

REDISTRIBUTING POWER

Stories from Women Leading the Fight against AIDS





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Introduction

With each passing day, women are more and more affected by the HIV epidemic. Today, more than half the people living with HIV around the world are women and girls. In sub-Saharan Africa the numbers are alarming, adolescent girls and young women are eight times more likely than their male peers to be HIV-positive. Research shows that a significant number of maternal deaths can be attributed at least in part to HIV-related causes. And women and girls are the caretakers for the majority of people living with HIV.

While the number of women infected and affected by HIV grows, the response to the epidemic has not responded accordingly. According to the *UNAIDS 2010 Global Report*, only 46 percent of countries have specific HIV activities in their budget for women. And despite studies showing a correlation between gender-based violence and HIV, only a few governments have enforced laws against domestic violence or taken action to prevent violence against women.

Clearly, women are not sufficiently represented at decision-making tables and their voices are not being heard. But that can be changed. There has never been a more pressing need to empower women to be leaders in the fight against AIDS.

In 2006, the *Advancing Women's Leadership and Advocacy for AIDS Action* initiative was launched to equip and empower a cadre of women from around the world with the knowledge and skills to strengthen and lead the global response to AIDS. The Ford Foundation-funded initiative was implemented by a consortium led by the Centre for Development and Population Activities (CEDPA) and including the International Center for Research on Women (ICRW), the International Community of Women Living with HIV/AIDS and the National Minority AIDS Council.

The initiative consisted of six global, regional and national workshops designed to enhance participants' confidence and self-efficacy, strengthen their program management skills and expand their professional networks. The participants were also provided with opportunities for meaningful participation in global and regional events to raise awareness of and advocate for policies and programs that address the unique needs of women living with HIV.

The successful initiative reached 140 women from 46 countries throughout Africa, Asia, Latin America, the Caribbean, the United States and the Pacific. In addition to attending the workshop, participants benefitted from a year-long coaching program upon completion of their workshop. They were paired with senior-level CEDPA-trained coaches in order to extend participant learning beyond the workshop setting to sustain their professional growth and performance.

The program's success was established by using an innovative combination of pre- and post-workshop knowledge assessments, daily workshop evaluations, final workshop evaluations and six-month skill utilization surveys for all participants. In addition, in-depth case studies of randomly selected participants who responded to the assessments were conducted by ICRW.

Participants indicated that, because of the workshop, their management and leadership capabilities increased and their technical knowledge had improved. Fifty-six percent of the respondents were promoted, 79 percent increased their work-related responsibilities and 62 percent initiated other changes in their jobs after the workshop.

Redistributing Power: Stories from Women Leading the Fight Against AIDS is based on the formal case studies conducted as part of the initiative. This publication profiles seven extraordinary women who passed through the program.

From civil war-torn northern Uganda to the edge of the Rocky Mountains in the United States, these women leaders share their struggles, their evolution and the passion they have for empowering those around them.

These profiles capture only a small glimpse of the potential that women leaders have in changing the course of the epidemic. Only 140 women leaders had the opportunity to be a part of the *Advancing Women's Leadership and Advocacy for AIDS Action* initiative, but they have gone on to share their new knowledge and skills with their organizations and communities. And, one by one, women will be empowered to advocate for their rights and ensure that their needs are met.



CASE STUDY:

LILLY ARACH UGANDA

After testing positive for HIV and losing her husband to AIDS, **LILLY ARACH** sat day after day in her home in Northern Uganda waiting for an answer or some direction. She had no income and had four children to feed.

Her only solace came from the frequent visits of community women. They were mostly widows who lost their husbands to the devastating civil war or to AIDS.

This impromptu support group offered Lilly comfort, compassion and solace. And, eventually, through sharing their stories of grief and desperation, they inspired each other to take action.

“We decided, ‘why are we seated here always? Why don’t we do something?’ And then we started a drama group. ...We started moving to the nearby villages to perform these dramas, dramas on HIV,” she says.

