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The Rises and Falls of Serving the PLHIV Population of South Bangalore

11 years ago in Bangalore, India, Meena walked into Jyothi Kiran’s office with two suitcases in hand and said, “You must help me”. Her husband, who had contracted HIV, recently died of AIDS and her in-laws now blamed her for bringing HIV and shame into their family. Meena and her four children were forced out of their home by discriminating neighbors and family members. Abandoned by everyone she knew, Meena reluctantly parted with her children at a neighboring care home and sought Jyothi Kiran, a woman who she had heard was counseling HIV positive women within a small office in south Bangalore. What started as a small counseling group for five HIV positive women is now MILANA, a family network of people living with HIV and AIDS, which encompasses over 350 HIV positive families.

An estimated 220,000 children are infected with HIV in India and the numbers for adults are even higher (Unicef 2010). As a leading nation in HIV transmission, India is at odds with its urge to grow and its plight to deal with mass numbers of infected people. Sexual relations and sexually transmitted diseases/infections are incredibly taboo topics in society. MILANA however challenges these social constructions. This small NGO

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-J30-

Journal for Service-Learning, Leadership, and Social Change Fall 2011
became a place full of warmth the minute I anxiously climbed up the narrow, winding steps to the office on my first day of work. The peach colored walls were chipping, covered with posters about the mission of MILANA, the transmission of HIV, safe sex practices, and photos from events held for the community. I learned that over time, MILANA had become more than a place of counseling; it was a major source of comfort and strength for people affected and infected by HIV/AIDS from all parts of Bangalore.

The MILANA staff, comprised of 15 HIV positive women comes to work every morning equipped with the will to fight the stigma and discrimination associated with HIV/AIDS. This staff builds alliances with other HIV positive women in different neighborhoods of Bangalore- informing, educating, and helping them feel human again through simple acts of kindness. By being a voice for vulnerable communities, MILANA facilitates just and democratic policies that promote advocacy campaigns to get medication to positive patients and address the immediate needs of those stricken with poverty as a consequence of their HIV status. A children’s support group called “CHIGURU”, meaning “sapling” in Kannada, ensures that children affected/infected with HIV receive emotional, mental, and physical support through group meetings, counseling, art therapy, nutritional, and financial support.

Months before my journey with MILANA began, I had already formed grand ideas about the work I was going to do in India for two months. I knew there would be moments when I felt uncomfortable, moments where I felt I did not belong in India, or 

-31-

Journal for Service-Learning, Leadership, and Social Change Fall 2011
felt alone. Nevertheless, in my mind, I was on a mission to rescue people from the troubles they were facing. I was expecting to feel satisfied with the work I was doing every day, to feel moral and content with my actions when I came home from work. These grand notions lasted all of a week and I was quickly confronted with the realities of joining a new culture I did not know much about and the reality NGOs face every day—the work is never easy and the results are not always positive or applauded.

In a country where several hundred languages are in use, my knowledge of two Indian languages could not get me far. Kannada, the regional language of the state of Karnataka, consisted of sounds my ears had never heard and my mouth had never uttered. This language barrier meant I needed a translator to be present at meetings, events and counseling sessions, which at times encumbered my progress at MILANA. I noticed that too often, I was the center of everyone’s attention in public. No matter how “local” I tried to appear, wearing traditional, loose-fitting tunics and draping scarves over myself, someone would always see through my disguise, recognizing that I was a foreigner from something as simple as my walk or hand gestures. My foreignness, always cost me a 100 rupees more than a local would pay—even when I thought I was getting a good deal. I also received unwanted attention or was accosted in public, which ironically caused me to feel incredibly lonely at times. More importantly, I was in constant internal conflict with my identity as an American born Indian. I was raised with Indian values in an American environment, which I assumed would give me advantage over my Caucasian roommate who knew nothing more about Indian culture than “Chicken Tikka Masala”. This double identity at times worked in my favor, there were
things about the Indian culture I was familiar with and therefore could adapt to. Every day at work when the staff would sit down to eat lunch, I would sit alongside them, not thinking twice about using my hands to carefully create little balls of scalding hot rice and *sambhar* in my plate. My roommate who would avoid anything too spicy and took an extra 20 minutes when eating with her hands, did not have the same luxury as I did. I felt separated from her and from American culture at moments like these. Nevertheless, at times I could not help but feel, look or be “American”. For instance, I had such strong opinions about sexual education being a part of school curriculum and was shocked to learn that it was a banned topic. I wondered how the Indian government could allow children to grow up without such knowledge when HIV/AIDS was ravaging their country. For the first time in my life, I was caught between two worlds, feeling like I belonged to neither. This feeling of not belonging unseated me from my proud and comfortable perch of “first world” college student coming to save the “third world” and gave me an identity shock of which I will never forget.

