



## HOW NORTH CAROLINA'S RELIGIOUS CONGREGATIONS ARE BUILDING A VOLUNTEER NETWORK TO SUSTAIN PEOPLE WITH HIV/AIDS: GETTING TO KNOW YOU THE POWER OF PERSONAL RELATIONSHIPS REGIONAL AIDS INTERFAITH NETWORK (RAIN)

“...part of my responsibility is to equip the saints to do the work of ministry, and RAIN offered me an opportunity to teach folk how to care about people that they ordinarily wouldn’t care about.”

Pastor Larry Hill

### Creating a Community of Compassion

Not everyone has the experience like the CareTeam member quoted above, who found her motivation to get involved in helping those with HIV/AIDS through her work in a hospital. And not everyone is moved to respond without some support network that allows them the courage to engage in what might otherwise be a daunting task: loving and caring for someone living with HIV/AIDS.

But it is personal experiences like those of Ms. Stewart that have motivated an increasing number of health care professionals and lay advocates to get involved in working with those who have HIV/AIDS. Recruitment efforts have been challenging, say AIDS care and prevention advocates, because of a society—indeed a world—that is bound by fear, isolation and stigmatization when it comes to those infected with HIV.

The question for advocates has long been how to address all the issues surrounding HIV, how to educate people about the disease in order to reduce fear, and perhaps most important of all, build significant support networks to help those who are infected.

This leadership story was written in 2005 by Amy Brooks, Jennifer Dodge, and Jonathan Walters. Amy Brooks is Leadership for a Changing World award recipient of the Regional AIDS Interfaith network. Jennifer Dodge is researcher for Leadership for a Changing World's Research and Documentation Component at the Research Center for Leadership in Action housed at New York University's Robert F. Wagner Graduate School of Public Service. Jonathan Walters is a writer and journalist. Additional co-researchers for this leadership story were Leadership for a Changing World award recipients Deborah Warren, Rev. Stephanie Speller-Henderson, Rev. Debra Kidd, and Rev. Amy E. Brook of the Regional AIDS Interfaith network. The leadership story is intended solely as a vehicle for classroom discussion, and is not intended to illustrate either effective or ineffective handling of the situation described.

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That was the original challenge that the Reverend Deborah C. Warren decided to take on when she began her work caring for people with AIDS, work that eventually led to the founding of the Regional AIDS Interfaith Network (RAIN) in 1992, which is dedicated to building a network of trained volunteers who help each other as they help to support those with HIV/AIDS. Now, almost 14 years later, RAIN is a thriving organization that has trained more than 2,600 volunteers, including more than 100 teams of people from 20 denominations and faith traditions to care for over 620 people living with the disease.

The story of RAIN's successful push to de-stigmatize the disease and to recruit help in the effort to comfort and care for those with AIDS is a story about faith-based activism that managed to overcome fear and build a community of compassion. In creating that community, RAIN has found answers to a host of challenging questions about getting people involved. Its strategy focuses on crossing social and religious boundaries, on community building, and on spiritual growth. Central to each of these strategies is the importance of building strong relationships between people, while at the same time creating the support structures needed to ensure those relationships endure in the face of often profound spiritual and social challenges that come with caring for people living with HIV and AIDS.

### **Responding to the Call**

RAIN was founded in Charlotte, North Carolina, in 1992 by Reverend Warren as a response to what she saw as a profound lack of support and care provided by faith communities to people living with HIV and AIDS. This lack of support was in opposition to the clear mandate that nearly all religious traditions have had for centuries: to feed and clothe those in need to comfort the oppressed and tend to the sick. Where, she wondered, was the compassion for those with HIV/AIDS? According to Warren, “the national denominations in various faith traditions had issued these national policies about how folks ought to be caring and compassionate and engage in AIDS ministry or mitzvah. But that was it. Nobody was actually doing it.” Yet Warren felt strongly that leadership on HIV/AIDS needed to come from faith-based groups, especially in the south, where many people turn to religious leaders for guidance on a host of issues.