The women’s drama group touched on issues beyond HIV prevention and treatment, such as property

rights for widows. In Uganda, many in-laws pressure widows to marry a brother or another male relative of her husband so ownership remains in his family—a situation Lilly experienced firsthand.

As the drama group’s success and popularity grew, Lilly and her fellow organizers registered it as a community-based organization called Kitgum District Forum for People Living with HIV and convened a board of directors. The local government even provided office space.

Though she was active with the drama group, Lilly still was afraid to make her status known publicly. She feared the stigma she and her family would face. But her silence was doing more damage to her health than the virus was.

"There was a fear within me that if I don't tell people then I will die silently ... and that made me go to my parents and tell them," Lilly explains. "At first they were saying 'No, no. We don't want you to go there to tell people that you are HIV-positive.' Then I told [my mother] ... 'you have to know you're going to bury me very soon if I don't go and tell people that I'm HIV-positive.'"

On World AIDS Day, Dec. 1, 2002, Lilly went on the local radio station and disclosed her status. She received both positive and negative reactions to her disclosure, forcing Lilly and her children to learn to cope. Now, they have adjusted. Her eldest daughter even chairs an HIV awareness club at her school.

Shortly after her public announcement, Lilly was asked to join the Kitgum District HIV/AIDS Committee as a peer mentor for people living with HIV (PLHIV). She began to reach out to her peers to raise awareness about HIV, encourage testing, provide counseling, organize groups of PLHIV and reduce stigma.

In July 2007, Lilly attended the *Advancing Women's Leadership and Advocacy for AIDS Action* global workshop in Washington, D.C. The workshop greatly improved Lilly's communication, advocacy and community mobilization skills and she learned how her appearance and mannerisms can enhance (or detract from) message delivery.

"Before I went for the workshop, if I was going to present an issue at the District AIDS committee, I always did so with a lot of anger," she says. "Now, I would bring out the issue and ... present in a meaningful manner, let the issue be smart. Have a goal for the issue ... how to present it clearly and smartly."

Most of all, Lilly became more self-confident. Before the workshop, she succumbed to cultural norms of women's status being considered low in society's hierarchy, expected never to take the stage, literally or figuratively.

"Sometimes [when] my supervisor told me 'I want you to go and represent me in a workshop' ... I would say ... 'I'm just a mere woman. How can I go and stand before those big people?' That was the feeling I had within myself," she says. But now, "I'm somebody who can stand up and talk about what is wrong and the way I feel. I think that is who I am."

What boosts her confidence even more is Lilly's growing knowledge and understanding of the facts about HIV and AIDS. Inspired by the workshop, she now makes it a point of reading background information as well as the latest news. As a result, her self-image has shifted from a beneficiary with a personal story to a decision-maker, and even a leader.

Her supervisor affirms Lilly's noted improvements in her advocacy, communication and leadership skills. Beyond relying on her as a community leader, he now regularly sends her to represent the organization at conferences.

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Now, Lilly focuses much of her outreach on women, who are particularly vulnerable to HIV, representing 59 percent of those infected in Uganda. A female adolescent is nine times more likely to contract HIV than one of her male peers. The situation is even more extreme for girls in Kitgum's camps for internally displaced people, where close quarters and limited privacy expose children to violence and the risks of sexual behavior at a young age.

Lilly continues to encourage women living with HIV to advocate for their rights at every level of government, and to access services that support healthy living. She wants them to see what they can accomplish once their eyes are open to the possibilities.

“The workshop taught me not to limit my work, but to extend my work to my people, many issues. After attending the Nepal workshop, my thinking changed... I gained the energy.”



CASE STUDY:

PRIYA INDIA

In 1999, **PRIYA KAGITHA**'s life was changed forever. She was eight months pregnant when she was told she was HIV-positive. She contracted the virus from her husband during the first two years of their marriage.

It is not uncommon for young, married women in India to have their world turned upside down by an HIV-positive diagnosis. While the epidemic in the country is primarily concentrated among high-risk groups—such as female sex workers, men who have sex with men, truck drivers and injecting drug users—more than one in 50 pregnant women in urban areas are living with HIV, according to 2008 estimates by the Joint United Nations Programme on HIV/AIDS (UNAIDS).

