

Sisters Helping Sisters to

Thrive

THE WOMEN'S COLLECTIVE MODEL



Women Taking Power Over HIV and AIDS!

Acknowledgments

There are so many to be thanked in the making of this story. I am sincerely grateful to each and every one of them. A few individuals, however, stand out and I do want to recognize them.

First and foremost we want to extend our thanks to The Ford Foundation for providing The Women's Collective with funding to produce *Sisters Helping Sisters to Thrive: The Women's Collective Model*. It has long been a dream of the agency to produce a publication about The Women's Collective model of care that is practical so that others can adopt, adapt, and create their own services and programs for women, girls, and families. We are especially grateful for the continued support of Terry McGovern, our Ford Foundation project officer. From the beginning of this epidemic, Terry has been a true and long time advocate fighting for the rights and inclusion of women living with HIV/AIDS at all levels of policymaking. In fact it was not uncommon for Terry to literally take women to meetings where decisions about their lives were being made without **their** participation. She has never spoken for women, but rather she has encouraged and supported our ongoing struggles to have our voices heard and respected.

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Patricia Nalls
Founder and Executive Director
The Women's Collective

Dedication



Sisters Helping Sisters to Thrive: The Women's Collective Model is dedicated to:

- The memory of my beloved husband, Lenny, and my beautiful daughter, Tiffany, and to my son, Shawn, and my daughter, Nikki. Their love and unfailing support give me the courage to be a visible and vocal advocate, and continues to inspire and sustain me.
- Some of the most powerful, caring, beautiful, courageous and outrageous women who shared their stories of hope and resilience with other women, girls, and families living with or at risk for HIV/AIDS. They faced the stigma, discrimination, and oftentimes cruelty associated with HIV/AIDS, but refused to be silent or invisible.
- The women who were there at the beginning, when The Women's Collective was simply a support group/safe haven that met every first and third Saturday of each month, rain or shine.
- To the memory of staff we have lost physically but who remain alive in our hearts:

Aleta
Toni
Joanie
Wanda C.
Wanda M.
Bertha
Annabelle.
Elsy



Patricia Nalls
Founder and Executive Director
The Women's Collective

The Women's Collective Commitment Statement

We are committed, **first** and foremost, to **servicing** women, girls, and their families in an environment in which they are **treated with the respect and dignity** they deserve. We believe that each woman and girl **is unique**. With that uniqueness come **individual issues** and circumstances that affect her life that **must be respected**.

We make a commitment to:

- Recognize women and girls living with or at risk for HIV/AIDS as the experts.
- Respect the diversity of the women and girls we serve—we will not discriminate based on race, ethnicity, disability status, sexual orientation, income, or educational level.
- Address all breeches of confidentiality both outside and inside the organization in a swift, professional, and just manner.
- Fully inform women, girls, and their families around their options for accessing services, understanding treatment information, and care options.
- Provide women and girls with effective HIV prevention services and programming.
- Respect all decisions a woman, girl, or her family makes in regard to services, treatment education, and care options.
- Enable women and girls to be their own best advocates by providing support and empowerment components to all of our programs and services.
- Provide safe and confidential programs and services to all women and girls living with and at risk for HIV/AIDS and their families.
- Never breach confidentiality or trust by divulging information without the express permission of the woman, girl, or family member.
- Assist women, girls, and their family members with any grievance procedures they feel are necessary to address their concerns both inside and outside the organization.

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A Day at The Women's Collective: A Snapshot



You remember the many thresholds
you cross in your journey with HIV.

I remember the first day I came to The Women's Collective. I remember breathing deeply as I mentally prepared for the other side of the entrance, saying a silent prayer and affirmation and putting on protective armor to fight my fears, memories of past bad experiences, rejections, and ignorance that sometimes greeted me in other places.

Located in the middle of the block of a bustling and historic neighborhood, the building that houses The Women's Collective sits back far from the street. It could have easily been by design that you're allowed to enter a protective space the minute you step off the U Street sidewalk and then be drawn slowly for several yards into the beginning of a peaceful, protective, and safe space that seems to embrace you and usher you in to the first set of doors. It's a courtyard with flowers and plants lining the walkway with an open space that is empty except for

the unobtrusive few cars parked on one side that represent the tenants in the "cause" inhabited building.

Beginning on that first day and continuing now each time I come, I call up to the Collective on a phone, announce who I am, and ask permission to be let inside. The always pleasant voice on the other end buzzes me in and each time I feel a sense of gratitude for the privilege of being welcomed without question or judgment. A short ride to the second floor and you step off the elevator nearly facing the door.

I enter into the large front room and am immediately taken by the peaceful and colorful energy. The exposed brick walls are like reminders that the outside should be as safe as the inside. The walls are adorned with inspirational art and words, plants and flowers, candles and photos. Around the large table in the middle of the room are chairs, some taken by women from the staff working on their various projects; clients waiting to see their case managers, children waiting with their mothers or guardians but being free and enjoying themselves in the process; or visitors with appointments to see Pat, the Executive Director or staff. At one end of the room are a few work spaces for the receptionist and other staff. It is a very small space for such big work.

Invited to sit on one side of the table, I continue to take in this new environment which had just welcomed me. Facing the door, my eyes are drawn to an altar with a candle and a Memory Book. I rise to look at it and pay my respects to sisters who are now gone but not forgotten. Returning to my seat, I follow the life moving around me. In the small kitchen, clients and staff alike go in and out. Clients comfortably go into the refrigerator or the cabinets and find something to nourish them. A basket of snacks sits on the table, a water cooler, a coffee maker, microwave, and toaster add to the sense of home that The Women's Collective is for the hundreds of women it serves.

Information and tools affirming, saving, and honoring good health and life are displayed and available throughout the office. The Resource Room next to the kitchen is set up like a living room, with a sofa, a TV, computer stations, tapes, reading material, and videos. Some women are there resting, talking with one another, interacting with their children, or checking out employment and other services on the Internet. A few small, enclosed offices provide the privacy for confidential, and sometimes painful, talks between caring and loving staff and the women whose journey many share.

There is a lot of coming and going through the door. Some more mundane missions are underway such as going to the restrooms or out for lunch. And then becoming more and more normal, but far from mundane, are the women who walk in to be tested. Their nervous-

I enter into the large front room and am immediately taken by the peaceful and colorful energy.

ness is palpable. Some leave with faces of fear and sadness; others leave with relief, gratitude, and more information and tools about how to stay safe. All are shown love and respect and are able to see and experience a place to which they can return for ongoing support. A small group of staff in uniform—white T-shirts with The Women's Collective logo and purple aprons, approach the door to leave. I'm told that they are Outreach Workers from the Prevention Team who go out into the community on the mobile van, spreading the word about the importance of getting tested, prevention, and the love and support available to them at The Women's Collective. Some are tested on the spot, learn their results, and, whether positive or negative, given information and support about where they must go from there.

This is my first meeting with the Executive Director. She walks up, smiles, and greets me warmly. Along the way she greets other women in the large room, giving each one a hug and a few words of care and encouragement. This, as it turns out, is a normal day and the normal way at The Women's Collective. Women, and often their children, coming to share their stories, their joys, their pains; clients and staff alike becoming one, with overlapping and intersecting lives and experiences. The physical place is a small and modest one. But the spirits who meet, grow, and remain there are huge, permeating, nurturing, and transforming. It certainly stays with me as I walk back out the door and into the world of my total life, so very grateful for the enduring spirit of this space that continues to nourish and heal me as it does for so many others.

Introduction



She begins her story with her first memory, a dark hallway with a light hanging from the ceiling. Her second memory is of her in and out of a crib. She figures both memories go back to her life before she was two years old. She believes it is a metaphor for her HIV journey of seeking light, and answers, and road maps for a life without any....She is scarred by the losses of two of her own children and over the years by the losses of scores of women she has met and “mothered” in The Women’s Collective.

(An excerpt from The Women’s Collective Photo Documentary Project.)

Purpose of the Document

Women of color are the emerging face of the AIDS epidemic locally, nationally, and globally, but policies and services do not always reflect this important fact. In response to this reality, The Women’s Collective, since its inception, has developed an innovative, comprehensive, woman- and girl-focused, family-centered, peer-based, and culturally competent model of providing high-quality services for women of color living with or at risk for HIV/AIDS and their families. In doing so, it has become a vital organization in the fight against HIV/AIDS in the Washington, DC, metropolitan area, the nation, and the world.

To produce this document that describes its unparalleled approach to women’s HIV care, prevention, empowerment, and advocacy, The Women’s Collective has engaged in a lengthy, interactive process with staff, clients, Board members, volunteers, funders, and allies. In the pages that follow, the model used to provide quality HIV care and prevention services, and transformational opportunities for women and girls living with or at risk for HIV/AIDS and their families is shared.

The purpose of this document is to contribute to the growing body of knowledge of effective models for addressing the comprehensive needs of women and girls of color living with or at risk for HIV/AIDS in the United States and beyond. One intended outcome is to disseminate a useful framework and tested strategies that can be tailored to meet the diverse needs of women living with or at risk for HIV/AIDS in distinct social, economic, cultural, and geographic contexts.

Importance of Model Documentation

Why should The Women’s Collective document its model of service delivery? By engaging in a formal documentation process, the vision, values, and commitment of the many women and allies who have helped to give birth to the organization and nurture it through its



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developmental phases is captured. In addition, greater insight is gained into the unique features of the model and the core values that shape it. Documentation also provides other women-serving organizations with a prototype for the delivery of quality services and programs to women living with or at risk for HIV/AIDS and their families.

This document contains the following sections:

Section 1: Background briefly examines the disproportionate impact of HIV/AIDS on women and girls of color living in the United States and Washington, DC, and makes the case for why a woman-visioned, woman-focused, and woman-led response is necessary. It also details the history and evolution of The Women’s Collective as an AIDS service organization.

Section 2: Sisters Helping Sisters to Thrive: The Women’s Collective Model describes the core values that have influenced the model’s development over the years, the major components, and unique features, as well as key factors that have contributed to the model’s successful implementation and effectiveness.

Section 3: The Way Forward: A Collective Vision of the Future incorporates the views and voices of many women and girls who have walked through The Women’s Collective’s doors—staff, clients, Board members, and allies. It puts forth a vision for The Women’s Collective’s continued growth and sustainability in the future.

HIV/AIDS in the United States and the Nation's Capitol



In the United States, women of color bear a disproportionate burden of HIV/AIDS. According to recent data from the U.S. Centers for Disease Control and Prevention (CDC), HIV infection and AIDS especially affect women of color. In 2004 black and Hispanic women have been hardest hit by HIV accounting for 64 percent and 15 percent respectively of cases among U.S. women.¹

In Washington, DC, the HIV prevalence rate is twice the national average making it the highest of any city in the nation. One in 20 Washington, DC, residents is estimated to be living with HIV and 1 in 50 residents has AIDS. The situation is even more alarming for women. A report issued in 2007 by the District of Columbia Department of Health revealed that 9 out of every 10 women who tested positive for HIV in Washington, DC, between 2001 and 2006 were African American with heterosexual contact being the most common mode of HIV transmission.² These disturbing statistics speak to the scope and scale of the AIDS epidemic in Washington, DC, and the United States and underscore the urgency of responding to the needs of women living with or at risk HIV/AIDS.

It is well documented that African American and Hispanic women who reside in the District of Columbia are not just at risk for HIV, but they are also at risk for a host of other chronic illnesses such as hypertension, heart disease, diabetes, and breast cancer. According to the report, *The Status of Women in the States*, published by the Institute for Women's Policy Research, "*The District of Columbia falls dead last, at 51st out of all the states.... Women in the District have among the highest rates of heart disease and breast cancer in the nation, the highest incidence of AIDS, and the worst rates of poor mental health among women.*"³

Not only do women of color experience certain health risks at rates that are disproportionate to their numbers in the overall population, they are also at greater risk for poverty, unemployment, drug addiction, domestic/sexual violence, homelessness, family destabilization, and disempowerment. When women and girls of color become infected with HIV, the virus merely exacerbates existing social, economic, and health disparities. It is, therefore, essential that any



I first became connected to The Women's Collective when Pat came to the Partnership. At the time, they were still meeting in her dining room. She spoke about how the system had failed HIV-positive women and said that they had a new vision. So the Partnership invested in them by making a grant to The Women's Collective about 10 years ago. We believe that they are one of the most important organizations in DC serving women of color who were absolutely overlooked.

*J. Channing Wickham, Executive Director
Washington AIDS Partnership*

response to HIV that is targeted toward women and girls of color take into account the plethora of challenges that women face on a daily basis in living out their lives.