Building on an institution woven deeply into the community's social fabric, Warren sought to address the plight of HIV-positive patients by drawing up an approach of service and care to help those who were suffering from the disease. She understood that the heart of the matter was a deep-seated theological tension between judgment and punishment, on the one hand; versus acceptance and compassion, on the other. This theological tension had manifested itself in the isolation and exclusion of many HIV positive people, not only within the walls of religious institutions but throughout society.

Given the incredible fear and social stigma that surrounded people living with HIV, Warren knew that any effort to bring the faith-based community into the fold would involve bridging significant divides in how people felt about and reacted to those with HIV/AIDS. It would also involve breaking down the barriers that prevented those with the disease and those without the disease from forming meaningful relationships,

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relationships that could only be forged by moving beyond the easy categories of right and wrong, good and bad. Warren understood the meager response to the call from national religious leaders to care for those living with HIV "was a clear indication that people in the congregations felt that they were entirely different and separate from the people who were becoming infected, and that if you had become infected, well, you had done something wrong."

But while theological tensions might naturally exist; there are also theological imperatives that argue strongly for action, thought Warren. All religious writings include powerful stories setting forth the kinds of ideals that frequently challenge congregations to step out and lead on difficult issues. Stories about outcasts, particularly the lepers in Matthew, are often invoked by RAIN activists and supporters in helping frame the contemporary issues around people living with AIDS and their place in society. "You know the whole idea of caring for the outcast and the poor is expressed all throughout the Hebrew Scriptures and also the Koran would say the same thing," says Cathy Hasty, a long-term supporter of RAIN.

### **Coming up with "Care"**

Warren decided to use the "CareTeam" approach first developed by the Robert Wood Johnson Foundation as a starting point. It is an approach that involves small groups of people joining together, not only to sustain an individual living with HIV, but also each other. Warren drew upon another model known as Clinical Pastoral Education (CPE), which has been used to train pastors and lay people in what is known as an "action-reflection" style of pastoral care, where those involved spend part of their time taking on a task and then part of their time reflecting on what it means to be so involved. It is a way, says Hasty, a mentor to most of its staff on CPE as well as a long-term supporter of RAIN, to investigate the "interface between ministry and psychology and group dynamics." Combined, the two models provide an avenue for individuals to reflect upon the meaning of their faith and to use that to take direct action through service, in this case service, to people living with and dying from HIV/AIDS.

RAIN CareTeams are made up of four or more volunteers, most often formed within congregations. They are trained by RAIN staff in the social, spiritual and medical aspects of living with HIV. Team members are encouraged to identify and use their own strengths and experiences in their ministry/mitzvah in providing care and comfort. They may listen, pray, drive, cook, talk, and socialize with the person they are helping, known as their "CarePartner." Again, the key to the CareTeam approach is that team members not only support their CarePartner, but also each other as they confront the challenges that inevitably arise, both emotional, physical and spiritual, say RAIN activists.

RAIN staff, all pastors trained in CPE, also work together as a team to support this process, providing a full range of services to CareTeams through education, training, team development and support, as well as grief debriefings, counseling and other support services. This full range of activities supports the various needs of the team through all the stages of team life.

As RAIN has grown, their particular model has been renamed "shared leadership." It is an approach characterized by deep, supportive relationships that embrace spiritual growth and development for all those involved. This means that there is sufficient trust and compassion among CareTeam members so that they can be honest with each other about their strengths and shortcomings. Under the RAIN model, program leaders model the shared leadership style that they hope will be reflected by individual CareTeam members. While doing so, RAIN staff also models a different way of living out their faith as an example to other religious leaders in the community – to be inclusive rather than judgmental or fearful. Reverend Stephanie Speller-Henderson says, "I feel like we are the prophetic voice in an age where people need to hear how to do something differently." She pushes this idea inside the African American church, which she is determined to change from the inside. "CarePartners are on the end of a gospel that is really not embracing them," she argues, "but separating them from the love of God. I actually put flesh and blood on a God that embraces them, even in the midst of their disease. Where the greater community does not really understand, and there's still a lot of judgment."