Priya's world crumbled around her. The idyllic vision of being a newlywed and the joy of having her first child were replaced by fear—fear for her life and the stigma she faced, but mostly for the life of her child. Her regular doctor refused to deliver her baby.

“She just said that HIV means you have AIDS, and AIDS means people will never live [long] and maybe your baby is also going to get infected,” Priya recalls her doctor saying.

Priya was determined not to endanger her baby. She sought information wherever she could find it. She found basic information at the government hospitals and learned that a Caesarean section (C-section) could reduce the chances of her child being born HIV-positive.

Priya found one hospital in the city that delivered babies of HIV-positive women. Though the delivery cost Priya her jewelry, an Indian woman's source of financial security, she was relieved that her baby was born without HIV.

Her joy was short-lived, however: Less than a year later, she lost her husband to AIDS-related complications.

By 2001, at the encouragement of an openly HIV-positive man in her community, Priya began actively managing her condition and, eventually, giving back. She entered a treatment program run by an international nonprofit called the LEPRa Society, one of the health care organizations she learned about from him.

When her health improved, Priya sought a job at the LEPRa Society. They hired her as a lay counselor.

“Being positive women, we need support. I decided to come out and talk about my positive status and motivate other positive people to live a healthy life,” says Priya.

She counseled newly diagnosed individuals about how they, too, can learn to manage the condition. Beyond one-on-one support, Priya leveraged her affiliation with the LEPRa Society (LEPRa) to take a broader role in the community. She was a principal organizer for the first stigma-free services project in the state run by and for people living with HIV and AIDS. She also lobbied for government funding for a project that employs HIV-positive women as counselors on preventing parent-to-child transmission at a local hospital.

In early 2009, 10 years after her HIV diagnosis, Priya attended the Asia regional workshop in Kathmandu, Nepal. She was encouraged to apply by the director of LEPRa, Dr. J. Subbanna, who saw the rapport Priya shared with the community and felt she would benefit from the intensive leadership training.

Priya says, “The workshop taught me not to limit my work, but to extend my work to many people, many issues.”

She learned practical skills such as fundraising strategies, which she eagerly applied when she returned home. Priya raised 70,000 Indian rupees (more than U.S. \$1,500) for court fees and to pay for an HIV-positive individual’s computer training. Her boss also noticed her improved advocacy and networking skills.

“After the training in Nepal, her confidence to advocate grew on issues that happened at ground level with [state government] officials, with National

AIDS Control Organization officials,” said Dr. Subbanna. “She was able to voice the field concerns.”

After her return, Priya was invited by the state government to speak to political leaders and newspaper editors to help them understand sensitivities surrounding soliciting and publicizing HIV-positive people’s stories and perspectives. Her presentation convinced them to institute a policy requiring journalists and politicians to protect HIV-positive individuals’ identities.

Priya’s increased advocacy skills extended beyond government officials to health-care providers ensuring that HIV-positive people get the surgery they need. Because of what she learned in the workshop, she now is able to set aside her emotions, examine both sides of an argument and state her case more calmly and objectively.



“I learned the right way to fight them,” Priya says, explaining that she understands now the need to voice appreciation for the services they do provide before gently nudging them to expand their offerings or shift their approach to the issue.

“After attending the Nepal workshop, my thinking changed ... [I gained] back the energy,” says Priya. “I started working with the general PLHA community again ... I can continue working for other people in the community, apart from my project.”

“I learned something on how you can prevent conflict...being proactive, how you can manage it when it comes, and how you can learn from it.”



CASE STUDY:

SANDRA ZAMBIA

SANDRA MUBIANA launched her first HIV-awareness initiative in 2004. She created a documentary about the Zambian government’s distribution of free anti-retroviral treatment (ART) for a video production class she enrolled in to further her journalism career.