Behind each alarming statistic lies a woman's or girl's compelling story, a range of life experiences, and a unique set of circumstances. She may be living in a homeless shelter or living in her own home. She may be under-insured or uninsured. She may be working or she may be unemployed. She may be a college or high school student or she may have never graduated from 9th grade. She may be a native Washingtonian or she may have emigrated here from her native land. She may be wrestling with an addiction to alcohol or drugs or wrestling with the responsibilities of being a single mom. There are countless stories of HIV-positive women



Early on, many AIDS service providers did not take into account these barriers that frequently kept women from fully participating in HIV programs.

who are attempting to live life on their own terms, but must now factor into the equation the management of a chronic disease like HIV/AIDS. Cheyenne’s* story sums it up best:

Cheyenne has had her own share of challenges and difficulties. As a young woman coming of age, she began to feel the burden of womanhood. Rather than feeling adored or encouraged by her family, she felt degraded and humiliated. Her parents seldom complimented her, recognized her, or attended to her needs and she felt betrayed by them when they did not stand up for her or protect her from her grandmother’s pain and torture. At 18, she saw an opportunity to be

“rescued” when she met the father of her children. Cheyenne thought she found someone to love unconditionally, and someone who would love her back. Meeting him “changed my life,” she says. Something awful ensued that, again, was life-changing and life-scarring. She tells of how on Thanksgiving Day in 1990 she innocently accepted the offer of a ride from a man who took her to an isolated place and raped her. Like most victims of rape, she blamed herself and felt again betrayed by someone’s seeming kindness. When she told her boyfriend about what happened to her, he responded by hitting her rather than soothing, comforting, and loving her. She felt guilt and shame, and even worse that she deserved what she got that day.

The rapist did not use a condom and Cheyenne, now in hindsight, is thankful that her grandmother had put her on birth control pills, saving her from getting pregnant by the rapist. The rapist blatantly told her that he was going to give her something to die from. She thought that he was referring to the degrading rape. Unbeknownst to her, he was purposely giving her HIV. Cheyenne later finds out she is pregnant by her then-boyfriend. It is at that time that she is tested for HIV and is told of her positive status while in the waiting room of a hospital in Washington, DC.

*Cheyenne is the name used to protect the client’s confidentiality.

Cheyenne suffered 12 years of abuse from her children’s father. In terms of her physical health, she had pneumonia 13 times, lupus, and pulmonary hypertension, requiring the use of an oxygen tank. After 5 years, she no longer needed the oxygen. About 10 years ago, during the numerous visits to the hospital, she came to learn about The Women’s Collective from a social worker. She is one of the early “patrons” of the Coffee House and today she is one of the leaders among the women of the Collective.

Becoming more and more empowered each year, Cheyenne began to confront her alcohol addiction first through her participation in AA meetings. She was able to recognize her alcoholic-related behaviors and began to feel real love and acceptance from people in the AA fellowship. Her anniversary celebration at AA was most powerful and affirming for her. Through the AA fellowship and through therapy, complementary therapy, and other loving support from The Women’s Collective, Cheyenne is now able to accept and love herself. She recently “graduated” out of therapy and has declared that she is ready to move forward in her life, equipped with the tools that she needs. (Source: The Women’s Collective Photo Documentary Project)

Why a Woman-Focused and Family-Centered Response is Crucial

In the early years of the epidemic, the number of women living with HIV in the United States and the District of Columbia was relatively small and programs designed to meet their needs were nonexistent. Addressing the needs of women, particularly women of color, was not always the highest priority of government, public health officials, health care providers, and community-based agencies.

During the first decade of the epidemic, many of the support services and interventions in which women living with HIV/AIDS participated were designed and based upon male-centered models of care that focused on the needs of gay, white men. As the numbers and demographics of persons living with HIV/AIDS began to shift, advocacy efforts from many sectors resulted in the availability of funding and other resources for specific population groups (i.e., women, youth, intravenous drug users, commercial sex workers). Targeted interventions designed to reach broader populations infected with HIV began to be initiated throughout the country.

Even well-intentioned AIDS service organizations did not always reach the mark in providing comprehensive services to women. For example, most programs employing male-based models of care and support did not understand that many female clients had the increased responsibilities of being mothers, single heads of households, and caregivers to their parents and extended family members. Women living with or

at risk for HIV/AIDS were often more focused on meeting their children’s and family’s needs. To offer effective programming for HIV-positive women, especially women of color, factoring in the needs of their families, as well as their personal need for respite from the duties of parenting and caretaking, would be critical to their management of HIV.

Early on, many AIDS service providers did not take into account these barriers that frequently kept women from fully participating in HIV programs. Often women were blamed for lack of attendance or follow-through with appointments largely because the workings of women’s lives were not understood, recognized, or honored. More often than not, in the early years of the epidemic, male members dominated support groups with only a few women present. For women who chose to participate in HIV support groups, they were usually unable to do so regularly because they lacked access to affordable child care and transportation, or because the hours fell during critical family dinner and homework times. The responsibility many women felt toward their children and families superseded the attention they gave to their own health.



Women of color did not always feel that their particular needs were adequately understood or met by many of the early HIV/AIDS programs. To fill the gap, women began gathering together in women-led support groups and sister circles to obtain support from their peers. In these settings, they were able to address the needs of their families, express their fear of disclosure to their children and partners, exchange information on new drug therapies and clinical trials, and learn which health and social service providers were sensitive to their needs. In the 1990s, services for addressing the unique and complex needs of HIV-positive women were largely fragmented and not comprehensive. However, as the numbers of women living with or at risk HIV/AIDS in Washington, DC, and the surrounding metropolitan area grew, the need for a woman-focused, family-centered, peer-based, and culturally competent approach became critical.

Given the current realities of the epidemic, comprehensive HIV care, treatment, prevention, and support services for women of color are more vital today than they were 25 years ago. Any approach that focuses only on a woman's or girl's HIV status, however well-intentioned, may not be effective because it will not address the other important aspects of her life and well-being.

The Women's Collective in the Formative Years

In 1987, after losing her husband and 3-year-old daughter to AIDS within six months of each other, Patricia Nalls, Founder and Executive Director of The Women's Collective, learned that she was HIV positive. At the time of her diagnosis, there were few, if any services designed specifically for women living with and at risk for HIV/AIDS in the Washington, DC, metropolitan area. In fact, at the time, few people understood or acknowledged that women could be, and were being, infected with HIV.

Pat found herself repeatedly trying to receive support and services in an environment that catered mainly to gay men. As a single mother, her family's needs were different and distinct from those of men. Like many women, she frequently found herself in situations where she faced challenges, not only as a woman, but also as a single head of household. While the men in the support group were having conversations about their single lifestyles, Pat worried about how to disclose her status to her children, how to deal with the grief her children were experiencing, and who would take care of her children if she got sick or died. It was a time fraught with anxiety by the secret of her diagnosis, which began as despair yet ultimately turned into the determination to live to see her children grow to adults.

Eventually, in 1990, to receive and give support to other women in similar situations, Pat set-up a private phone line in her home for women living with HIV to share their struggles and concerns. The phone line, which she advertised through flyers in her doctor's office, gave her and the women she spoke to strength and hope in knowing that other women in their community were in similar situations, dealing with similar worries. Over time, the phone line, kept secret because of the stigma that existed, transformed into a support group as the number of women affected by the epidemic increased. The group called itself the Coffee House to allow women to freely participate without having



to worry about disclosing their HIV status. It provided a safe space for women to come together and laugh, cry, share resources, and gain strength from each other. The group proved to be a powerful vehicle for women. As their numbers grew, so did their knowledge of HIV care and services.

In 1995, a friend involved as a volunteer supporting the Coffee House, suggested that the women incorporate as a non-profit organization. The Women's Collective was the name stated on the application to the Internal Revenue Service. A Board of Directors was established and new energy and skills were injected into the Coffee House. The goal was to support women and their families and to realize a vision of creating a full-fledged, woman-focused organization. Board members organized events, set up training sessions, and slowly began to identify funding sources, enabling support group members to realize their vision. Women in the Coffee House also began advocacy efforts with local providers, policymakers, and the District of Columbia Department of Health.

Based on her personal experience and that of the women in the support group, Pat and a long-time supporter and then-Board Member Belinda Rochelle, began applying for small grants to support The Women's Collective's desire to reach more women in concrete ways. To support programs and services over the past 20 years, funding from many sources including federal and local government agencies, philanthropic foundations, and businesses has been received. In addition, a wide variety of in-kind services have been donated from members of the local community to strengthen programming to women and their families.

A first grant of \$5,000 was received in December 1996 from the Ms Foundation's Women and AIDS Fund to support group activities emphasizing empowerment and advocacy. In June 1997, the Washington AIDS Partnership provided a grant that enabled the Board to conduct a peer-based training for women living with HIV/AIDS and to place them in HIV testing sites around the region to speak with women, share their stories, pass on HIV prevention information, and distribute Coffee House support group flyers. This program, called *Sisters Helping Sisters to Survive*, was the first formal programmatic effort launched to reach, teach, and empower women.

Women who participated in the program were motivated by their negative experiences in HIV counseling and testing, in seeking care, and in disclosing their status to health professionals. After receiving a positive HIV diagnosis, some women were simply given a business card and sent out of offices by themselves with no support. Others were



When I was diagnosed with HIV, I isolated myself from help and support. I was told I had two years to live. I thought I had to deal with this by myself. I looked at my two surviving children, who at the time were ages 4 and 8, and all I could think of was what was going to happen to them. I stayed in a self-imposed exile for two years before I realized I wasn't dying and that I wasn't actually living either. And living with HIV is what I had to do for their sake and mine.

*Patricia Nalls, Founder and Executive Director
The Women's Collective*

told over the phone, and still others were just handed some condoms—all entirely inadequate responses. A few women from the Coffee House shared that they wanted to commit suicide upon receiving the news of their diagnosis. With no support or connections, women were left on their own with the terrifying news that they were HIV positive. Most felt like they were the only ones living with HIV. *Sisters Helping Sisters to Survive* was designed to prevent these experiences from happening by connecting women to The Women's Collective before and after the testing process.

In 1998, two additional grants were received from the Ms Foundation's Women and AIDS Fund and the Washington AIDS Partnership. The grant from Ms Foundation enabled The Women's Collective to develop the *Fighting for Our Lives* advocacy training conferences for women living with HIV/AIDS. An extension of the grant provided technical assistance in building organizational infrastructure, developing Board member capacity, and purchasing the first computer.



The Washington AIDS Partnership's second grant was earmarked for organizational development. This support made it possible to move The Women's Collective from Pat's dining room to an office space, and to hire a full-time staff member, Cathleen Maine, who was at the time a volunteer. The first office was a two-room space with a kitchen on Connecticut Avenue, NW, where the building owner, impressed by the women's sense of passion and mission, rented The Women's Collective its first office.

In 1999, Pat and a small group of women from The Women's Collective met with Adisa Douglas, Senior Program Officer at the Public Welfare Foundation, at the new space without a single piece of furniture. With nothing more than a computer on the floor and some pillows to sit on, the women shared what The Women's Collective meant to them and their desire to create a new model of service delivery for women and families. With general support funds from the Public Welfare Foundation, The Women's Collective formally began helping women identify appropriate services for themselves and their family members and helping them in managing the everyday realities of living with the disease. Adisa Douglas states, *"There is one thing that The Women's Collective does well and that is creating a safe space for women. Every woman who walks through the door is important. And no single woman is more important than anyone else. Services are provided by HIV-positive women who understand the women who walk through the door because they are those women!"*

An initial grant from the Washington, DC, Department of Health, HIV/AIDS Administration (HAA) came in 1999. With these funds from the Ryan White CARE Act Title I Program (now known as Part A), the organization was able to implement the *Access Advocacy Program*. This funding resulted in hiring a full-time peer to conduct outreach to newly diagnosed women, seek out HIV-positive women who were out of the system of care, and to provide them with referrals to care services and support. This program made it possible for women to have a critical link to a peer who could share her personal experiences and support her in concrete ways because the peer understood the realities of an HIV diagnosis.

A second grant from HAA in 1999 through Ryan White CARE Act Title II (now known as Part B) funds provided a full-time case manager to act as an advocate and resource to ensure women and families were linked to care and services. This initiative grew into a family-centered program that was awarded a demonstration grant before it was institutionalized into the overall organization. In 2000, The Women's Collective formally added HIV prevention services with a peer-based outreach and referral program through additional funding received from HAA.



