigación, la competencia será de las Direcciones Territoriales de Salud. Cuando se deba practicar pruebas fuera del

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Por el cual se reglamenta el manejo de la infección por el Virus de Inmunodeficiencia Humana (VIH), el Síndrome de la Inmunodeficiencia Adquirida (SIDA) y las otras Enfermedades de Transmisión Sexual (ETS)

territorio de una Dirección Seccional, Distrital o Local de Salud, el Jefe de la misma podrá comisionar al de la otra Dirección para su práctica, caso en el cual señalará los términos de su duración.

ARTICULO 73o.- Vigencia de la Sanción. Cuando una sanción se imponga por un determinado periodo tiempo, éste empezará a contarse a partir de la ejecutoria de la providencia y se computará para efectos de la misma, el tiempo transcurrido bajo una medida de seguridad o preventiva.

ARTICULO 74o.- Vigencia. El presente Decreto rige a partir de la fecha de su publicación y deroga las disposiciones que le sean contrarias, en especial el Decreto 558 de 1991.

PUBLÍQUESE Y CÚMPLASE

Dado en Santafé de Bogotá, D.C., a los 12 días del mes de junio del año 1997.

ALMABEATRIZ RENGIFO LOPEZ
Ministra de Justicia y del Derecho

IVAN MORENO ROJAS
Ministro de Trabajo y Seguridad Social

MARÍA TERESA FORERO DE SAADE
Ministra de Salud

JAIME NIÑO DIEZ
Ministro de Educación.

BIBLIOGRAPHY

Works Consulted

- Acuna, C. and Bolis, M., (2005) Stigmatization and Access to Health Care in Latin America: Challenges and Perspectives. Pan American Health Organization. Washington, D.C.
- Alvarez, L.S. ND, MPH, PHD candidate. Professor at Universidad de Antioquia. Colombian Health System Reform. *Revista Salud Colombia*. Medellin, Colombia.
- Airhihenbuwa, CO., Obregon, R. A. (2000). *Critical assessment of theories/models used in health communication for HIV/AIDS*. Suppl: 5-15,
- Altman, D., (2003)"Understanding HIV/AIDS as a Global Security Issue". *Health Impacts on Globalization*. 33-45, 2003.
- Armada, F., and Muntaner, C. (2004). *The Visible Fist of the Market: Health Reforms in Latin America in Unhealthy: Health Policy: A critical anthropological examination*, by Arachu Castro and Merrill Singer, Walnut Creek, Calif. AltaMira Press
- Babbie, E.I; Benaquisto, L.; (2002) *Fundamentals of Social Research*. First Canadian Edition, Wadsworth Thomson Learning
- Bartley, G., M. and D. Blane (1990) 'The Black Report on Socioeconomic Inequalities in Health 10 years on', *British Medical Journal*, 301: 373-7;
- Black, D. J., Smith, C. and Townsend, P. (1982) *Inequalities in Health: The Black Report* (New York: Penguin Books);
- Berman, P., and Bossert, T (2000) A Decade of Health Sector Reform in Developing Countries: What have we learned? DDM Report No. 81, Harvard School of Public Health. "<http://www.hsph.harvard.edu/ihsg/ihsg>" www.hsph.harvard.edu/ihsg/ihsg.

