Pick up any American newspaper these days, and all of the stories coming out of Haiti are negative: earthquake relief work is going slow, displaced people are still living in tented camps, men and women are still struggling to find work. And while these facts can’t be disputed, there are many other stories that are being left untold. Working in Haiti [6] earlier this month, I encountered six women who are on the front lines of the battle against Haiti’s HIV & AIDS epidemic, who shared their stories with me.
In the bustling, dense Delmas section of Port au Prince, these women come together at place called La Maison l’Arc-en-Ciel (Rainbow House). [9] A Haitian non-governmental organization (NGO), La Maison l’Arc-en-Ciel provides outreach to families infected with and affected by HIV & AIDS. The women are part of a group of a dozen known as the “mères déléguees” (mother delegates) who provide care and support to people in their community living with HIV & AIDS. The women I met ranged in age from 40 to 68.

Their tasks are many: they make home visits to those who are sick, and provide care and support to people who experience discrimination or stigmatization in their own families and communities because of their illness. They obtain medicines for those who aren’t well enough to go to the pharmacy. They teach parents how to administer medicines to their sick children, and they find financial support to pay the school fees for children of sick parents.

In some cases, they do even more. Ronite Dorval, 59, has been a mère déléguee for four years now, and she explained to me that the risk of suicide is very great among those who are newly diagnosed. Each mère déléguee pays special attention to those who have just learned their HIV status. The women have been known to either temporarily move into the home of someone who has recently learned their status, or take them into their own homes, to provide the personal support and emotional strength needed during this critical time.

Every month, these 12 women visit 470 families, making two visits per family. Their work is completely voluntary; they receive no pay. They do it simply because people are sick in their community, and they believe they can and should help them. The work that they do illustrates a key Management Sciences for Health (MSH) [9] belief – which is that health and health care begin in the household, with the individual and his or her family.

MSH has been collaborating with La Maison l’Arc-en-Ciel for almost two years now, supporting a leadership development program. The women began this program earlier this year, and are finding it useful for developing the skills they need to advocate for people living with HIV & AIDS. As one of the women told me, “We were already leaders. It is just now we have more confidence in ourselves, more vigor and more courage.”

Stemming the tide of the AIDS epidemic is challenging and requires courage. These days there is much talk about the integration of HIV & AIDS services into the overall health system as the best way to move forward. It is important to remember that integration of HIV & AIDS services must begin with the needs of the individual, their families and their caretakers in mind. This is the “whole of society” health systems approach that MSH advocates [10]. It is what Ronite Dorval and her fellow mother delegates – and the people they care for – deserve.

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