To ensure the needs of women living with HIV were recognized by policymakers, The Women's Collective was simultaneously making women's voices heard at Ryan White Title I Planning Council meetings and in other policy- and decision-making settings. The organization worked tirelessly to ensure that the perspectives and voices of women of color living with or at risk for HIV/AIDS were represented at the very tables where decisions were being made that irrevocably affected their lives. Advocates demanded that child care be made available at important meetings so that mothers, grandmothers, and caregivers could participate. They highlighted the power imbalance in male-female relationships that led to an increased rate of HIV infection in women and provided critical information to the media and policymakers. According to Desiree Flores, Program Officer for Health at the Ms Foundation's Women and AIDS Fund, The Women's Collective was one of the Fund's first grantees to equip women to do policy and advocacy work. Ms. Flores summed it up best by stating that *"The Women's Collective is an organization made up of women living with HIV/AIDS everyday who are committed to leaving things better off for the next generation."*

Over the course of 20 years, The Women's Collective has evolved from the single vision of one woman to the collective vision of many women. Because of the efforts of committed women, coupled with support from community allies, volunteers, and funders, the organiza-

The Women's Collective is an organization made up of women living with HIV/AIDS everyday who are committed to leaving things better off for the next generation.

tion has transformed itself from a dining room support group to a full-fledged 501(c)(3) non-profit organization. Through grants that focused on institutional strengthening, an administrative and programmatic infrastructure was created to support a growing number of HIV care and prevention programs. Advocacy projects were initiated that focus on influencing HIV policy in the United States and globally by mobilizing women living with or at risk for HIV/AIDS to give voice to their concerns.

Exhibit 1, below, includes a timeline that highlights key milestones and defining moments in The Women's Collective history:

Exhibit 1: Timeline of Major Milestones and Defining Moments

DATE	MILESTONES/DEFINING MOMENTS	BACKGROUND NOTES FROM FOUNDER
1990	Pat develops a flyer and puts a secret telephone in her home and begins speaking with women on the phone in an attempt to get and give support without women showing their faces.	<i>"I did this because I wanted to meet other women living with HIV/AIDS; I thought that I was the only woman with this disease; I was living in total isolation without disclosure to family, friends, or coworkers."</i>
1993	In addition to telephone support, support groups are now held in Pat's home around the dining room table for those who are comfortable with showing their faces.	<i>"We were quickly discovering that our needs as women were not being met."</i>
1995	The Women's Collective (TWC) becomes incorporated as an organization in Washington, DC. Coffee House meetings are held outside of the home in more public venues.	<i>"Upon the advice and help of a supporter, Articles of Incorporation and By Laws were established and filed in Washington, DC. A group of friends choose the name The Women's Collective as it represents sisterhood, yet didn't reveal the nature of the agency in its name."</i>
1995	The Women's Collective receives 501(c)(3) status from the Internal Revenue Service for a preliminary period of 5 years.	<i>"Through the assistance of a dedicated Board member who understood the long-term implications of applying for nonprofit status, we were able to begin to build an agency."</i>
1995-1997	Pat is a key consultant with the Metro DC Collaborative for Women Living with HIV/AIDS Project. This project is designed to train, empower and link women living with HIV/AIDS to local and national policymakers to change policy to include the needs of women.	<i>"Many women from the Coffee House were recruited to participate in the project and after the women were empowered and trained, they began to meet with policymakers in structured dialogue in order to create an awareness of the issues and needs of women. As a consultant on the project, I was able to ensure that the project's direction and its activities were in line with women's needs. I was nominated to the Ryan White Title I Planning Council, making sure that federal funds are spent fairly and represent the needs of women with HIV/AIDS."</i>
1997	TWC receives its first (\$5,000) of three grants from the Ms Foundation Women and AIDS Fund.	<i>"Our first grant application was submitted by a Board member and funds were used to support advocacy and empowerment training, in addition to establishment of the agency infrastructure and Board development activities."</i>
1998	TWC receives the first of dozens of grants from the Washington AIDS Partnership (WAP) for the Sisters Helping Sisters to Survive (SHSS) program. WAP remains an outstanding and long-term supporter of The Women's Collective's mission.	<i>"Sisters Helping Sisters to Survive was conceptualized by women of the Coffee House and Board member and the grant application was submitted by a Board member. The project placed women living with HIV/AIDS in testing sites in Washington, DC, and provided women with prevention information and referrals in addition to peer counseling. This gave newly diagnosed women the tools, safe space, and hope they desperately needed to make it through that critical stage while also sharing their stories and expertise. Board members developed SHSS training manual and held one-day training at my home."</i>
1998	TWC receives the second Washington AIDS Partnership grant to hire staff and obtain office space at 1875 Connecticut Ave, NW.	<i>"This grant enabled the hiring of our first staff person who worked with me from August 1998 to July 1999 to identify office space, research grant opportunities, set up the agency infrastructure, and organize financial records."</i>

DATE	MILESTONES/DEFINING MOMENTS	BACKGROUND NOTES FROM FOUNDER
1999 March	TWC receives its first Department of Health HIV/AIDS Administration grant from the Ryan White CARE Act Title I Program for the Access Advocacy project.	<i>"The Access Advocacy project enabled the agency to hire a Peer Advocate who conducted outreach to women in the broader community seeking to identify women living with HIV/AIDS. The Peer Advocate also provided peer support/counseling, referrals, and other information. The Women's Collective operated this instrumental program for eight years."</i>
1999 April	TWC receives its first Department of Health, HIV/AIDS Administration grant from the Ryan White CARE Act Title II for the Case Management program.	<i>"This grant enabled the formal development of a case management program, which up to this date had been informal and carried out by women in the Coffee House. With the advent of this grant, a case manager was hired full-time and women were enrolled into care and provided with critical assistance in accessing services and support."</i>
2000 January	TWC secures vital general support funding from the Public Welfare Foundation, which becomes an outstanding and long standing ally.	<i>"After meeting on the floor of The Women's Collective with Adisa Douglas, Senior Program Officer of the Public Welfare Foundation, vital funding was secured and remained in place until the Foundation's priorities shifted in 2008."</i>
2000 January	TWC secures funding from the HIV/AIDS Administration for HIV prevention activities targeting black women in the District of Columbia.	<i>"TWC carried out several HIV prevention interventions including outreach and referral services, individual, group, and community level interventions, and Fighting For Our Lives, a primary and secondary prevention conference for women living with and at risk for HIV/AIDS."</i>
2000 June	TWC receives final approval from the Internal Revenue Service of The Women's Collective 501(c)(3) status.	<i>"This confirmed our standing as a 501(c)(3) and enabled us to continue our operations."</i>
2000 July	The offices are moved from 1875 Connecticut Avenue, NW to 1436 U Street, NW.	<i>"In order to accommodate a growing staff and expanded activities, a larger office space was needed."</i>
2001 April	The Women's Collective successfully becomes a demonstration site for Family-Centered Case Management services in Washington, DC. TWC proves the validity of these services in assisting women and families resulting in family-centered case management services becoming a standard of care in the Eligible Metropolitan Area. Family-centered care is something that TWC demands while having a voice on the Ryan White Planning Council.	<i>"These funds were dispersed through a DC Department of Health, HIV/AIDS Administration grant from the Ryan White CARE Act Title II Demonstration Grant. The Women's Collective continues to implement this program, which is a core part of our overall HIV care management program."</i>
2003 January	An addition of woman-centered HIV counseling, testing, and referral (CTR) services is made to the HIV prevention program, making it the first of its kind in Washington, DC, to target women.	<i>"After a local AIDS service organization, Us Helping Us, placed HIV testers at The Women's Collective for 12 months, TWC applied for and received our own Counseling, Testing, and Referral grant for implementation."</i>

DATE	MILESTONES/DEFINING MOMENTS	BACKGROUND NOTES FROM FOUNDER
2004 April	A new programmatic thrust of providing group-level interventions to black women living with HIV/AIDS is initiated beginning the Prevention with Positives Program (PWP).	<i>“Initially funded under Ryan White CARE Act Title II, the Positive Perspectives program transitions to the Prevention with Positives Program. TWC developed its own group-level curriculum, Prosper!, addressing the specific primary and secondary prevention needs of black women living with HIV and supplements the CDC intervention, Healthy Relationships.”</i>
2004 April	This new programmatic thrust receives additional support to sustain it for many years.	Note: <i>Prosper!</i> went through two years of development with funding from Washington AIDS Partnership, Johnson & Johnson, and the National AIDS Fund under the GENERATIONS: Women and Families Initiative. In March, 2007, HAA funds <i>Prosper!</i> as part of its Prevention with Persons Living with HIV/AIDS Program.
2004 July	The U.S. Centers for Disease Control and Prevention (CDC), for the first time, makes prevention funding available to community-based organizations (CBOs). TWC receives direct funding to implement HIV Counseling, Testing, and Referral Services (CTR) targeted to black women.	<i>“This grant eliminated the pass-through to the DC Department of Health, HIV/AIDS Administration and enables TWC to work directly with CDC on CTR. TWC purchased and maintained its mobile testing unit, which reaches deep into the areas in the Washington, DC, where infection rates are highest.”</i>
2005 March	Additional HIV care management services are added to TWC’s services with Ryan White CARE Act funds. These include Mental Health Therapy and Complementary Care Services.	<i>“We learned over time that women needed additional in-house services to alleviate additional referrals that stood as barriers to women accessing services that had an impact on their mental and physical health.”</i>
2006 August	TWC formalizes its long history of advocacy by creating the Policy & Advocacy program through funding by the Ford Foundation, Human Rights Division.	<i>“Building on our long grassroots history, TWC is approached by the Ford Foundation in an unusual move to provide funding to smaller CBOs. This helped to create a national coalition of women living with HIV/AIDS to address women and AIDS policy while developing the TWC model for dissemination. TA was given to providers in need of models to support services for women living with HIV, with an emphasis on the rural South and Mid-Atlantic region.”</i>
2007 September	The Office on Women’s Health (OWH) awards a grant to TWC under the Intergenerational Approaches to HIV/AIDS Prevention in Women Across the Lifespan Pilot Program. The program is refunded in 2008.	<i>“This opportunity enabled TWC to design an innovative group level intervention, using our own curriculum titled Sisters InterActing (SisterAct), to work with African American women ages 12 and up, with an emphasis on girls and young women’s kinship networks. The intervention seeks to promote healthy communication, empower women and girls to know their status, and reduce their risk for HIV.”</i>
2008 June	The M•A•C AIDS Fund awards TWC a grant, one of eleven from around the world, under its Global Youth HIV-Prevention Initiative. This funding enables the agency to build on its work with youth.	<i>“We were thrilled to receive this funding to strengthen our work with young women ages 12-25 in DC who are at risk. The HIV infection rate for young women is alarming and we feel compelled to increase their awareness and knowledge with our Between Us Girls curriculum, while empowering them to become active voices for HIV prevention in their communities through a service learning component.”</i>
2009	The Women’s Collective moves to a new office space to accommodate a larger staff and increased programmatic activities.	<i>“With the increase in staff and programs, additional space is required to effectively implement programs and services for clients and their families.”</i>

Two Decades Later: Evolution of The Women’s Collective

Since its inception, The Women’s Collective has evolved into an organization with over 25 dedicated staff members, countless committed volunteers and allies, and a Board of Directors with a diverse set of skills. A key to its success is having a clearly defined vision, mission, and set of core values; a cadre of skilled, committed staff, volunteers, and Board members; institutionalized and rigorous financial management systems and procedures; and an organizational structure that supports programmatic activities and ongoing reflection and evaluation processes.

To accomplish its mission, The Women’s Collective is structured into four distinct departments, or teams—HIV Care Management, HIV Prevention, Policy & Advocacy, and Administration.

- **HIV Care Management.** The HIV Care Management Team provides the essential services for women and girls living with or at risk for HIV/AIDS and their families, including family-centered case management, which assists them in identifying their needs and seeking resources (i.e., primary medical care, housing, food, and medicines) and solutions. In addition, care management services include mental health therapy services, comprehensive risk and counseling services (CRCS), group-level skills-building interventions, such as the Prevention with Positives (PWP) program designed to assist women of color living with HIV with behavior modification techniques to protect themselves, disclose their status to family and partners, adhere to their medication, and live a healthier lifestyle. The HIV Care Management Team is also tasked with implementing support activities to respond to the self-identified needs of women and their families.
- **HIV Prevention.** The HIV Prevention Team implements a wide range of primary and secondary prevention interventions, including, but not limited to in-house and mobile HIV counseling, testing, and referral services (CTR) and prevention education outreach and referral services. HIV prevention programming includes individual-, group-, and community-level interventions on HIV prevention, risk reduction, and behavior change for African American women and girls. Efforts are focused on strengthening intergenerational communication through HIV prevention and risk reduction initiatives.
- **Policy & Advocacy.** The Policy & Advocacy Team promotes women’s involvement in policy advocacy and is viewed as an important aspect of the work. The voices of women living with or at risk for HIV/AIDS are often absent in venues where health policies are formulated that impact women’s access to life-saving medicines or technologies and plans are developed to determine their needs. Therefore, a necessary

Since its inception, The Women’s Collective has evolved into an organization with over 25 dedicated staff members, countless committed volunteers and allies, and a Board of Directors with a diverse set of skills.

part of the work of the Policy & Advocacy Team is to provide women with information about key policy issues so that they can speak with authority to the issues that affect the quality of their everyday lives. Involvement in advocacy is an important part of this Team’s work as it provides a mechanism for women to speak for themselves and have their experiences in living with HIV made known to a larger audience of policymakers and funders.