- Bossert, T., Ph.D. (2000) Decentralization of Health Systems in Latin America
A comparative Analysis of Chile, Colombia and Bolivia. Harvard School of
Public Health.
- Bulman, D.; Coben, D.; Van Anh, N.. *Educating women about HIV/AIDS: some
international Comparisons*. Compare: A Journal of Comparative
Education Vol. 34, No. 2, June 2004, (34-52)
- Campbell, C., (1999) *Women, Families, and HIV/AIDS- A Social Perspective
no the Epidemic in America*. Cambridge University Press.
- Cespedes, J.E., (2000) HIV/AIDS; Its Social and Economic Impact in Colombia.
Revista de Salud Publica. Vol. 2 No. 2. pag 145-164
- CIDA's HIV/AIDS – Action Plan 2nd Edition July 2000.
- Clair, R.P., (2003) *Expressions of Ethnography – Novel approached to qualitative
methods*. State University of New York Press.
- De Groote, T., De Paepe, P., and Unger, J. P. (2005) Colombia: In vivo test of
health sector privatization in the developing world in International Journal
of Health Services Vol. 35, Number 1, pages 125-141.
- Drager, N. Beagle Hole, R. (2001) *Globalization Changing the public Health
Landscape Editorial – Globalization, WHO 2001*. Bulletin of the WHO,
2001. 79(9)
- Evans, T., (2002) "A Human Right to Health?" *Third World Quarterly*. 23 (2).
- Farmer, P., Connors, M., Simmons, J., (1999) *Women, Poverty, and AIDS – Sex,
Drugs and Structural Violence*, Common Courage Press, Monroe, Maine
- Frank, J. W. & J. Fraser M., (1995) 'The Determinants of Health from a
Historical Perspective', *Daedalus*, 123(4)
<http://children.metrotor.on.ca/taskforce/must.html>
- Fuller, L.K.; (2003) *Media-Mediated AIDS*; Hampton Press, Inc. Cresskill, New
Jersey
- Granger, M.M., Fischhoff, B.; Bostrom, A.; Atman, C.J. (2002) *Risk
Communication: A Mental Models Approach*. Cambridge University Press
- Hammer, C.M. (2004) *A Woman's Guide to Living with HIV Infection*. The John
Hopkins Press. Baltimore, Maryland.
- Herd, G. (2001). Stigma and the Ethnographic Study of HIV: Problems and
Prospects. *AIDS and Behavior*. Vol. 5 No. 2.

- Hogan, K. (2001). *Women Take Care – Gender, race, and the culture of AIDS*. Cronell University Press. Ithaca and London.
- Jaramillo, J. (2002) Evaluacion de la descentralizacion de la salud y la reforma de la seguridad social en Colombia. *GAC Sanit.* 16(1): 48-53.
- Johansen, R. C. (2000) 'Enforcing Norms and Normalizing Enforcement for Humane Governance', in P. Wapner & L. E. J. Ruiz (eds.) *Principled World Politics: the challenge of normative international relations* (Lanham: Rowman and Littlefield) 209-230;
- Koivusalo, M. (2003) 'Assessing the Health Policy Implications for WTO trade and Investment Agreements' *Health Impacts on Globalization*.162-175.
- Leon, D.A., G. Walt & L. Gilson (2001) 'International Perspectives on Health Inequalities and Policy', *British Medical Journal*, 322 (March): 591-94;
- Ministry of Social Protection. (2003) *National Policy on Sexual and Reproductive Health*, Bogota, D.C.
- Ministry of Social Protection (2004) *Plan Intersectorial de Respuestas ante el VIH/SIDA. Colombia 2004-2007*. Bogota, D.C.
- Marmot , M & Wilkinson, R.G. (2006) *Social Determinants of Health* , Second Ed, Oxfor University Press, New York
- Murray C.J.L. & A. D. Lopez (1996) *The Global Burden of Disease: A Comprehensive Assessment of Mortality and Disability from Diseases, Injuries and Risk Factors in 1990 and Projected to 2020* (Boston: Harvard University Press)
- O'Leary, A & Jemmott, L.S. (1996) *Women and AIDS: Coping and Care*. Plenum Press. New York and London
- PAHO/WHO. (2001). *Health in the Americas, Core Health Profile – Colombia*,
- Patton, C., (2002) *Globalizing AIDS*, University of Minnesota, 2002J.L. & A. D. Lopez (1996) *The Global Burden of Disease: A Comprehensive Assessment of Mortality and Disability from Diseases, Injuries and Risk Factors in 1990 and Projected to 2020* (Boston: Harvard University Press)
- Poku, N.K., and Whiteside, A, Eds. (2004) *Global Health and Governance: HIV/AIDS*, NY: Palgrave