When another course member showed her a pamphlet about the program, Sandra felt the urgency to get the word out. Zambia’s annual count of AIDS-related deaths had just peaked after steadily climbing for over a decade: More than 80,000 Zambians died of AIDS in 2003.

“At that time so many people were dying of HIV and AIDS, and helpless,” she explains. “Many people were not so much aware of anti-retrovirals. ...So I wondered how many people knew about this [government program] because I’d never heard it on the news or the radio. ...When I saw the brochure, I thought, maybe we can do something so that people know about it.”

Sandra was really impressed with the people she met working on the documentary. She decided she could do more and took a communications job with the Center for Infectious Disease Research in Zambia (CIDRZ), the government agency coordinating the ART program. She was a quick study: Sandra was promoted twice in two years and even traveled to the United States in late 2007 to advocate for AIDS funding in Africa.

The new position exposed Sandra to the factors contributing to the epidemic in Zambia. Girls and women in Zambia face men’s dominance in sexual relationships, society’s common condonation of men’s extramarital affairs, men’s unwillingness to

use condoms even in high-risk encounters, and men's use of sexual violence and coercion. As a result, HIV prevalence is significantly higher among women (18 percent) than men (13 percent), and young women ages 14 to 19 are up to six times more likely to have HIV than their male peers.

"I don't think [women] are really playing [a] leadership role," says Sandra. "What I would like to see is that women begin to see themselves as people who contribute to society."

Sandra worked closely with people living with HIV and AIDS to raise awareness via drama groups and radio programs on issues such as the importance of adhering to ART treatment. While the messages apply to both men and women, she strived to portray men and women as equal partners whenever possible.

In 2008, Sandra read about the *Advancing Women's Leadership and Advocacy for AIDS Action* regional workshop in Nairobi, Kenya. She applied to the workshop to improve her advocacy and leadership skills, but she learned so much more.

When she returned from Nairobi, her supervisor noticed a difference right away and gave her significantly more responsibilities.

"There are other people in the team in similar positions to her for as long as she has been here who are quite good people," her supervisor says. "But she seems to have done more, and [perhaps] you can attribute that to the fact that she's had that training that the rest of the staff on the team have not had."

Sandra says she improved her facilitation and communication skills from the techniques used during the workshop. She now uses specific techniques to generate frank discussion around sensitive topics such as sex and sexuality.

"You know, the issue of sex: It's taboo to talk about that openly, but we know at the same time that these are issues that, if not handled carefully, they bring HIV."

Sandra also credits the workshop with helping her to deal with the inevitable conflict that arises when dealing with such sensitive topics.

"I learned something on how you can prevent conflict...being proactive...how you can manage it when it comes, and how you can transform it when it comes, learning new things from it and also moving forward," she says.

In addition to her new responsibilities, Sandra has taken the initiative to identify gaps in her organization and to make improvements where possible. She has pushed for a more formalized effort to monitor and evaluate CIDRZ's programs and developed a survey to assess accessibility to information and to better understand the information people wanted.

"Previously we just implemented and implemented but we [didn't] sit down to reflect [on] whether it was working," Sandra explains.

"I came back a different person, because I was just so confident about myself knowing that as a woman, I can contribute to my country."

This idea for a survey made a big impression on her colleagues.

"It is here that I can say I've seen Sandra bloom," says Sandra's supervisor. "She had a very good sense of where we were going."

Sandra says the workshop experience catalyzed a shift in her approach to work, benefiting not only herself, but also the organization and the communities where she works.

"I came back a different person, because I was just so confident about myself knowing that as a woman, I can contribute to my country," says Sandra.

“Opportunities like CEDPA and other leadership workshops for women are essential for growth. “There is a place to be with other women, in a safe environment.”



CASE STUDY:

SHANNON USA

“My mission has become making sure that the next woman who is diagnosed has a smoother transition into the HIV world than I did,” says **SHANNON BEHNING**, an HIV and AIDS advocate from Denver, Colorado.

In 1992, when Shannon was diagnosed with HIV at the age of 27, she felt isolated. As a heterosexual, white woman, she was a minority in the HIV-positive community in Denver.