This team works at the local, state, national, and global levels to ensure the voices and concerns of women of color living with HIV/AIDS are heard at key policymaking tables. Women living with HIV/AIDS are nurtured and trained to serve as policy advocates. The Team works with women to build their communication, advocacy, policy analysis, and outreach skills and to ensure the long-term involvement of women living with HIV in policy conversations.

- **Administration.** The Administration Team ensures that the day-to-day operations that support program implementation are carried out efficiently and effectively. The primary activities include: fiscal management, human resources management and development, facility management, grant writing and reporting, program development and monitoring, Board relations, and fundraising activities. The overall goal of this Team is to monitor the fiscal security and strategic development of the organization over time in an ever-changing and demanding environment.

Sisters Helping Sisters to Thrive: The Women's Collective Model



TWC is unique in that its policy work is totally authentic because it is based on the needs of the women they serve. It is one of the few DC advocacy groups with a direct services component. They know what women need and that's what they fight for in their advocacy work.

Terry McGovern, Program Officer, Ford Foundation

The aim of The Women's Collective Model is to meet the self-defined needs of women and girls living with or at risk for HIV/AIDS and their families. This is accomplished primarily by reducing barriers to care, strengthening networks of support, providing essential services, empowering women and girls to advocate for themselves, and assisting them in transforming their lives. The term "model" is defined here as a collection of programs, interventions, and approaches that have been demonstrated to be effective over a period of time and that have been adapted and adopted by others. A model grows out of a particular context and may be replicated with some adaptations. While neither perfect nor static, The Women's Collective Model is a useful approach that can be adapted to fit different social, cultural, and geographical contexts in addressing women's needs.

To provide an in-depth description of The Women's Collective Model, this section is organized around six sub-themes: Core Values, Unique Features of the Model, Major Components of the Model, Effective Implementation of the Model, Sustainability of the Model, and Lessons Learned in Implementing the Model.

Core Values Underlying The Women's Collective Model

The Women's Collective has adopted a set of **13 core values** that inform its mission, philosophy, programs, and services. The following core values influence the planning and implementation of all programs, services, activities, and advocacy efforts:

- **Value #1: Peer Leadership.** Women and girls living with and at risk for HIV/AIDS are in the best position to provide leadership to the organization because they know firsthand the struggles, challenges, and needs of clients and their families. Through peer leadership, the perspectives of women and girls living with HIV/AIDS are integrated into programmatic activities and impact all decision making.

- **Value #2: Equality.** Every woman and girl who comes through the door of The Women's Collective is equal to those who came before her, regardless of education, age, income level, work experience, credentials, job title, personal circumstances, or life story.

- **Value #3: Respect, Acceptance, and Non-Judgment.** All women and girls are treated with the highest degree of respect and dignity and are not judged based upon their lifestyles, life choices, or life stories. The Women's Collective fosters an environment where the values of respect, acceptance, and non-judgment are practiced on a daily basis. When women revert to behaviors that place them at risk, they may stay away from the organization for long periods of time. Whenever they return, they are always welcomed back into the fold and treated kindly, respectfully, and non-judgmentally.

- **Value #4: Compassion.** A genuine sensitivity to the needs and concerns of women, girls, and staff is exhibited by all who are involved in The Women's Collective's programs, services, and activities. Staff are continuously encouraged to "walk a mile in another sister's shoes" and to feel her joy, fears, anxieties, hope, and pain.

- **Value #5: Empowerment.** Empowerment of women, girls, and staff is foundational to the



Empowerment of women, girls, and staff is foundational to the mission of The Women's Collective.



The Women’s Collective is committed to providing the highest quality programs and services that improve the health and transform the lives of women and girls.

mission of The Women’s Collective, as is creating an organizational culture where women and girls become empowered with marketable job skills and professional development opportunities that help them to grow.

- **Value #6: Health and Well Being.** The Women’s Collective is devoted to promoting the mental, physical, emotional, and spiritual health and well being of women, girls, and staff, and to encouraging all to live healthy and full lives.

- **Value #7: Transformation and Restoration.** Personal transformation and restoration are core values that are woven throughout all programs, services, and activities of The Women’s Collective. Women, girls, and staff are mentored and supported to become their best, most confident selves and are given a sense of power and hope that helps them to restore their own lives and transform their circumstances.

- **Value #8: Cooperation and Teamwork.** To deliver effective services to women, girls, and their families, staff agree to work collaboratively and to adopt a spirit of teamwork. The focus is placed on cooperation and collective responsibility versus competition and individualism. Each staff member strives to work collegially with her peers to ensure the success of the organization, and not just of her own individual program.

- **Value #9: Commitment to Excellence.** The Women’s Collective is committed to providing the highest quality programs and services that improve the health and transform the lives of women and girls.

- **Value #10: Commitment to Families.** Central to its mission is a commitment to focus, not solely on the needs of women and girls, but on the needs of families as well. There is a commitment to accepting, without judgment, the self-defined family in all its various forms.

- **Value #11: Commitment to Creating a Safe Space.** Clients are often dealing with complex issues such as sexual and domestic violence, drug addiction, homelessness, and stigma, which make their lives unsafe. They need a sanctuary filled with warmth, acceptance, and love. Offering a safe space to women, girls, and their families is a core value of The Women’s Collective.

- **Value #12: Commitment to Creating a Healing and Stigma-Free Space.** There is a commitment to creating a warm, comforting, healing, and stigma-free space for women, girls, and their families and making this an important feature of any program or service that is delivered.

- **Value #13: Commitment to Creating Effective Advocates.** The Women’s Collective is dedicated to supporting policy advocacy by and for women and girls living with or at risk for HIV/AIDS and building the capacity of HIV-positive women and girls to advocate for themselves.

These 13 core values have become organizational norms for The Women’s Collective and are key elements of every client interaction. The values operate at every level of program planning, implementation, evaluation, and administration. Adopting this set of core values has led to the creation of an environment where women and girls feel a sense of ownership, warmth, welcome, love, acceptance, safety, and hope. One client put it this way, *“I am honored every day that I walk in and see that there is a safe place that women can come and get what they need—the very thing that I didn’t get when I was first diagnosed. So it gives me great pride to know that there is now a place to go when you’re diagnosed to be treated with love and dignity.”*

Every staff member is committed to fostering and sustaining a safe and nurturing space for clients and staff whether they are on the mobile HIV testing van, in the kitchen or food pantry, at a Coffee House gathering, or in a counselor’s office. One staff member said, *“We always want to create a relaxed atmosphere for our clients. We set the tone by personally greeting women at the door and making them feel as though they are being welcomed by a long-lost friend when they walk into the office space.”*

Unique Features of the Model

In-depth interviews with a cross-section of individuals who have been involved with The Women’s Collective throughout the years have

resulted in the identification of **13 unique features** of The Women’s Collective Model. The following elements describe the model’s defining features:

- **Woman-Visioned.** The vision for The Women’s Collective came from the mind and heart of a committed, compassionate HIV-positive woman who founded the organization *with* HIV-positive women to meet the needs *of* HIV-positive women.

- **Woman-Focused.** All organizational resources are focused on serving women and addressing their specific needs. This approach recognizes that women are different from men, and that programs must be designed that reflect these differences. At The Women’s Collective, HIV-positive women and girls are not included as a footnote in program planning and implementation but are viewed as the main focus of the work.

- **Woman-Led & Managed.** The Women’s Collective is led by a dynamic team of women who are committed to nurturing staff, implementing effective programs, managing a growing organization, and advocating for women’s needs in local, national, and global settings. The Women’s Collective is managed by a talented, all-female staff with skills in administration, financial management, human resources, program planning, program implementation and evaluation, community outreach, counseling, case management, and fundraising. It is staffed by HIV-positive women, as well as HIV-negative women, who are sensitive and committed to meeting clients’ diverse needs.

- **Peer-Based.** Since many staff members are women of color living with HIV/AIDS, a unique



peer relationship is established with clients. This provides new clients with support from another woman who shares her same experiences, anxieties, fears, and hopes. Experience has shown that women and girls living with HIV are often more comfortable receiving services from members of their own peer group. Using a peer-based approach, clients are mentored to become volunteers, and eventually staff members, enabling them to learn new skills and serve as peers to other women. It is understood that a woman living with HIV/AIDS is in a unique position to help a peer who is living with HIV/AIDS to find ways to address her needs.

- **Client-Centered.** The primary focus is on meeting the HIV related needs of the client and her family, including those needs that go well beyond HIV/AIDS. The needs of clients determine the types of services that are offered by The Women's Collective. Being client-centered means working with each client to determine what her concerns are and creating services around these self-identified needs.
- **Family-Centered.** Many of The Women's Collective's clients are part of a family unit that may also need services and support, therefore supporting families is another way of supporting women. Children and family members of clients are always welcome at the office and it is not unusual to see children being hugged by staff or hearing them refer to staff members as "Auntie." Clients, staff, volunteers, and Board members also feel they are part of an extended, loving, and caring family system. A strong bond of sisterhood and motherhood exists among clients, staff, volunteers, and Board members. This results in women caring for and supporting one another, regardless of their role in The Women's Collective.

- **Culturally Competent.** Women and girls who seek services from The Women's Collective come from different cultures, backgrounds, and traditions. Programs, services, and activities are planned in a manner that takes into account the unique cultural context from which clients come. Staff are trained to deliver culturally sensitive and competent services.
- **Comprehensive and Holistic.** Client services are comprehensive in scope and do not follow a one-size-fits-all design. Women and girls have different needs, so different approaches must be taken to ensure that programs and services address women where they are. Therefore, a broad range of comprehensive care management, prevention, and family support services have been customized to fit client's lives based on their self-identified needs. The continuum of services offered to clients is also holistic, speaking to the needs of the "whole person"—physically, mentally, spiritually, and emotionally.
- **Capacity Building.** Since its inception, The Women's Collective has been intentional about building the capacity of its clients and staff. Many women who started out as clients have become staff and Board members. Many other clients have gained marketable skills by volunteering in the office and using the Resource Room. This increased capacity and confidence has enabled women and girls to start their own businesses, find satisfying jobs, take professional development courses, or return to school to earn their high school diploma or college degree.
- **Empowerment-Oriented.** Women and girls are educated and supported to take personal responsibility for their health and their lives, and to assume leadership roles in the organization, in business, and the wider community. A culture of empowerment exists at The Women's Collective and it is the single thread that ties together our vision, values, programs, and services. Clients and staff are empowered with information and resources, but most of all women and girls are empowered with hope.
- **Outcome-Oriented.** All programs and services are outcome-oriented and have an evaluation component that helps to measure program success and assess whether the work with clients is effective. An intensive referral system has been established to support clients as they move through the community accessing additional services.
- **Advocacy-Oriented.** Advocacy for HIV-positive women and girls, by HIV-positive women and girls, and with HIV-positive women and girls is a priority. The Women's Collective is committed to developing a cadre of women who are effective advocates for their own needs, as well as the needs of their families and communities. Women and girls



living with or at risk for HIV/AIDS are encouraged to speak up and speak out for themselves, and to impact policies that directly affect the quality of their lives.

- **Creative Use of Office Space.** The Women's Collective has a finite amount of office space to use for HIV/AIDS programming and service delivery with women and their families. A unique feature of this model is how a single open space and a few offices have been maximized for multiple programmatic purposes. Depending on the occasion, the existing space has been used as a Coffee House, spa, and conference center, as well as for special events and memorial services.

Major Components of the Model

There are four major components of The Women's Collective's Model: HIV Care Management, HIV Prevention, Policy & Advocacy, and Administration. Each of these components are intentionally designed to be interdependent so that efforts can be well-coordinated, ensuring that the comprehensive needs of women and girls living with or at risk for HIV/AIDS are met.

▪ Component I: HIV Care Management

The goal of the HIV Care Management component is to ensure effective and efficient access to care, services, and resources that are appropriate to meet the needs of women and girls living with HIV/AIDS and their families. The aim is to provide compassionate, empowering, and non-judgmental family care and support services in a culturally appropriate context. Women, girls, and families are experts in identifying their own needs, therefore care services must be flexible enough to address the distinct needs of each individual woman, girl, and family.

Women and girls living with or at risk for HIV/AIDS are encouraged to speak up and speak out for themselves, and to impact policies that directly affect the quality of their lives.

This component of the model involves the family in a comprehensive and collaborative way to address the complex issues faced by women, girls, and families. Families are self-defined by the primary client and are supported by the HIV Care Management Team consisting of staff in the various care programs. The Team works together with client, family, and a network of providers and health care professionals in the delivery of comprehensive, coordinated, and collaborative family-centered services.