- Restrepo-Zea, J. Año 'El Seguro de Salud en Colombia. Cobertura Universal? Revista Gerencia y Políticas de Salud No. 25
 "http://www.javeriana.edu.co/biblios/revistas/salud/pdf/revsta2/salud-espacio-2pdf"
 www.javeriana.edu.co/biblios/revistas/salud/pdf/revsta2/salud-espacio-2pdf
- Robinson, F. (1999) 'Globalizing Care, Ethics, Feminist Theory and International Relations; Boulder, Colo.: West view Press, 1999.
- Roth, N.L., Fuller, L.K., (1998) *Women and AIDS: Negotiation Safer Practices, Care, and Representation*. The Haworth Press. New York and London
- Rubin, H. J.; Rubin, I. S. (2005) *Qualitative Interviewing: The Art of Hearing Data*. 2nd edition. Sage publications
- Singhal, A. (2003) *Combating AIDS: communications strategies in action* Thousand Oaks: Sage.
- Terry, D., Gallois, C. & McCamish, M. (1993) *The Theory of Reasoned Action. Its Application to AIDS-Preventive Behavior*. Pergamon Press. Oxford, New York, Seoul, Tokyo
- The Lancet. (2001) *The Global Health Fund: Moral Imperative or Industry Subsidy?* Vol. 358 – Aug. 18 2001
- Thomas, C. (2003) 'Trade Policy, The politic of Access to Drugs and Global Governance for Health' *Health Impacts on Globalization*. 177 –189.2003
- Valdiserri, R. (2003) *How the HIV/AIDS Epidemic Has Helped to Strengthen Public Health*, Oxford University Press
- Vision Mundial (2004) *Acercandonos el VIH/SIDA en America Latina y el Caribe*. Oficina Regional para America Latina y el Caribe. 1a. ed.

Works Cited

- Barlow, J. (1992) Social Issues: An Overview, in *Working with Women with AIDS: Medical, Social, and Counselling Issues*, edited by Judy Bury, Val Morrison and Sheena McLachlan foreword by Margaret Jay. Tavistock/Routledge. (Pag. 23-31) London and New York

- Bisset, K., Gray, J., (1992) Feelings and needs of women who are HIV Positive, in *Working with Women with AIDS: Medical, Social, and Counselling Issues*, edited by Judy Bury, Val Morrison and Sheena McLachlan foreword by Margaret Jay. (Pag. 125-234) Tavistock/Routledge. London and New York
- Bookman, A., and Morgen, S. (1988) "Carry It On': Continuing the Discussion and the Struggle." In *Women and Politics of Empowerment*, Edited by Ann Bookman and Sandra Morgen, 314-22. Philadelphia: Temple University Press.
- Bury, M. (1982) Chronic Illness As Biographical Disruption. *Sociology of Health And Illness* 4: 167-182
- Bury, M. (1995) Women and HIV/AIDS: Medical Issues. In L. Doyal, J. Naidoo, And T. Wilton (Eds.) *AIDS Setting a Feminist Agenda* (pp 30-41). London Taylor and Francis
- Bury, M. (2003) Sociological Theory and Chronic Illnes: Current perspectives And debates" *Austrian Journal of Sociology*, 27,4, 7-22
- Campbell, M. (2003) Dorothy Smith and Knowing the World We Live In. in *Journal of Sociology & Social Welfare*. March, Vol. 30, Issue 1, p3 p20
- Calderon, R. (1997) *Regional Accomplishments and Lessons Learned. Synopsis*. Latin America and Caribbean Regional Office, AIDS/CAP/Family Health International.
- Ciambrone, D., (2002) Informal Networks Among Women with HIV/AIDS: Present Support and Future Prospects, "Qualitative Health Research Vol. 876 (12-32)
- Ciambrone, D, (2003) *Women's experiences with HIV/AIDS: mending fractured selves*, NY: Haworth Press, 2003.
- Cohen, F., Durham, J. (1993) *Women, Children, and HIV/AIDS*. Springer Publishing Co. New York, NY.
- Corea, G. (1992). *The Invisible Epidemic*. New York: HarperCollins.
- Creswell, J. (1994) *Research Design: Qualitative and Quantitative Approaches*. Thousand Oaks. Ca. Sage Publications. London