It's a simple but powerful way to encourage other pastors to also use the power of the pulpit to promote AIDS ministry, to be caring and compassionate, not fearful or judgmental, say RAIN advocates. As Pastor Larry Hill, whose Presbyterian Church supports two CareTeams puts it, "According to Ephesians 4, part of my responsibility is to equip the saints to do the work of ministry, and RAIN offered me an opportunity to teach folk how to care about people that they ordinarily wouldn't care about."

### **The Transformational Power of Relationships**

Central to the RAIN strategy is the transforming power of relationships. By encouraging people to form relationships and work together, activists help one another in work that might otherwise never be taken up by a single person alone. This group approach allows people to consider and try new things even as they wrestle with their own fears, concerns and limitations. The team approach creates strength that can be shared and also extended to a wider community. As member Denise Shropshire says, this approach "enables someone who is maybe a little shyer than someone else, who doesn't meet people well, but really has compassion for them and really cares about them, to still do something for other people. And a team member helps you along." According to RAIN CareTeam members, the relationships that the RAIN approach fosters create a spiritual support system that sustains all the team members in tough times.

Perhaps the most important strategy that RAIN uses to encourage people to get involved is through personal testimonials. They do this, for example, by asking CareTeam members and CarePartners to present at training sessions, as well as at churches and synagogues. One fundamental assumption behind this approach is that a community cannot address an issue like HIV/AIDS, with its heavy social stigma and isolating nature, through impersonal charity; it must be addressed through relationships that cross boundaries – racial, economic, health, age, and gender boundaries. A key part of this method has to do with supporting experiences that put people in touch with each other's

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humanity, say CareTeam members. The relationships have a profound transformative effect on both CareTeam members and CarePartners; say those who have been involved in the process.

Ruth Deal of Cross and Crown Lutheran Church describes how deeply moved she was to hear of an older gentleman, a professor with HIV/AIDS, being cared for by a young team member, who, unlike his CarePartner, wasn't highly educated. Yet the two men found a way to relate to each other--the younger man was teaching the professor how to fish, something he had never done before. The effect that these two men had on each other, in spite of their very different backgrounds and experiences, was clearly powerful and positive. "That touched me so much," says Deal. "The difference in backgrounds and yet when there is a common purpose, how meaningful it is and what a difference it has made in his life. I wanted to make a difference in someone's life." The story inspired her and her congregation to form their own CareTeam, which now supports two partners.

Inspiring others to form CareTeams is one point of transformation that the program can affect. But in other cases, it is the CareTeam itself that experiences profound change and development. For example, one team from St. Ann's Catholic Church moved across significant racial and economic lines to work with a young African American woman who had a history of substance abuse and little family support. As they worked together, the young woman eventually began to feel like a sister to team members. She and the team celebrated holidays and birthdays and even special occasions like the first communion of a team member's daughter. In her final days the team helped arrange for their Partner's baptism, at her request, and they organized and participated in her funeral, which was held at the CareTeam's church where the partner had often attended.

As people come to know each other, they are confronted with differences of life experience they might never otherwise encounter in a casual relationship. They may also try new things they might never otherwise try. The team from St. Ann's struggled to accept their Partner's decision to continue with dialysis long past any medical benefit; after she died they planned her funeral with the blessing of their parish priest – an activity they had never done and would not usually do as laypeople in the Catholic Church.

It is the sort of shift from "stranger" to "family" that has profound effects on all those involved. Beverly, a Care Partner with two young children, spoke of the tremendous support she received from her Care Team, "They call me all the time," she says explaining that her daughter is also HIV-positive, "and take us to our doctor's appointments." Simple enough, but taking care of these daily tasks has made a tremendous impact on her life and the lives of her family members. "At Christmas, we were just overfilled. And it has taken a lot of the burden off of my sister," who lives far away and was making trips several times a week to help out before the arrival of the Care Team. "It's cut down a lot on her stress, as well as mine."