The goals of this component are to:

- Link women, girls, and families to crucial services, including but not limited to primary medical care, mental health therapy services, and emergency assistance through the provision of pro-active referrals and follow-up.
- Reduce barriers to care for families through capacity building within the HIV care system and in the general service arena. This includes the provision of training, organizational development, information dissemination, and team building.
- Reduce fragmentation of services through utilization of a team approach to providing comprehensive care services.
- Empower women and girls with skills to reduce their risk for HIV re-infection or co-infection, and navigate and adhere to complex treatment regimens.



Education and training are the first steps in preparing clients and family members for self-efficacy.

- Engage the entire family unit in order to foster communication and supportive interpersonal relationships among family members.
- Strengthen the knowledge, capacity, and ability of women and girls living with HIV/AIDS to live safe, healthy, and strong lives.

HIV Care Management utilizes a peer-based approach to engage and retain women, girls, and families in care. Peers provide counseling and in some instances, accompany them to medical visits and conduct home and hospital visits. Staff also incorporate the appropriate use of physical empathy and support for women, who far too

often, are not hugged or embraced due to their HIV status and the stigma surrounding the disease. Clients appreciate being embraced and view this as an appropriate expression of empathy and comfort.

Hours of operation are tailored to meet the needs of clients, particularly those who are homeless. Staff come in early and stay late to ensure clients' needs are met. For those clients who lack work experience or need to enhance their job skills, the HIV Care Management Team encourages them to volunteer in the office to develop computer, telephone, and clerical skills and receive social support. Over the years, the Team has established positive working relationships with community, educational, and fraternal organizations who act as volunteers and interns in helping to achieve program goals.

Through the HIV Care Management component, clients are offered a wide range of support services and activities to meet their distinct needs:

- **Medical Case Management–Family-Centered Services.** Since 1999, high quality family-centered case management services have been provided to indigent and under-insured women and their families infected and affected by HIV/AIDS. These services are the foundation of the HIV Care Management component and address the compre-

hensive needs of women and girls, as well as the host of barriers that impede them from accessing services. Access to psychosocial and primary medical care and myriad other services are offered to women, girls and their family members.

Medical Case Management-Family-Centered services are effective because they reject the traditional helper/helpee model and move women and girls to a place of self-efficacy and sustainability. Clients are cared for in a compassionate and culturally appropriate manner without discrimination by meeting them where they are in their lives. Family members are also provided emotional support in a nurturing and safe environment and are empowered to participate in activities specifically designed in response to their stated needs. This approach to care helps families feel less isolation as a result of HIV stigma because they see and interact with other families affected by HIV/AIDS in an organized and supportive environment.

Education and training are the first steps in preparing clients and family members for self-efficacy. Efforts are made to increase their knowledge base, skill level, and/or sensitivity to issues relevant to members of the family. Training is designed to address complex issues such as treatment adherence and risk reduction skills to improve physical, emotional, and mental health. Clients are also linked to peer-based support groups and other support services. Through a comprehensive network of care and support, women and families have been effectively served, stabilized, empowered, and transformed.

- **Mental Health Therapy Services.** Therapeutic mental health services are provided to clients through the HIV Care Management component. The goal is to improve the overall mental health of women and girls. HIV-positive women and girls are disproportionately affected by poverty, violence, and other social injustices that can have negative repercussions throughout their lives if not properly addressed and treated. Many of these damaging experiences have directly or indirectly led to HIV infection. If left unaddressed, many of these traumatic events can lead to unhealthy lifestyles such as drug and alcohol abuse, which inhibits a client's ability to adhere to her treatment or prohibits her from forming healthy relationships and bonds with her family. Working with women and girls to address past traumas, including sexual violence, and improving their mental health is a vital part in helping them live fuller, happier, and more successful lives. These services, which are an essential part of the HIV Care Management component, increase knowledge of HIV and psychotropic medications and their side effects. Treatment therapies and strategies are discussed and supported by the mental health therapist.

- **Prevention with Positives Program.** Women and girls living with HIV/AIDS are linked to this important secondary prevention program focused on preventing re-infection and co-infection. Issues addressed include: substance use and abuse, problems with treatment adherence (not taking HIV medicines on a daily basis and/or missing appointments with their physicians), negotiating safer sex as a means to protect themselves from re-infection and co-infection, coping with stress, and physical, mental, and cultural factors that affect HIV risk. More detailed information on the can be found in the HIV Prevention Component description that follows.
- **Pro-Active Referral System.** A pro-active referral system has been created to provide immediate and intensive follow-up to ensure that clients are expeditiously connected with care and support services. Clients are not just given a card with a telephone number and address, but staff initiate contact with providers on behalf of clients. Peers also provide a listening ear and emotional support and will accompany a woman to appointments to ensure that she is comfortable navigating an often complex health care and service delivery system.

Through a comprehensive network of care and support, women and families have been effectively served, stabilized, empowered, and transformed.



for clients who need to take the GED (General Educational Development) exam. GED training is provided to ensure women overcome barriers to continuing education and includes assistance with developing literacy.

▪ **Community Kitchen and Food Pantry.** A well-stocked kitchen is available for clients to prepare nutritious snacks and light meals throughout the day. The kitchen includes items such as bottled water, juice, coffee, tea, chips, croissants, burgers, soup, and an assortment of healthy snacks. In addition, a food pantry is available for clients in need of food items and takes into consideration the entire family's needs, not just those of the individual client.

▪ **Resource Room.** For clients or family members who wish to research their health conditions, identify employment opportunities, or simply stay connected with family and friends, a resource room is available that offers computers with high-speed Internet, educational reading materials and videos, as well as free phone lines.

▪ **Coffee House Support Group.** One of the most important ways that women and girls receive ongoing support is through the monthly peer-led Coffee House support groups. This is a safe space created for women to receive information, inspiration, and encouragement in a confidential setting. The Coffee House takes place once a month from 5:00 pm – 7:00 pm and is guided entirely by clients. Over the years, clients have taken on full responsibility of organizing speakers and activities at the Coffee House, freeing staff up to perform other tasks. Officers have been elected to provide leadership to the Coffee House group and to assist in designing a successful and fulfilling monthly event for their peers. Women decide on topics and speakers and handle all the necessary logistics. Topics have included, but not been limited to, medication adherence, diabetes, menopause, and safer sex. At times, no topics are pre-selected in order to give women an opportunity to discuss their own issues of concern. The Coffee House also organizes family picnics and group trips.

The Coffee House is limited to HIV-positive women and girls, although a close family member, sister, or friend may accompany a woman during her first visit. The discussions are kept confidential and an atmosphere of respect and affirmation is encouraged. Dinner is always provided. One long time participant said, *“Before I came to the Coffee House, I would just go home and live with my diagnosis. But once I started coming here, I just kept coming back.”* She further commented that, *“Being a part of the planning for the Coffee House has taught me that there is something of value I have to offer to others.”*

▪ **Tiffany Fund—Emergency Financial Assistance.**

The Tiffany Fund was created in the memory of Tiffany Nalls, the daughter of Founder and Executive Director, Patricia Nalls, who passed away from AIDS at age 3. It supports women, girls, and families with financial assistance for needs that are often not met by other sources of emergency funding. Clients' families can access funds in order to assist with burial and memorial costs or other related expenses that allow them to properly honor the lives of their loved one. The fund is designed to be responsive to the financial needs of families who often live well below the poverty level with little room to spare in their budgets. With the increasing costs of living, funds of this kind are vital in assisting families.

▪ **Education Fund & GED Training Program.** This program assists clients with addressing unmet needs for educational supplies as well as provides vouchers for school uniforms, backpacks and school supplies. It also provides training

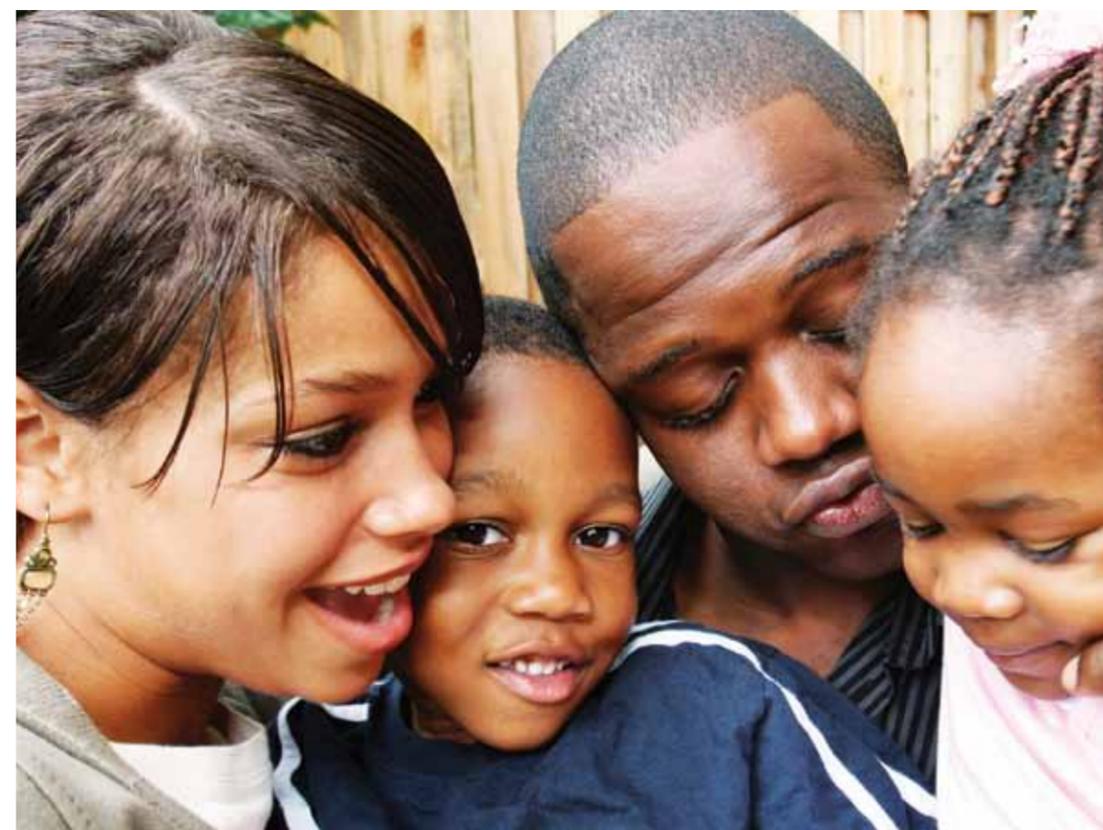
▪ **Special Events.** During the course of the year, many social activities and special events are organized by and for clients and help to create a sense of community. They include the Easter basket distribution, Mother's Day celebration, and summer family picnics. Other events include the end-of-the-school-year movie matinee for students who have excelled during the year, the back-to-school drive that provides children with school uniforms, shoes, and school supplies, and the Thanksgiving turkey basket distribution. Each year ends with the Annual Holiday Celebration that includes a dinner for clients and gifts for parents and their children, as well as the observance of Kwanzaa which is facilitated at The Women's Collective by a volunteer.

Kwanzaa, the cultural celebration of the seven principles, allows staff to come together and reflect on their cultural heritage and reinforce positive and affirming values to incorporate into their work days and lives in general. Usually celebrated December 26-January 1- with a principle applied to each day, The Women's Collective staff instead chose to gather each month and in creative, participatory, and interactive ways apply each principle to their life goals and aspirations. This activity provides an opportunity for team-building among

GED training is provided to ensure women overcome barriers to continuing education and includes assistance with developing literacy.

staff and any clients who wish to participate, personal and collective reflection, and tools for maintaining internal and group peace and harmony.

▪ **Complementary Therapy.** The Women's Collective directed a Complementary Health Care Clinic (CHCC) at the agency for three years under the Ryan White CARE Act Part A, which provides funding for support/care services for individuals living with HIV/AIDS. CHCC operated as a part of the HIV Care Management



component by providing therapeutic massage sessions in a client-centered and holistic health care approach tailored for the unique needs of women and girls living with HIV/AIDS. Practitioners provided personal care plans for therapeutic full body and seated massage and acupuncture designed individually to address the unique, acute and on-going health conditions and concerns of each client. Unfortunately, funding for complementary therapy services under Ryan White was eliminated on February 29, 2008 and the Women’s Collective closed its Complementary Health Care Clinic. However, complementary therapy remains an important element of The Women’s Collective Model.

▪ **Health and Wellness Days.** To deal with the stress that clients and staff experience in their everyday lives, health and wellness days have become an integrated part of this component. A relaxing, spa environment is created in the office space and clients are invited to take advantage of services such as massage, acupuncture, manicures, pedicures, and facials. Clients are also encouraged to bring in their friends for HIV counseling and testing and are given incentives like gift bags and baskets for their recruitment efforts.