When Shannon began to look for services and support groups in her area, she found the ones available predominantly served gay men, injecting drug users or African-American women. When she attended these local meetings, and even some national conferences, she felt her needs were not being met.

“I would go to these conferences and bring up stuff that was happening with ... women living with this disease,” says Shannon. “I was not heard.”

Not one to wait for others to solve her problems, Shannon began her own organization, the Women’s

Lighthouse Project. The project was designed to support and empower HIV-positive women via education, advocacy and linkages to health and legal services.

She also began working with public, issue-based councils, such as the Ryan White Planning Council and the People Living with HIV Council. She soon recognized that she was no longer speaking only for herself; she was the voice of other HIV-positive women, as well.

“I was at the decision-making tables, making decisions that impacted women’s lives,” explains Shannon. “It made me more aware that I could take a bigger role than just being Shannon. I can really play a role for women who are positive, who didn’t have the courage to come to the table.”

In 2007, Shannon came across an announcement for the *Advancing Women's Leadership and Advocacy for AIDS Action* global workshop.

"I was reading through all that we would learn [and thought], 'Those are all things that I need to learn more about to get me to the point of where I want to be as a community leader, as an executive director of a nonprofit and as a woman living with HIV,'" says Shannon.

Shannon was accepted as a participant for the workshop, and she knew from the first day that this was different from any other conference or workshop she had attended in the past.

"I walked into this room with all these women who come from all over the world, and I felt as welcomed there as I've ever felt. And I felt loved and accepted and listened to and heard," she says. "That was probably one of the most empowering moments for me, being able to be in that place and be heard."

The workshop sessions on advocacy reinforced Shannon's understanding of how legislative bills and policies are formed and how she could be involved in the process. She learned the importance of being prepared with facts to deliver the biggest impact.

"Being a woman living with HIV and going into an office and sharing that story is 'old' in my growth," says Shannon. "Now I have statistics and numbers and facts and talk about what my agency is doing and what's happening locally, nationally, internationally."

The workshop enhanced Shannon's leadership skills as well. She learned about her own strengths and weaknesses, and how these influence the way she engages with her staff. Before, rather than confronting her staff for not completing assignments, Shannon would complete the assignment herself, adding to her own responsibilities. Since the workshop, that has changed.

"Being able to ... have those tough conversations, that definitely was something that came out of that conflict resolution [session]," she says.

Her colleagues noticed the change.

"There's an increased confidence in her ability as a leader," said Kara Schmitt, the project's grant writer. "The skills have been there, but I think her feeling [confident] about herself was kind of what's come across to me."

After the workshop, participants were assigned a CEDPA coach to serve as a guide in applying what they learned. With the help of her coach, an experienced and trained CEDPA alumna, Shannon realized that if she were to leave, the organization could be in jeopardy. She was taking on too much responsibility.

"[We talked] about our agency and what we need to be doing to go from point A to point B," explains Shannon. "Before I would see everything that I had to do and it was too overwhelming. [My coach was] able to help me take the overwhelming picture and put it into perspective."

She began to implement a plan that would ensure that the organization could go on if she stepped down. The plan was approved by the organization's board and her staff, who were happy to see the project become "an organization unto itself."

Unfortunately, with the economic collapse over the past couple of years, the Women's Lighthouse Project had to close its doors in November 2010. Though this has been a blow to Shannon, her hopes are high. She is maintaining the project's Web site and still advocates for women living with HIV.

Shannon continues to apply the knowledge, skills and abilities that she gained from the workshop to all parts of her life. She recognizes the benefits she received from the workshop, and hopes that others will be given the same chance to reap the rewards.

"Opportunities like CEDPA and other leadership workshops for women are essential for growth," says Shannon. "There must be a place to be with other leaders who are women, in a safe, supportive and educational environment."



“I knew there were advances in the field of HIV which we [didn’t] know about in Ghana. I saw this as an opportunity to learn more, to acquire knowledge which I could use to enrich my work.”