- Crystal, S., and Sambamoorthi, U. (1996). Care Needs and Access to Care Among Women Living with HIV. In L. Sherr, C. Hankins, and L. Bennett (Eds) *Aids as a Gender Issue: Psychosocial Perspectives* (pp-191-196). London: Taylor and Francis
- Evans, R., M. Barer and Marmor. (1994) *Why are some people healthy and others not? The Determinants of Health of Populations*. New York: Walter de Gruyter, Inc.
- Frankish, CJ et al. (1996) "Health Impact Assessment as a Tool for Population Health Promotion and Public Policy." Institute of Health Promotion Research, University of British Columbia, Vancouver.
- Fundacion Agenda Colombia (2004) *VIH/SIDA y Desarrollo. Impacto Economico De las Ciencias Sociales y la cultura para detener la pandemia en Colombia y en America Latina*.
- El Congreso de Colombia. (1993) Ley 100 de 1993 100/Art.162.
- Garcia Abreu, A. Moguer, I and Cowgill, K., (2003) *HIV/AIDS in Latin American Countries –The Challenges Ahead*. The World Bank
- García, R. (1999) *Respuesta Estatal*. AIDS National Project in Colombia
- Gilkes, Cheryl Townsend (1994). "'If It Wasn't for the Women...': African-American Women, Community work, and Social Change" In *Women of Color in U.S. Society*, edited by Maxine Baca Zinn and Bonnie Thornton Dill. Philadelphia: Temple University Press.
- Green, L. Ottoson, J.M. (1999) *Community and Population Health*, Eight Edition. ECB McGraw-Hill Company Inc. USA
- Gumucio-Dragon, A. (2001) *Comunicacion para la Salud: El reto de la participación*. OPS/OMS
- Hope, K.R., (1999) *Aids and Development in Africa: A social science perspective*. The Haworth Press, Inc. Binghamton, N.Y.
- Instituto Nacional de Salud. (2003) "Sida: Situación en el mundo y en Colombia veinte años después" Editorial Revista *Biomédica*. Vol. 23, No. 3 October 2003.
- Kleinman, A., (1988) *The Illness Narratives: Suffering, Healing, and the Human Condition*. Basic Books, Inc., Publishers, NY
- Mancoske, R.J., & Smith, J.D., (2004) *Empowerment-based models and Program Applications*. The Haworth Press. New York- London- Oxford.

- Miguez-Burbano, M., Angarita, I., Shultz, J.M., Shor-Posner, G., Klaskala, W., Duque, J.L., Lai, H., Londono, B., Baum, M.K. (2000). "HIV-Related High Risk Sexual Behaviors and Practices among Women in Bogotá, Colombia". *Women & Health*. Vol. 30 (4), p.110.
- Ministerio de la Protección Social (2003) *Política Nacional de Salud Sexual y Reproductiva*.
- Ministerio de la Protección Social. (2004) Plan de Respuesta Intersectorial para el VIH/SIDA.
- Ministerio de Protección Social & ONUSIDA (2006) Infección por VIH y SIDA en Colombia. Estado del arte 2000-2005, Pro-offset Editorial Ltda. Colombia
- Naples, N. (1991) "Contradictions in the Gender Subtext of the War on Poverty: The Community Work and Resistance of the Women from Low-Income Communities". *Social Problems* 38, no.3 (August) 316- 32
- National Cancer Institute. (2001) *Theory at a Glance for Health Promotion Practice*. The National Institute of Health Communication
- Obregon, R., (2003). Lessons Learned from Asia, Africa and Latin America. Presentation at *Seminar on Global Perspectives on HIV/AIDS*
- Paredes N. (2004) La salud pública: entierro definitivo. En: Borrero, C, editor. Reelección: *el embrujo continúa*. Bogotá: Plataforma Colombiana de Derechos Económicos, Sociales y Culturales. Pp. 109-119
- Paternostro, S. (2001) *En la Tierra de Dios y del Hombre- Hablan las mujeres de America Latina*, Editorial Suramericana, Buenos Aires
- Piltrow, P, (2002) *Advancing Health Communication, the PCS Experience in the Field*.
- Ratzan, S.C. (1993) *AIDS effective Health Communication for the 90's*, Emerson University, Boston Massachusetts, 1993, p.5
- Rhodes, T (1997) Risk Theory in epidemic times: sex, drugs, and the social organization of 'risk behaviour' in *Sociology of Health and Illness* Vol.19 No. 2 pp 208-27. Blackwell Publishers Ltd. Editorial Board 1997. USA.
- Riascos, J.C. (2002) *En el Laberinto de la Esperanza*, Editorial Norma, Bogotá.
- Rodriguez-Trias, H. and Marte, C. (1995) Challenges and Possibilities: Women,