▪ **Altar & Memory Book.** As a result of losing so many loved ones to HIV, a longtime client suggested the creation of a memory book and altar to honor those that have passed away. The Women’s Collective has created an altar to keep the memory of their beloved clients and staff alive. The altar is placed near the entrance and is the first thing that people see when they enter the office. A “memory book” of photos, obituaries, funeral programs, and words of remembrance has been placed on the special altar with candles and other memorabilia. The memory book is not only created to honor the lives of clients or staff who have passed away, but it also honors activists in the community or staff working in other agencies who have passed away due to HIV/AIDS.

▪ **Grief Counseling and Support.** Given the cumulative loss and grief that is experienced as a result of HIV, an important aspect of the HIV Care Management component is offering individual and group grief counseling support to clients and staff. When a staff member or client is dying, staff will take turns going to the hospital, hospice, or home to take care of them, night and day. After the loss of a client or staff person, staff members participate in a ritual of sitting in a circle and expressing the importance of the deceased in their lives. This process allows staff members a chance to collectively reflect, grieve, and cope with their loss. Often staff plan a formal memorial service and clients and individuals in the wider community are invited to come and celebrate the person’s life.

Exhibit 2
Summary of Component I: Key HIV Care Management Interventions and Activities

Medical Case Management–Family-Centered Services	Resource Room
Mental Health Therapy Services	Coffee House Support Group
Prevention with Positives Program	Special Events
Pro-Active Referral System	Complementary Therapy Services
Tiffany Fund–Emergency Financial Assistance	Health and Wellness Days
Education Fund & GED Training Program	Altar & Memory Book
Community Kitchen and Food Pantry	Grief Counseling and Support

▪ **Component II: HIV Prevention**
 An important part of the model is programming that provides primary and secondary HIV prevention services to women and girls in the wider community. The approach to HIV prevention includes empowerment through education and information sharing. This is coupled with an emphasis on HIV counseling, testing, and referral services for women, girls, and their partners. The HIV Prevention component aims to:

- Educate women, girls, their partner(s), and families about HIV/AIDS.
- Empower women and girls with skills to reduce their risk for HIV infection, co-infection, or re-infection, and negotiate condom use and practice safer sex.



- Strengthen the knowledge and capacity of women and girls living with and at risk for HIV/AIDS to live safe, healthy, and strong lives.
- Enable women and girls to access free, confidential, non-judgmental, and women-focused HIV counseling, testing, and referral services.

Primary and secondary HIV prevention interventions are developed by and for women and girls infected or affected by HIV. These interventions are implemented in the office and community by women and girls who represent diverse social, economic, racial, and cultural backgrounds.

Primary Prevention Interventions. To prevent HIV transmission, a broad spectrum of primary prevention interventions is offered to clients and members of the wider community:

- **Confidential and Rapid HIV Counseling, Testing, and Referral Services.** This intervention is provided in the privacy of the office, at health fairs, and on the mobile HIV testing van. The mobile van is an important part of the outreach strategy aimed at identifying HIV-positive women and getting them into care. It makes regular stops in many different neighborhoods of Washington, DC, and is frequently a part of community-wide health fairs. Confidential HIV testing targets women and girls ages 13 and older and their partner(s), with a particular focus on the African American women. HIV testing is provided at no cost.
- **Intergenerational HIV Prevention Intervention.** *Sister-Act* is a group level, intergenerational HIV prevention intervention created to reach African American girls and women, ages 13 and above. This interven-

The mobile van is an important part of the outreach strategy aimed at identifying HIV-positive women and getting them into care.

tion combines education and skills-building about HIV/AIDS and safer sex with HIV counseling and testing. It is grounded in the premise that by building and strengthening communication across generations, girls and women will be empowered to share safer sex information with each other and engage in safer sex practices that reduce their risk of HIV infection.

- **Girls’ HIV/AIDS Education and Skills Building Intervention.** *Between Us Girls* is a youth-focused program targeting African American girls and young women ages 12–25 living in the Washington, DC, metropolitan area. It aims to increase awareness and knowledge about HIV/AIDS transmission, prevention, and care among girls and young women, while empowering them to become active voices on HIV prevention in their communities.
- **Community Outreach and Education.** This intervention is conducted on an ongoing basis in the wider community by skilled peer outreach workers and is coupled with HIV counseling and testing. Peer outreach workers wearing The Women’s Collective apron reach out across the city distributing safer sex tools and resources while encouraging confidential HIV testing.
- **Incentives for Participation in Programs.** Incentives are used as a recruitment strategy for encouraging women and girls to test for HIV. While there is debate in some circles about the advisability of using incentives to promote healthy behavior because some fear it will lead to client’s not taking personal responsibility for their own health if incentives are not present, the experience of The Women’s Collective has



been quite positive. While incentives encourage clients to come in for services, the types of incentives provided help clients who are having financial challenges obtain food and other necessities of life. Some of the incentives offered by The Women's Collective include hygiene bags, \$5 gift cards to local supermarkets or fast food restaurants, and gift baskets used for special HIV prevention events such as National HIV Testing Day, Valentine's Day, and Mother's Day. One staff member commented, "Incentives are so very important to women. To see the joy and relief incentives bring to women who are challenged to provide the very basic necessities like medicine, hygiene products, and shoes for themselves and for their families is heartwarming because there is often shame that sometimes comes with having to acknowledge that they don't have these items and must now ask someone for them."

▪ **Hygiene Bags.** As a result of outreach, it became apparent that many women in the target population were living in shelters or on the streets and lacked basic hygiene products. Staff identified a company to design a customized, eye-catching bag with The Women's Collective logo and a tagline that reads: "Sharing Our Stories, Saving Our Lives." Each bag contains shampoo, conditioner, lip balm, lotion, body wash, bath scrubs, powder, deodorant, mouthwash, toothpaste, and a tooth brush. The hygiene bags are distributed on the mobile testing van and are offered as an incentive to those seeking testing. An average of 1,200 hygiene bags are distributed by staff each year.

Secondary Prevention Interventions. To prevent re-infection or co-infection of HIV positive women and girls, secondary prevention interventions are offered to clients:



- **Prevention with Positives (PWP) Group-Level Interventions.** *Prosper!* and *Healthy Relationships* are group-level interventions targeting African American women 18 and older living with HIV/AIDS. *Prosper!* was developed by The Women's Collective in response to the secondary prevention needs of women, which were not included in the *Healthy Relationships* curriculum. Clients are provided with HIV information and capacity building training in topics including: living well with HIV, practicing safer sex as an HIV-positive woman, building pride and empowerment, gaining skills for disclosing an HIV-positive status to loved ones, understanding and adhering to HIV medication, and strengthening coping skills.
- **Comprehensive Risk Counseling and Services Intervention (CRCS).** This individual-level intervention includes intensive, client-centered, one-on-one counseling sessions to help clients adopt and maintain HIV risk reduction behaviors. CRCS is offered to HIV-positive women 18 and older who are at high risk for acquiring or transmitting HIV and other sexually transmitted infections. Clients who struggle with a wide range of issues often need an intensive intervention. Some of the issues women face might include: disclosure to family, friends, and partners; substance use and abuse; problems with treatment adherence; lack of skills to negotiate safer sex to protect themselves from re-infection and co-infection; an inability to cope with stress; or other physical, mental health, and cultural factors that affect their HIV risk. The ultimate goal of CRCS is to enact behavior changes or modifications that will reduce the risk of HIV transmission or re-infection among HIV-positive clients.
- **Pro-Active Referral System.** A pro-active referral system has been created to provide immediate and intensive follow-up to women and girls who test positive to ensure that they have their diagnosis confirmed and are expeditiously connected with an HIV care provider to ensure access to primary care. The unique aspect of this referral system is that it is peer-based and sensitive to a woman's fears and needs. Women are not just given a referral card with a telephone number and address, but the peer outreach worker or counselor will actively make

an appointment with a health provider on behalf of the woman. Peers also provide a listening ear, emotional support, and will accompany a woman to her follow-up medical visit to take a confirmatory HIV test. If the woman's diagnosis has been confirmed and she is interested in coming into care at The Women's Collective, the peer outreach worker will immediately take her referral form to the HIV Care Management Team and follow up to make sure the connection has been made.

- **Distribution of Safer Sex Tools.** Our Counseling, Testing, and Referral/Outreach program distributes safer sex kits as part of our outreach and education efforts. These kits are another of the safer sex tools that we distribute in the community and are especially effective when working with girls and women as they include a variety of safer sex materials in a package. Safer Sex Kits include informational cards, in both English and Spanish, which explains how to correctly put on a condom; lubricants; flavored and regular condoms; dental dams, and an informational card on TWC that includes our contact information. The Safer Sex Kits are one of a variety of resources we distribute to girls, women and their partners in the community in our effort to increase education about and access to safer sex resources. Other resources include a wide variety of male condoms, the female condom, flavored and un-flavored lubricant, flavored and un-flavored male condoms, dental dams, finger cots, novelty items such as condom pals and condom key-rings, and an array of informational brochures on topics including HIV/AIDS, STDs, girl and women-focused health issues, among others.

Exhibit 3
Summary of Component II: Key HIV Prevention Interventions and Activities

Confidential and Rapid HIV Counseling, Testing, and Referral Services (CTR)	Hygiene Bags
Intergenerational HIV Prevention Intervention: <i>SisterAct</i>	Prevention with Positives (PWP) Group Level Interventions: <i>Prosper!</i> and <i>Healthy Relationships</i>
Girls HIV/AIDS Education and Skills Building Intervention: <i>Between Us Girls</i>	Comprehensive Risk Counseling and Services (CRCS)
Community Outreach and Education	Pro-Active Referral System
Incentives for Participation in Programs	Distribution of Safer Sex Tools

Advocates are provided with the necessary informational tools to voice their opinions and to tell their inspirational stories to policy and decision makers and concerned members of their community.

▪ **Component III: Policy & Advocacy**
 The Policy & Advocacy component of the model works to ensure that women and girls living with HIV/AIDS are an integral part of local, national, and global discussions about issues that affect their lives. Rarely do women and girls living with HIV/AIDS, particularly women of color, receive the opportunity to sit at policymaking tables. The absence of their voices is particularly alarming due to the great impact the disease has on women of color. The Women's Collective has established a national network of women living with HIV/AIDS to address this disparity. Encouraging, supporting, and mobilizing women and girls to become involved in advocacy strengthens their collective voices.

Advocates are provided with the necessary informational tools to voice their opinions and to tell their inspirational stories to policy and decision makers and concerned members of their community. The objectives of the Policy & Advocacy component are to:

- Support women advocates living with HIV to better improve their advocacy skills.
- Train a new generation of women advocates living with HIV to work on issues affecting their lives.
- Seek out and create new opportunities for women and girls living with HIV to become involved in advocating for issues that affect them and their families.

The involvement of women and girls living with HIV in advocacy activities is a matter of necessity, and the only way to ensure that they will





have essential services and effective policies. However, for most women involvement in advocacy activities remains a luxury, since many struggle to survive. Involvement in policy advocacy is often difficult as women with HIV seek to balance work and family with very few resources and opportunities. The Women’s Collective mission over the years remains the same—to provide women and girls the support they need to advocate for themselves, their families, and other women at all levels. Women need to be supported, informed, and nurtured as they tackle what can seem like very distant, intimidating, and impenetrable arenas. Over time and with support, however, women can speak up and out and will not be intimidated into silence.

By developing a bridge between established empowerment activists, such as those working on issues of HIV/AIDS, violence against women, reproductive health and justice, microbicides, and a National AIDS Strategy, a broader understanding of how the theme of empowerment connects to a variety of issues that affect the lives of women and girls is achieved. To accomplish policy and advocacy-related goals, The Women’s Collective capitalizes on the strengths of women through existing social networks.

The Women’s Collective mission over the years remains the same—to provide women and girls the support they need to advocate for themselves, their families, and other women at all levels.

Exhibit 4
Summary of Component III: Key Policy & Advocacy Programs and Activities

Create a national coalition of women living with HIV/AIDS to advocate on a variety of issues.	Identify opportunities to assist women living with HIV/AIDS in advocating on their own behalf.
Support women in presenting their concerns to governmental agencies, legislative bodies, and others to influence policies impacting their lives.	Involve women on national and international HIV policymaking bodies, as well as in special advocacy initiatives.

Component IV: Administration

The Administration component of the model is critical to the successful implementation of all other components. A strong organizational infrastructure is necessary to realizing the collective vision of supporting women and girls living with or at risk for HIV/AIDS. As an organization, The Women’s Collective has a long-standing commitment to transparency and integrity, and since its inception has set high standards of service delivery. The Administration Team works primarily to ensure the smooth operation of all facets of the organization through sound financial management, program development and implementation, human resource management, the creation of organizational policies and procedures, and successful fundraising.

The Administration Team has established a system of financial accountability and internal controls, and monitors the expenditure of program funds. This component of the model is important in that it establishes and maintains the proper infrastructure and systems required to support staff to realize overall programmatic goals. Because of its strong financial systems and controls, The Women’s Collective has never experienced a budget deficit or been unable to honor invoices, meet payroll, or provide financial support to its projects.