CASE STUDY:

ELSIE GHANA

“Putting women with HIV on display—decoration, tokenism, manipulation—got me mad,” says **ELSIE AYEAH**, an advocate for women living with HIV. “Until we as women get up and take control of our lives, say what would work for us and stop being at the receiving end, we will not make any change in our lives.”

Elsie’s profession has changed over the years, but her passion for empowering women has remained constant.

With a bachelor’s in agronomy, she began her career as a crop scientist teaching farmers techniques to improve productivity. She quickly noticed that although men attended her trainings, they were not the primary ones working in the fields.

“It was the women who were doing all the work,” says Elsie, who also noted women’s tendency to put themselves down and discount their knowledge. “I went into gender because I saw that there was a challenge to overcome.”

She launched a special unit at her organization to enhance women farmers’ knowledge, to help them arrange bank loans and to set up microcredit programs. She even set up a child-feeding center to support women unable to breastfeed.

Elsie then was offered a job as gender program officer at Planned Parenthood Association of Ghana. Her role was to ensure the association’s programs and initiatives benefit women, especially at the community level.

In 2004, her life took an unexpected turn. She developed unusual symptoms, so she made a decision to get HIV testing at Planned Parenthood’s clinic. Some colleagues tried to dissuade her, even though voluntary HIV testing and counseling was a major part of their work. Elsie, however, wanted to know.

She was always strong, but she was not expecting what came next. Her clinician burst into tears as she tried to relay Elsie's HIV-positive diagnosis. Elsie actually ended up comforting and counseling the nurse, but it wasn't always easy to keep her fortitude.

"Of course I went through serious self [stigmatization], which lasted one week," Elsie says. "Then I pulled myself up by my boots."

She urged colleagues to get tested, and many shared their results with her. She set up a Planned Parenthood support group for HIV-positive clients, which is still running today. And she applied for the Ford Foundation-funded *Advancing Women's Leadership and Advocacy for AIDS Action* workshop to enhance her knowledge about HIV and AIDS.

"I knew there were advances in the field of HIV which we [didn't] know about in Ghana," says Elsie. "I saw this as an opportunity to learn more, to acquire knowledge which I could use to enrich my work, which I could use to encourage other women. I know that women are the ones who are bearing the brunt of HIV."

She's right. While Ghana's overall HIV infection rate is relatively low, the epidemic disproportionately affects women: 2.7 percent of women are HIV-positive, compared to just 1.6 percent of men.

Participating in the training helped boost Elsie's self-confidence as a leader. She and the other women were encouraged to review their personal and professional achievements at the workshop. This was the first time Elsie had listed everything she had achieved and she was impressed with herself.

"[I saw that] I had done so many things to be proud of," says Elsie. "It helped me believe more in myself and my abilities."

In addition, her fellow participants were remarkable women in their own right. Since the workshop, Elsie feels part of a broader network of women working in HIV that she can turn to for advice.

Since returning to Ghana, she has applied what she learned to foster women's leadership on issues of HIV and AIDS.

"I see myself in the role of a catalyst in getting women to be actively involved," Elsie says.

As a direct result of her networking during and after the workshop, Elsie was invited by numerous organizations in Ghana to conduct women's leadership training. She also helped establish a national network of HIV-positive women in Ghana called the Positive Women Leadership Network (POWLEN).

Even informally, Elsie cultivates leadership and self-confidence in other Ghanaian women by connecting them with trainings and support groups. She is sharing what she learned at the workshop about reproductive health, contraception, preventing mother-to-child transmission and even cervical cancer.

She even arranged for her support group participants to be tested for cancer at a hospital clinic. She negotiated with a local AIDS organization and the hospital to support the effort. Three women presented with pre-cancerous lesions and now are being treated.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) recently hired Elsie for a newly created position as part-time coordinator of its HIV-positive staff in Ghana. Undaunted by the "unmapped road" stretching before her, Elsie says her first step will be to determine the needs of the HIV-positive staff, and then devise appropriate strategies to address them. This is a new approach for her.