- HIV, and Health Care System in the 1990s. In B.E. Schneider and N.E. Stoller (Eds.), *Women Resisting AIDS: Feminist Strategies of Empowerment* (pp. 299-321). Philadelphia: Temple University Press
- Somekh, B. and Lewin, C. (2005) *Research Methods in the Social Sciences*. Sage Publications, London Thousand Oaks-New Delhi.
- Sommer, R.; Sommer, B. (2002) *A practical Guide to Behavioral Research: Tools and Techniques*. Fifth Edition. Oxford University Press, New York
- Springer, E. (1992) Reflections on women and HIV/AIDS in New York City and the United States, in *Working with Women with AIDS: Medical, Social, and Counselling Issues*, edited by Judy Bury, Val Morrison and Sheena McLachlan foreword by Margaret Jay. (Pag. 32-40) Tavistock/Routledge. London and New York
- Stanfeld, S. (2006) Social Support and Social Cohesion in *Social Health Determinants*, Second Ed. Oxford Press, New York
- The Global Fund. (2004) *Portfolio of Grants in Colombia*.
- Thomson, K. (1992) Being Positive, in *Working with Women with AIDS: Medical, Social, and Counselling Issues*, edited by Judy Bury, Val Morrison and Sheena McLachlan foreword by Margaret Jay. (Pag. 125-141) Tavistock/Routledge. London and New York
- UNAIDS and Pennsylvania State Univ. (1999) UNAIDS Communication Framework for HIV/AIDS
- UNAIDS, (2001) *Iniciativa Nacional para la reducción de la Transmisión vertical del VIH in Colombia*,
- UNAIDS, (2002) Epidemiological fact sheets on HIV/AIDS and Sexually Transmitted Infections, Update
- UNAIDS. (2004) *HIV/AIDS and Population in Developing Countries Application No. 169*. European Commission. Thematic Budget Line B-6212 – Project Summary
- UNDP/UNFPA/WHO/ World Bank (2003) – HIV infected women and their families: Psychosocial support and related issues – A Lit Review, Who/ HIV/ 2003/07
- UNFPA, (2004) *Strategic Guidance on HIV/AIDS Prevention*.

- USAID. (2002). *The "ABC's" of HIV Prevention Report of a USAID Technical Meeting on Behavior Change Approaches to Primary Prevention of HIV/AIDS*.
- Wengraf, T. (2001) *Qualitative Research Interviewing: Biographic Narrative and Semi-Structure Methods*. Sage publications
- Wilkinson, R. (1996) *Unhealthy Cities: The Afflictions of Inequality*. New York: Routledge
- Wilkinson, R.G. (1997) 'Health Inequalities: relative or absolute material standards?' *Education & Debate* (22 February).
- Wilkinson, R.G., in Marmot & Wilkinson, (2006) *Social Determinants of Health*, Second Ed., page 341. Oxford Press, New York.
- Wight, D. (1993) A re-assessment of health education on HIV/AIDS for young heterosexuals in *Health Education Research – Theory & Practice*, Oxford University Press, Vol.8 no.4 pages 473-483
- WHO. (1986). Health and Social Welfare Canada, and Canadian Association for Public Health. *Ottawa Charter Health Promotion*.