In addition to assuming responsibility for creating a solid organizational infrastructure, the Administration Team, in collaboration with the Board of Directors, is tasked with the responsibility of engaging in a strategic planning process. The end result of this process is a detailed plan that charts the strategic direction of the organization over a five-year period. A strategic plan was developed by a previous Board of Directors for the period 2003 – 2008. The current Board of Directors is preparing to enter into another strategic planning process to examine the current internal and external environment in which The Women’s Collective is operating so that a new strategic direction with measurable goals and objectives will emerge.



The Administration Team is also responsible for identifying and responding to funding opportunities, which are developed with relevant program managers. Program staff provide important feedback and lend assistance in writing sections of proposals related to their areas of expertise. In the early years, the Board of Directors identified and wrote grants, prior to hiring a professional grant writer. However, in recent years, the current Board of Directors has not taken the lead in grant writing, but contributes periodically to proposals and has implemented a “Power of 100 Campaign” aimed at raising funds from individual donors.

Critical to the achievement of programmatic objectives identified in the strategic plan is the recruitment, retention, and development of skilled staff who are committed to the mission of the organization. The Administration Team is responsible for creating innovative strategies to recruit, retain, and develop existing staff. Far too often, staff who provide support do not get the proper care and attention to release their stress and balance their lives. Given the multiple demands that staff face on a daily basis in providing an exceptional level of care to clients, the Administration Team is committed to coordinating different “Care for the Caregiver” activities designed to promote the health and

The Women’s Collective has a long-standing commitment to transparency and integrity, and since its inception has set high standards of service delivery.

well being of staff and to prevent burnout and turnover. Some of the activities designed specifically for staff have included:

- Participation by staff in onsite Health and Wellness Days.
- Opportunities for staff to attend skills-building conferences and workshops.
- Access to one-on-one counseling or group support when grieving the loss of a family member, colleague, or client.



- Annual weekend retreats and special staff events such as a week-long trip to the Caribbean where each staff member was able to have the costs of the trip deducted from their salary over the course of the year to make it financially feasible for every staff member to participate.
- Monthly recognition of birthdays, anniversaries, and other special days in the life of staff members.

Effectiveness of the Model

The effectiveness of The Women’s Collective Model is measured through ongoing assessments that provide information that is used to inform programmatic decision making. Some indicators used to measure effectiveness of the model include:

- Client feedback on whether programs and services meet their needs.
- Changes in knowledge, attitudes, and behaviors of women and girls participating in HIV prevention interventions.
- Stabilization of women, girls, and family needs and measured progress towards positive health outcomes.
- An increase in the number and skill level of women and girls who serve as advocates.
- The degree to which quality assurance is conducted for HIV related services and activities.
- Success in raising funds to expand programs to meet needs.

Every opportunity is taken to obtain feedback from clients to ensure that the services they receive meet their particular needs.

Exhibit 5

Summary of Component IV: Key Activities Implemented by the Administration Team

Manage fiscal activities and record keeping, including accounts payable, accounts receivable, and invoicing.	Monitor all aspects of grant management (i.e., budget monitoring and implementation, tracking expenditures, and attributing expenses to projects as required).
Ensure annual audits occur and the organization meets all local and federal requirements related to 501(c)(3) status.	Facilitate all aspects of human resources management and development for staff, volunteers, and contractors.
Ensure the fiscal security and strategic development of the organization over time.	Provide support to the Board of Directors in developing and revising the five-year Strategic Plan.
Conduct development and fundraising activities with federal and local governments, private foundations, corporations and individuals.	Coordinate staff activities that promote “Care for the Caregiver.”
Ensure the fidelity of program design, implementation, and evaluation through program monitoring.	

Measuring the effectiveness of HIV care management activities.

Success is measured by monitoring the goals set by clients with their social workers, which are to be achieved within a specified period of time. Lab reports are also used as markers to determine if clients are adhering to their medical and mental health regimes.

Staff provide the bulk of HIV care management services. To ensure that client services meet the acceptable standards of practice, a licensed clinical social worker provides direct supervision of social workers and reviews client records. This helps to promote quality assurance for clients who receive counseling and care management services.

Every opportunity is taken to obtain feedback from clients to ensure that the services they receive meet their particular needs. Client feedback is used to make necessary changes in the way that services are delivered and in the types of new services that are offered. This feedback can be written, but is usually provided verbally to social workers and other staff at The Women’s Collective, including the Executive Director. An open environment has been created where clients are encouraged to share their concerns and ideas about program content and service delivery with those in leadership positions.

Measuring the effectiveness of HIV prevention interventions. Pre- and post-testing is incorporated into HIV primary and secondary prevention interventions in order to assess whether there has been any change in participants’ knowledge, attitudes, or behaviors as a result of specific interventions. Behavior change is tracked through the assessment of post-test results. In addition, in-depth interviews are conducted with a cohort of women and girls who have participated in various primary and secondary prevention interventions to determine how they have been helped by the program, as well as what program components need to be changed.

Stage-based behavioral counseling measures are also used to determine a client’s overall progress with one-on-one comprehensive risk counseling services.⁴ Adjustments are made based on an assessment of a client’s needs. The six stages include:

- **Pre-contemplative.** Client acknowledges risk but does not think it will happen to her or thinks she has control over it.
- **Contemplative.** Client acknowledges risk and may want to change, but there are obstacles that prohibit change.
- **Ready for Action.** Client knows she must do something to reduce risk and is unsure what should be done.
- **Action.** Client is trying to change and is implementing steps to do so. Client has made the change for less than six months.
- **Maintenance.** Client has made the change for six months.
- **Relapse.** Client has reverted back to risky behavior.

Measuring the effectiveness of policy and advocacy activities. The effectiveness of advocates is evaluated through the use of bi-monthly phone interviews which assess the work that the advocates have undertaken, as well as the support they need to continue their efforts. An assessment tool has been developed to identify the specific barriers advocates have come up against in doing policy and advocacy work. This tool also collects data on how to create a more supportive network to enable women to become better engaged in policy and advocacy work. The assessment is conducted using telephone interviews and an anonymous Internet survey that allows women advocates to elaborate on their concerns. The information that is captured is fed back into the program to make needed improvements.

Measuring the effectiveness of administrative activities. Progress in this area is monitored daily, monthly, and annually through a variety of mechanisms. Fiscal activities are conducted according to the

An open environment has been created where clients are encouraged to share their concerns and ideas about program content and service delivery with those in leadership positions.



Generally Accepted Accounting Principles required of nonprofits by the American Institute of Certified Public Accountants and the Financial Accounting Standards Board. An outside auditor conducts an annual audit and provides feedback on an ongoing basis to ensure fiscal practices are current and appropriate. The Women’s Collective has developed a financial management policies and procedures manual that guides all fiscal activities. Development activities are measured against the success of retaining funding for current services and securing a diversified funding base for new needs identified by The Women’s Collective and clients. The rigorous reporting requirements of funders, including federal and local government and private foundations, have been met for over 12 years by the organization.

Quality assurance measures include rigorous reviews of all personnel, administrative, and human resources files. Performance reviews at

the three-month mark from date of hire, and on an annual basis, are important measures used to assess staff ability and capacity to meet the requirements of their positions. Every effort is made to ensure that staff have many opportunities to achieve their program and professional development goals. Strategies for addressing challenges are developed in partnership with staff and supervisors.

A strong organizational infrastructure is necessary to realizing the collective vision of supporting women and girls living with or at risk for HIV/AIDS. Some of the organizational characteristics that are needed to successfully implement The Women's Collective Model are highlighted below. Most nonprofit organizations understand that most of these elements are not in place when an organization is conceived, or when its initial programs or services are launched. However, if the aim is to provide women and girls with a comprehensive array of HIV related services in a welcoming and supportive environment, it is important to develop a plan for incorporating the following characteristics over time:

- Effective, visionary leadership by HIV-positive women and girls.
- A clear sense of purpose and a shared understanding of the desired outcomes.
- Experienced and well-trained program and administrative staff, or staff who are willing to learn.
- A "Care for the Caregivers" component that provides staff with the intensive support and respite they require, while preventing burnout and frequent staff turnover.

- A commitment among staff to exemplify the organization's core values.
- Mechanisms for actively receiving feedback from clients and using their input to inform program design.
- Supportive funders who believe in the organization, its mission, leadership, and strategic direction.
- An administrative infrastructure that supports the organization's vision, mission and programs.
- Diverse sources of funding that support various programs, services, and activities over the long term.
- Non-restricted funds that can be used to build organizational capacity and administrative infrastructure.
- Dedicated volunteers and community supporters and allies.
- A "hands-on" Board of Directors that supports the organization's mission and is actively involved in helping it to achieve its strategic goals.

Sustainability of the Model

In order to sustain the model over time, The Women's Collective relies heavily on staff, Board, clients, volunteers, community partners, and funding agencies to varying degrees. In the long-term, a concerted effort is being made to look for funding directly from sources such as the Health Resources and Services Administration, the U.S. Centers for Disease Control and Prevention, the Substance Abuse and Mental Health Services Administration, the Office on Women's Health, and private foundations and corporations. The main source of funding for HIV Care Management programs is the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, which faces an uncertain future and has largely been streamlined by the elimination of many critical support services that were vital, especially to women and families. Continued changes to the intent of the Ryan White CARE Act continue to adversely affect service provision. Diversifying and strengthening the organization's funding base will be critical over the next several years for both HIV care and prevention programming.

To promote sustainability, The Women's Collective recognizes the importance of community support in sustaining the model and is seeking to establish new partnerships and strengthen existing ones by drawing on local expertise and resources. For example, The Women's Collective currently serves as a placement site for Georgetown University's Women's Law and Public Policy Fellowship Program, which enables a diverse group of new public interest lawyers from across the United States to gain invaluable experience advancing women's

rights. Fellows work in Washington, DC, with a variety of organizations involved in legal and policy issues affecting women, such as domestic violence, employment discrimination, sexual harassment, immigration, education, health care, homelessness, poverty, disability rights, civil rights, HIV/AIDS, and international human rights. A Law Fellow has been an invaluable asset to the Policy & Advocacy Team.

Interns from a host of local universities including, but not limited to, Howard University, The George Washington University, and American University assist with program implementation, research, evaluation, and communications. In addition, members from the AmeriCorps program, through the National AIDS Fund AmeriCorps/Caring Counts Program, have provided invaluable prevention program support for almost a decade. The Women's Collective will continue to strengthen its connection to schools of public health to strengthen its program design and to impact program outcomes.

Lessons Learned in Implementing the Model

The Women's Collective has had its share of growing pains and has learned countless lessons as a result of conceiving, giving birth to, and nurturing the model of providing high quality HIV care, prevention, and advocacy services to women and girls living with or at risk for HIV/AIDS. The major lessons learned in implementing The Women's Collective Model are summarized below:

- **CREATE** a safe space that is warm, welcoming, and nurturing so that women, girls and their families will feel supported, accepted, and loved.
- **INVOLVE** women and girls living with or at risk for HIV/AIDS in programmatic decision making. This says to HIV-positive women and girls that their input is valued and their voices are heard.
- **DESIGN** an organizational structure where women and girls living with and at risk for HIV/AIDS are in key leadership positions. This ensures that their needs are fully understood and met.
- **ESTABLISH** a clear vision, mission, core values, and strategic plan. This serves as a focal point to keep an organization on track.
- **OBTAIN** technical assistance and support to build a solid and transparent organizational and administrative infrastructure. It is critical to lay a strong foundation at the very beginning.
- **IDENTIFY** dedicated individuals who are willing to commit their time and energy as active Board members. Seek persons who are able to provide leadership and assist with strategic planning, communications, and/or fundraising tasks.

Every effort is made to ensure that staff have many opportunities to achieve their program and professional development goals.

- **RECRUIT** staff who are passionate about the work and are committed to living out the core values. This results in a good match and leads to excellent programming and service delivery.
- **COMMUNICATE** with funders often to share the organization's program updates and successes. This can lead to the establishment of strong, viable, long-term relationships.
- **SEEK** unrestricted sources of funding to be used for general and administrative support. This is equally important as obtaining funding to support basic programs and services.
- **DEVELOP** innovative fundraising strategies such as direct mail campaigns, annual events, and special appeals. This helps to diversify the organization's base of financial support so that is not solely reliant on government and foundation grants.
- **DEVELOP** mechanisms to evaluate the success and effectiveness of programmatic efforts. Most funders will want to know, in measurable terms, if their resources have been able to make a meaningful difference in the lives of women and their families, and many will require organizations to conduct formal process and outcome evaluations.

The Way Forward: a Collective Vision for the Future



There is a **collective vision** for the future of The Women's Collective that is passionately embraced by clients, staff, and Board members. It is also shared by members of the broader community who have collaborated with The Women's Collective over the past 20 years.