## **Dispelling Fear and Prejudice Around HIV/AIDS**

Behind CareTeam success stories is the tremendous amount of work that RAIN staff put into building relationships among CareTeam members and partners, and in training both Team members and Partners alike point to the comprehensive nature of the support that RAIN offers CareTeams and CarePartners all along the process, from recruiting CareTeam members and partners, to training, to celebrating community and connection, to grief debriefing in the event that a team should lose a CarePartner. For many it is an approach that allows them the confidence to step up even in the face of the fear, the uncertainty and the challenge. "It allows you to get in there and do what you need to do," says Reverend Larry Hill, the Pastor of Woodland Presbyterian Church in Charlotte.

In training CareTeam members RAIN's approach is extremely comprehensive, covering issues as basic as breaking the stereotypes surrounding those with HIV/AIDS, to dispelling myths about how HIV is contracted. While RAIN distributes a wealth of material on paper to trainees, it's not an academic exercise. "They don't just hand you the material," says Pamela. "They explain it to you so you understand. And I think that makes a big difference."

RAIN staff seeks a balance between the difficult twin tasks of making sure people get the right information and understanding it, on the one hand; and ensuring that people feel safe enough to talk about a range of sensitive issues that accompany caring for someone with HIV, on the other. These conversations can focus on team dynamics, cultural and racial differences, and even religious tolerance. Reverend Carl Arrington, assistant minority program director with RAIN, emphasizes that, "in the training, we talk about RAIN's philosophy. That is, one that promotes inclusion rather than exclusion." One CareTeam member says she especially appreciated the focus on spiritual sensitivity. "Because we are in a faith network, it was stressed to us to be very sensitive because they are people who may not have the same belief that we have," says a CareTeam member. A constant RAIN refrain is that CareTeam members "be tolerant and understanding of others whose beliefs may not be the same as yours." Part of this sensitivity, RAIN staff is quick to point out, means being mindful not to push partners who may not practice any religion at all.

But a lot of the support RAIN staff gives begins after the training is over as volunteers are assigned to CareTeams and start working with CarePartners. RAIN staff offers regularly scheduled check-in meetings with CareTeams, are available for spur-of-the-moment consultation, in house or in the field, and support members who find themselves in a new, confusing, or difficult situations. For example, one Team member took a CarePartner to a hearing for a domestic dispute. The judge started asking questions of the Team member, assuming she was present to vouch for the Partner. Feeling uncomfortable, the Team member was able to page someone from the RAIN office and receive guidance on clarifying her role in the situation. This sort of immediate consultation often involves discussion about the importance of boundaries in relationships and the importance of doing only what is in your comfort zone. The staff is available to help troubleshoot difficult situations which arise occasionally, thereby

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helping the volunteer remain engaged in the task without taking on more than may be needed or appropriate to the care giving role.

Conversations about differences also continue well after formal training, as people begin to confront their assignments—and assumptions—in real-life situations. As Reverend Arrington puts it, "Once they go back to their individual churches, we go down the Careful Path where you sit down and actually talk about cultural issues (1). And you get people to start examining how they feel about certain kinds or classes of people." That is when RAIN "begins to help [CareTeam members] get a different perspective," says Reverend Amy Brooks, Director of Education, "and see where they're operating out of their own experience, which just by nature is going to be limited and perhaps prejudiced. Not that it's necessarily a deliberate thing, but that's just what their experience has been."