At the inception of my journey with MILANA, I was gripped by the notion that I had the ability to “save” people just by being an educated person from the “first world”. The women around me quickly dismantled this arrogant and erroneous belief with their stories and experiences. Instead of me imparting my “first world wisdom” on them, more times than not, the women of MILANA taught me new things about life and its different meanings. Through them, I learned what struggle meant and how one can never really understand it unless they have experienced it. I remember when I sat with Anasuya—a
gentle woman of about 30 years old with a delicate face and laugh one hot July afternoon—and began to talk about her life. Aware that my Kannada was restricted to a few silly phrases, she talked to me in broken, but completely coherent English for two hours. She explained how her husband, an electrical engineer travelled to Mumbai often for work, how he had contracted HIV and never revealed his positive status to her. She only learned of his status after she and two of her three children became sick and tested positive for HIV. By then, her husband’s HIV had progressed to AIDS and he passed away within a short time. Overcome by grief, Anasuya attempted her own suicide and attempted to kill her children. I remember her looking into my eyes as she told me this story. Her hands were clasped and shaking from the power of the memories, she was reliving to me. Even though I had never experienced anything like that in my life, I felt connected to her—I could empathize with her without having a basis of understanding. In this way, I became connected to all the women who shared their stories with me.

Gradually I noticed that everything I knew thus far about HIV/AIDS was taught to me in the classroom or from my own research online or through literature. I realized this could never compare to the real life experiences of these women that I was learning about face to face. So often, learning is defined as sitting in a classroom and listening to a lecture as slides pass by on an overhead projection—it is the mainstream American college approach. However, nothing can compare to actually listening to these women as they shared their stories. In retrospect, every time I engaged in these discussions.
with them, I was experiencing knowledge rather than simply acquiring it. I learned more about the HIV/AIDS crisis from case studies and interviews than I ever have through literature, which makes my experience rich and unique to have had first hand resources to learn from.

With the realization that I was learning experientially came personal development in the time I was with MILANA. Within the first month, I had learned a few words and phrases that would help me understand conversations without a translator present all the time. I also developed an intrinsic emotional compass to decipher the feelings in the room during counseling sessions and group meetings, which made me much more sensitive to the PLHIV cause and attentive to those around me. As time passed, and I developed more of a routine, I found myself becoming more immersed in PLHIV initiatives and asking tough questions that no had answers to yet. Before my trip, I never thought of myself as someone who enjoyed being around children. However, my experiences with the children of MILANA changed that. I could now see the hope that fills every child—the pure, untapped potential and innocence parents and loved ones want to protect so dearly. Each of their giggles and squeaky voices left an imprint on my mind and heart.

The more I engaged with PLHIV and fought for their rights, the more passionate I became about my work. I took pride in doing small tasks around the office as well as larger ones because I realized that no task was trivial but rather that each was necessary for the advancement of the cause. Each day, I fell more in the love with the
work—willing to accept it with its flaws and lack of applause but also its tender moments of sharing and joy that seemed to permeate the walls of MILANA.

The small adaptations I had made while in India, followed me back on my 15-hour flight to America. There were things about myself I could tell had changed as I walked out of Newark Airport into the scorching August sun. For one, many of my priorities had shifted. Being raised in a culture where materialism is all around us, I found myself wanting fewer possessions after my trip. I was aware of a stark difference between the two cultures in terms of people’s priorities alone and their sources of happiness in life. I remember our visits to the outskirts of Bangalore where people would swarm me, begging me for food I did not have and asking me if I would speak to their village leader to convince him to ration the food fairly. People would show up to the office asking for money to pay their child’s school fees and yet, so many of these people experience genuine joy and wake up with an enthusiasm about life in the morning. I found myself wanting to emulate these qualities, to create a humbler self that appreciates the smaller things in life—especially because I have so much. As I mulled over all the things I had experienced in my 82 days in India, I finally understood that these people do not need “saving” as I thought they did. In retrospect, I think they have done a better job teaching and saving me than I could have ever done for them.

The way MILANA as organization carries itself in Bangalore is representative of the type of leader I hope to become. MILANA is an advocate for all vulnerable communities, looking to create social change through the empowerment of HIV positive
women. It is a fluid structure that easily adapts to the changing environments of PLH in India. MILANA is also constantly evaluating its impact to see if its members are receiving adequate support. MILANA is a beacon for PLHIV in Bangalore because of its dedication and persistence to reaching goal. This flexibility, ability to adapt, honing of creative skills, and a keen interest in vulnerable communities are qualities I hold in high esteem and desire to reflect in the work I do in my future. The knowledge and perspective I have gained from participating in MILANA, serves as motivation for me to do well in my academics and pursue my goals. MILANA solidified in me, the desire to help others and create a future that strives to perform service for the benefit and advancement of vulnerable communities.

MILANA began as a small office with peach colored walls and posters but is now a place of strength, development, creativity and service. The concept of MILANA is unique because it is built on a sincere hope to see PLHIV succeed and thrive. It is a place of sharing, healing, and learning through experience. The incredible team camaraderie and the belief in the pursuit of a common goal make MILANA dynamic and powerful. I am grateful to have spent two months with MILANA embracing a new culture, learning about my identity and realizing that I want to dedicate my life to service. I want to use my skills and passion to create sustainable initiatives that benefit vulnerable communities and allow people to help themselves advance. Fortunately,

-37-

*Journal for Service-Learning, Leadership, and Social Change* Fall 2011
working with MILANA has provided me with an exemplary model from which to learn about service and the way in which the desire to help others, can change lives for the better.

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Works Cited


-38-

Journal for Service-Learning, Leadership, and Social Change  Fall 2011