The vision is of an organization with **expanded programs, services, and facilities** to meet the increased needs of growing numbers of newly diagnosed women and girls of color and their families.

Included in this new vision is an organization that has committed its resources to developing the next generation of leaders from within, diversified its current funding base in innovative ways to ensure long term program sustainability, and obtained greater involvement of its Board of Directors in charting a successful course for the future.

A Collective Vision for HIV Program and Service Delivery

In the near future, it is expected that HIV program and service delivery will be expanded significantly to meet the needs of the growing numbers of African American women and girls in Washington, DC, newly diagnosed with HIV. Traditional HIV care and prevention services provided by The Women's Collective would continue to be offered to new and existing clients alike, making it necessary to grow the organization by recruiting additional staff. While organizational growth can be positive, it will be important to ensure that The Women's Collective does not grow so rapidly that its core values and unique features become compromised.

To have a greater impact, existing HIV prevention programs would be augmented by activities such as disseminating and providing technical assistance on effective prevention interventions, utilizing unique opportunities such as "prevention parties" to promote HIV primary and secondary prevention, and expanding HIV counseling, testing, and referral services to the broader community. Emphasis would be placed on outreach at existing events such as family reunions and parties to disseminate prevention, care, and treatment information, tools, and messages. A cadre of outreach staff would be trained to promote HIV prevention in the community, reaching people where they are. One Board member stated, *"We can brand this promotional group, give it a fun name, and reach out to people in more relaxed settings to talk frankly about HIV and sex."*



Expansion of HIV related programs and services might also include:

- Adding a primary medical care clinic to round out client services, enhancing clients' ability to access a full range of care services under one roof.
- Establishing skills training and development programs for clients to help them live "financially healthy" lives.
- Increasing the programming to support broader health issues for women and girls such as diabetes, heart disease, breast cancer, lupus, and hypertension.
- Offering the types of enhanced support services that clients and families need.

Realizing this vision of expanded program and service delivery will necessitate the purchase or lease of a larger office facility. The Executive Director states, *"Obtaining a larger space is our number one priority as an organization because it will help us to provide additional services that women and families need. At present, we are bursting at the seams and need extra capacity to expand our services and provide adequate space for our staff to work in. We are hesitant to apply for certain grants because we want to make sure we have enough space to perform the required tasks."*

Emphasis would be placed on **outreach at existing events** such as family reunions and parties to **disseminate** prevention, care, and treatment information, tools, and messages.

In looking toward the future, the common vision is of an organization that not only helps sisters to survive, but provides the proper mix of services and transformational opportunities to help sisters and their families to thrive.

A Collective Vision for Leadership Development

The Women's Collective has been a viable organization for the past two decades, but must now engage in a thoughtful process of leadership development and succession planning that ensures the continuation of strong, viable leadership by women and girls living with or at risk for HIV. The vision is to create a formal leadership program and/or track within The Women's Collective that identifies leaders from within the organization to ensure that the voices of HIV-positive women provide the strategic direction for the organization in the decades to come. The Board of Directors could serve as mentors to those clients and staff identified as emerging leaders. To inform this process, it will be important to document how leaders have historically been "home grown" from within the ranks of The Women's Collective.

A Collective Vision for Enhancing The Women's Collective's Funding Base

The vision with respect to fundraising involves securing additional funding from diversified sources so that larger numbers of women, girls, and families can be served. While traditional funding sources such as government and foundation grants will continue to be pursued, there is a desire to explore innovative revenue-generating strategies such as corporate sponsorships of an annual "signature" event that gives exposure to The Women's Collective, while simultaneously raising funds through events such as a Tiffany dinner, an auction, a radiothon, or a celebrity gathering.

Other strategies could include special mail appeals, an annual women and girl's AIDS walk or race, the creation of a small business that can be operated within the office building by clients and staff (i.e., a café, bookstore, or gift shop), a public relations and marketing strategy to increase exposure of The Women's Collective brand so that women and girls will identify with the organization and donate privately, and/or a special fundraising campaign that is conceived, planned, and implemented by the Board of Directors.

A key role for the Board of Directors in the realization of this vision would be to collaborate with the Development Director in creating a short-term and long-term funding strategy and action plan. The bulk of this work could be done as a part of the strategic planning process and will be critical in securing a bright and stable future for The Women's Collective. Another role for Board members would be to assist in proposal development efforts and in identifying specific funders and taking responsibility for building a relationship with them over time.

A Collective Vision for Engaging the Board of Directors in Strategic Ways

Engaging the Board of Directors in strategic thinking, planning, oversight, external communications, and outreach is a critical factor in realizing this shared vision. The Board of Directors of any organization is uniquely situated to move the vision of that organization forward. The leadership of The Women's Collective is committed to working with its Board in new and exciting ways to map out a plan that contains realistic and achievable action steps that take into account constraints that Board members might face. Central to this plan is investing time in equipping each Board member with up-to-date information and talking points on the organization's history, core values, programs, and services so that they can become champions of The Women's Collective and adequately represent its interest on

planning bodies, with government and corporate leaders, and in their own social and professional networks.

In the early years as an organization, The Women's Collective began its programmatic thrust through a project called *Sisters Helping Sisters to Survive*. In looking toward the future, the common vision is of an organization that not only helps *sisters to survive*, but provides the proper mix of services and transformational opportunities to help *sisters and their families to thrive*. During the past twenty years, The Women's Collective has evolved from the *single* vision of one powerful, courageous, and determined woman to the *collective* vision of many powerful, courageous, and determined women who have committed their time, energy, and lives to this important work.

The vision that is universally held by clients, staff, and Board members alike is of "a world free of AIDS," where AIDS service organizations become unnecessary, and even extinct. Until such a world emerges, The Women's Collective will remain committed to providing high quality services, a safe haven, and a loving and embracing environment for women and girls living with or at risk for HIV/AIDS and their families. In the words of Linda Lopez, a client-turned-staff member:

I found The Women's Collective six years ago after learning that I was HIV positive. And if someone were to ask what The Women's Collective has done for me the first thing I'd say is that they have given me a voice. Second, they've set me on a career path, and third, they've taken away some of the stigma that I placed upon myself, and that society has placed upon people who are infected. Now, I'm not only an advocate for myself, but for many other women as well. These are the things that The Women's Collective does, not only for me, but for any other women who walk through their doors.

Now, I'm not only an advocate for myself, but for many other women as well.

Endnotes

- ¹ U.S. Centers for Disease Control and Prevention (CDC), *HIV among Women Fact Sheet*. Revised June 2007.
- ² District of Columbia, Department of Health, HIV/AIDS Administration (HAA), *District of Columbia HIV/AIDS Epidemiology Annual Report 2007*. November 2007.
- ³ Institute for Women's Policy Research (IWPR), *Status of Women in the States, 5th Edition*. November 2004.
- ⁴ U.S. Centers for Disease Control and Prevention (CDC), *CRCS Implementation Manual*. Revised Spring 2006.

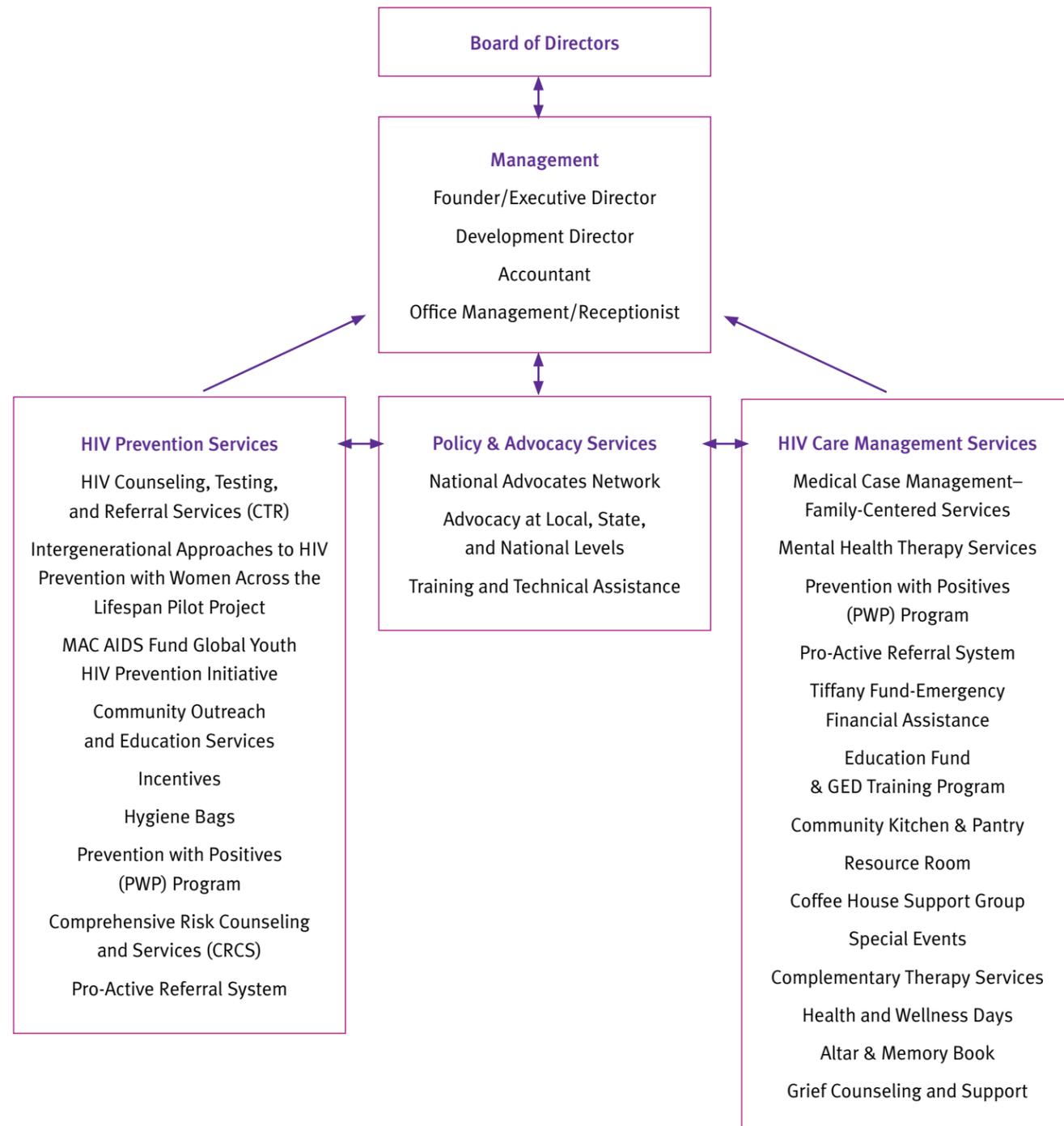
Appendix A: Persons Interviewed for the Documentation Report

1. Adisa Douglas, Public Welfare Foundation
2. Desiree Flores, Ms Foundation
3. Belinda Rochelle, Health Resources and Services Administration
4. Dr. Ron Simmons, Us Helping Us
5. J.Channing Wickham, Washington AIDS Partnership
6. Staff of The Women's Collective
7. Clients of the Women's Collective
8. Board Members of The Women's Collective

Appendix B: List of Awards Received by Founder Patricia Nalls

- Courage Award from Whitman-Walker Clinic (1999)
- Award of Merit from Solutions 2000
- Linowes Leadership Award from the Community Foundation for the National Capital Region(2000)
- The Thurlow Evans Tibbs, Jr. Award
- The Caribbean People's International Award (2003)
- The Washington Free Clinic Community Leadership Award (2003)
- WJLA Channel 7 Tribute to Working Women (2003)
- National Association of People with AIDS (NAPWA) Certificate of Recognition (2004)
- National Association for the Advancement of Colored People (NAACP) Youth Council Of DC's Outstanding Leadership Award in Health (2004)
- Recognized as Honoree in Hero in the Struggle by Black AIDS Institute
- Prestigious Gloria Award by the Ms Foundation (2005)
- Washington Area Women's Foundation Leadership Award
- The Congressional Black Caucus HIV/AIDS Braintrust: Certificate of Special Congressional Recognition
- Council of the District of Columbia Resolution
- The NAACP Youth Council of Washington, DC, Outstanding Leadership Award
- MAP: Massachusetts Asian & Pacific Islanders S.H. Chua Award

Appendix C: Organizational Chart



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- 1.69 trees preserved for the future
- 4.86 lbs of water-borne waste not created
- 717 gallons of wastewater flow saved
- 79 lbs of waste not generated
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- 1,195,440 British Thermal Units (BTUs) energy not consumed



The mission of **The Women's Collective** is to meet **the self-defined needs of women, girls, and their families** living with or at-risk for HIV/AIDS, **reducing barriers to care** and strengthening their **network of support and services**.