In fact, one RAIN activist tells a powerful story about his own transformation in that regard. Larry Hill admits he harbored fears about ministering to an HIV positive parishioner, a reticence that he managed to overcome. "Somehow he trusted me, but he didn't know that in that day, I was one of those who was ignorant and scared," says Pastor Hill. "And I didn't get too close because I thought that if I got too close that I might get AIDS." While Hill took it upon himself to learn about what HIV, it was the initial relationship with his HIV-positive parishioner that inspired him to face what he learned was an irrational fear of the disease, and in his own words "be healed" when it came to that fear.

While some might come to RAIN with natural fears--or prejudices--others actually have used the program as a way to help support people living with HIV/AIDS who they see as being victims of discrimination. "There are people who want to be involved because it's another way to help the cause of oppressed people to move forward again," says Rev. Hill. "So they use this as a means to attack the whole range of discrimination instead of just AIDS by itself." He recalls a woman in his church, a deacon, who had ties and influence, and "wanted to make a political statement of, 'This is what we need to be about'" by coming forward one morning in church. It's just another way in which the RAIN approach broadens and enriches participation—RAIN not only makes it possible for people to take part in the care of someone in need, but also offers them a concrete way to begin addressing larger issues of prejudice and discrimination.

### **Something to Give, Something to Receive**

Most people join CareTeams because they have something to give. But frequently they learn that they have a need to receive as well. "When I first started, I of course saw this as a way to help a group of folks that I felt were marginalized, ostracized and mistreated," says Reverend Debbie Kidd, a program director with RAIN. "But as I continue to work here, what I see is that I've ended up getting something back as well." The CareTeam experience, say those who have been involved in the process, isn't only an opportunity to

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1. Rain adopted the Careful Path curriculum from the Eddy Visiting Nurses Association.

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help someone in need, but also a chance to think more deeply about one's own faith, one's relationship to God, and how one's beliefs play out in daily life, and to rethink preconceived notions of others and themselves.

Sometimes the reciprocity is even more down-to-earth and direct. Initially, the energy initiated by the team moves in one direction, towards the CarePartner, say team members. Team members frequently report, though, that that energy is often reflected back. As CarePartners become comfortable with team members, they begin to care in return, calling team members to check on them, sending them birthday cards, asking about their family members who might be ill. Reverend Brooks recalls an instance where a CareTeam member was diagnosed with cancer in the middle of ministering to a CarePartner. While her team members were strongly supportive, "The CarePartner participated, too," says Brooks, "by living in her house and taking care of her dog when she was out of town for treatments."

### **Something Valuable**

In order to sustain themselves and the work they do, CareTeam members not only rally around one another and their partner, but are encouraged to identify practices "that feed the heart" and contribute to their own spiritual growth and development, such as singing, eating together, walking, celebrating, having fun, and praying; all ingredients essential for renewing commitment. One member says that, "A lot of what's been keeping us motivated is our praying time together. We have meditation. And that's something that started a couple of months ago. People come and I have the candles already burning. And sometimes we have a little soft music. We just come in regardless of how rough things get in our lives and in others' lives."

Such simple but fundamentally important rituals and activities build the bonds that keep groups together, say RAIN participants. They create a trusting environment where team members can both challenge each other and guide each other in spiritual growth. It's a concept that extends to RAIN staff as well. As Reverend Warren says, "our own spiritual development is perhaps why we've all been able to stay in AIDS work so long."

Acceptance and compassion. Growth and spirituality. Powerful and close relationships built in the name of caring and helping. These have all helped create a sense of healing and of greater strength among team members, partners and RAIN staff.

All these elements help sustain RAIN and its mission, say activists. But nothing helps do that more than the individual stories of those with HIV/AIDS to whom RAIN actively ministers, say RAIN participants. One Partner, a former chef who had to go on disability, decided to give his CareTeam cooking lessons. The team eagerly signed up. It might seem like a small thing, say team members, but what the team did was give the partner the chance to use his skills while regaining what is probably most important to any individual – a sense of self-worth. As he took up the tools of his trade and settled his

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team members down for their lesson, the partner was no longer someone with AIDS who needed help; he was a human being, ready, willing and more than able to give something back.

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