"I know that women are the ones who are bearing the brunt of HIV."

Prior to the workshop, she listened to others rather than putting her own opinions forward. She felt like her capacity to reason had been diminished by HIV.

The workshop helped Elsie realize that her ability to lead was separate from the health issues she faced.

"[Leadership] is not something you take off like your blouse at the end of the day, but it's your life," says Elsie.



CASE STUDY:

EKTA NEPAL

A dynamic, young woman of 25, **EKTA THAPA MAHAT** is a prominent voice for drug users' rights in Nepal. She was a founding member of Recovering Nepal, a network of nearly 300 Nepalese drug users, 70 percent of who live with HIV.

Thanks to the prolonged efforts of determined activists such as Ekta, Nepal is slowly changing its public health policies. The country was one of the first developing countries to adopt a harm-reduction strategy which features needle exchange programs for injection-drug users (IDUs) (1981) and a methadone maintenance program (2007). By 2007, HIV prevalence among IDUs had dropped to 34.7 percent compared to 68 percent in 2004.

In the summer of 2008, Ekta was asked to lead the Women's Wing of the National Association of People Living with HIV/AIDS in Nepal (NAP+N). The association is made up of 120 organizations that include/serve/reach a total of 7,000 people living with HIV (PLHIV).

Though she was excited about the opportunity to reach so many people, she faced a challenge. She understood the needs and concerns of women drug users through her own experiences using drugs, trying to stay clean, attending rehabilitation clinics and surviving in police detention centers. Ekta had some difficulty trying to relate to the struggles of HIV-positive women who were not drug users.

"I never felt discriminated against being HIV-positive, but I have hundreds and hundreds and hundreds of bad feelings and bad events and bad troubles that I went through because I am a drug user. Even being a single mother was not so difficult as being a drug user," says Ekta.

Since she was a child, Ekta was surrounded by men and boys, which led to her own prejudice about why women faced the challenges they faced.

"I used to have a different idea of gender before," explains Ekta. "My idea was [that] because women feel they are inferior, they are weak biologically or physically, that's why they want special treatment. They are not asking for equality, they want special treatment."

Ekta took the job leading the women's wing and applied the skills she developed over the years as an advocate for drug users, but communication was an issue.

"My language [was] very different than theirs," she explains. "If [they] are a drug user, you shout...we say, 'Look at you, you have nothing, you are a drug user, you won't get a job anywhere, no one will marry you, look at your face.' We say it like that. This is therapy. But if you say the same thing to an HIV-positive woman, she will begin to cry. I was very confused initially."

In March 2009, when the opportunity arose to attend the Asia Regional workshop in Nepal, she seized it. She hoped to deepen her understanding of how HIV affects women and girls, especially those who are not using drugs.

"I learned a lot from the [other] women—an attitude thing. I was the only drug user," she says. "The women were so caring. I learned a lot of women things—women's responsibility in society."

Since the workshop, Ekta has refined how she communicates with Women's Wing members; she is learning more from them and servicing their needs better. She now focuses on education as a key capacity-building strategy for HIV-positive housewives and mothers, who typically married and started a family without having completed school.

"If I go and talk about a project, they will talk about their home. Now I know how to talk, I talk to them about the price of aloo (potatoes) in the market," says Ekta. "The training really helped me to adjust my thinking to the women here."

But it wasn't just deeper understanding of gender issues and communication that Ekta gained from participating in the workshop. Another take away was an appreciation for how evidence and context can enhance advocacy and resource mobilization.

"It helped me in preparing documents for doing advocacy," she says. "They taught us how to use

evidence. You need to have evidence even if you write a proposal, or if you develop a resource mobilization campaign."

Currently, Ekta is urging the Nepalese government to consider methadone a public health issue tied to IDU treatment and recovery, rather than just a criminal issue for law enforcement to handle. And in order to ease the stigma women IDUs face when seeking treatment, Ekta is calling for one methadone clinic to set aside at least 10 percent of its 260 spots for women, and bumping them to the top of waiting lists given their family and household duties.

She also deepened her planning and programming skills based on what she learned from the project management session of the workshop. When presenting to donors or policymakers, or preparing to facilitate a workshop, she arrives armed with facts, statistics and written leave-behinds to highlight project activities and successes.



Ekta now uses some of the training techniques and the session designs in her own trainings. One technique that stood out to her was that of capturing past accomplishments. She uses this method to motivate her participants the way she was motivated.

After displaying a chronological list of accomplishments to her participants she tells them, "Our senior people, they did this. Now, it is your turn to make history. ...Now, it's your turn to do the work."

“The other women taught me to be patient, and the workshop taught me to be more analytical. Because of this, I made our restaurant open even though it seemed impossible.”



CASE STUDY:

ERLENCY COLOMBIA

“I felt like a ‘woman of the world’ because I learned from the experiences of so many amazing women around the world. It was an inspiration for me. I am stronger and better because of it,” says **ERLENCY SCARPETA MOSQUERA** about the Latin American and Caribbean Regional Women’s Leadership workshop in HIV/AIDS early in 2010.

She relished the opportunity to connect with two dozen like-minded Latin American and Caribbean women. Even though she had worked in the HIV community for 16 years, Erlency found it humbling to hear about her peers’ past sufferings, obstacles overcome, impressive achievements and tireless determination to improve HIV prevention, treatment and support.

“I learned humility. I thought my life was difficult. Now I realize that there are many other women leaders out there who have suffered far more than I have,” Erlency says. “I admire them and was inspired by them.”

Director general and legal representative for an HIV information and support program that is part of Colombia’s National Network of Positive Women, Erlency was surprised by the changes she saw in herself after the workshop.

“I went to the workshop a perfectionist, and I came back as a different person,” she explains. “I am more patient and more compassionate. I learned that not everyone is the same and we need to respect other people, be more flexible and work harder.”

Upon returning home, Erlency began implementing the action plan she developed during the workshop.

She now appreciates how vital patience and persistence are for any project manager—from the proposal phase through implementation.

“It is too easy to just say ‘it is impossible because of blah, blah, blah.’ Now I know that you have to keep working and trying,” she says. “The other women taught me to be patient, and the workshop taught me to be more analytical. Because of this, I made our restaurant happen even though it seemed impossible.”

With her leadership, the organization was able to implement a long-standing project idea for a restaurant employing HIV-positive women who are heads of household. The idea had been languishing due to a potential donor’s indecision.

In the three months following the workshop, Erlency spearheaded the proposal’s re-draft, identified and engaged new potential partners, and successfully solicited funding from a brand new donor, a local business. Today, four part-time employees work at the restaurant, and plans are underway to double staff size by the end of Year One.



Erlency credits the CEDPA workshop for her enhanced motivation, increased focus and morale boost. She uses every opportunity she gets to pass on what she has learned.

“I want to share this important work and experience with as many other women as possible,” says Erlency. “The workshop was the biggest gift of my life.”

Beyond the Initiative

CEDPA and its partners are pleased with the program’s success and recognize that the Ford Foundation’s support of the initiative has made a vital and unique contribution to women’s empowerment and leadership in HIV.

To continue the investment beyond the life of the initiative, and to reach more women leaders with critical skills, CEDPA developed a manual for trainers that presents a scaled-down adaptation of the workshop training curriculum. The training manual was prepared as a resource for CEDPA alumni and other trainers to build the leadership, advocacy and management skills of grassroots women leaders and others working in HIV. The curriculum is intensive and highly participatory, reflective of CEDPA’s training history of creating a supportive learning environment that promotes the exchange of expertise and experience.



The initiative’s partners were honored to have the opportunity to meet and learn from the dozens of inspiring women who participated in the program over the past four years and are delighted to know that the program’s success will continue as alumni and others benefit from this manual.

The women in these profiles and many more were able to participate in the Advancing Women's Leadership and Advocacy in AIDS Action initiative thanks to the generous support of the Ford Foundation.

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