

# Diocesan program extends loving care to families confronting HIV and AIDS

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Guest contributor

Last year, an infant died in one of the families with whom the Diocese of Rochester's Maternal and Child AIDS Intervention Program staff had worked.

Staff members went to the funeral home in the afternoon. The mother was not there. The only people there were agency people.

I asked the funeral director if he knew the mother's whereabouts. He said she probably had had no way to get to the funeral home.

We made sure in the evening that she had a way to get there.

As a member of the middle class, it's hard to imagine a mother who couldn't afford to get to her own child's funeral. But that is the reality for many people the program serves.

The families we deal with have a multitude of problems compounded by HIV, the virus that causes acquired immune deficiency syndrome. Many are single-parent families headed by women of color. A history of sub-

After reading the article, I wondered if there was something we could do here in Rochester to care for these children?

Along with three other people, I went to Albany and met with Sister Maureen Joyce, then serving as director of Ferrano House, to learn about their program. On our way back home to Rochester, we discussed many different avenues a similar program might take here.

Once back home, we met with officials from the Monroe County Department of Social Services to get their input and suggestions.

We were told that Monroe County did not have a problem with "boarder babies." DSS policy in the county includes keeping biological parents and family involved with the babies whenever possible. And, realistically, Rochester was too far away from New York City to develop a program for "boarder babies" together.

Out of these discussions, however, came the Women and AIDS Project, which eventually

vides women and children with case-management services and links them with needed support services in the community. The house can accommodate up to four women and four children at one time.

The program also offers case-management services to anyone in the community affected by HIV, not just Mary's House residents. Currently, we are serving 36 individuals or families, and I've got six more cases waiting on my desk.

The people need help with social services, legal services, school systems and child-care. Many have such basic needs as food, shelter and clothing.

From the start, I have thought of HIV as a family problem. We have to focus on the whole family's needs, not just the person with AIDS or HIV disease. The program's case-management staff visit the homes and get to know all the family members — their strengths and weaknesses. The focus is on life and living, on taking control of one's life and



Sister Maureen Joyce stands outside the Farano Center for Children.



Inside the center, Sister Joyce sits on a rocking chair and plays with one of the babies who reside at the home. Sue Van Alstine looks at a book with another young resident.

stance abuse often exists, coupled with physical and sexual abuse. And because there is still the stigma of AIDS in the black and Hispanic community, women are often trying to cope with their problems without the support of their families.

My first contact with AIDS and HIV disease was in the spring of 1987, shortly after going to work as executive director of Facilities for Group Homes of Rochester, Inc. The organization was helping AIDS Rochester develop a housing program for men with AIDS.

I felt apprehension the first time I went to AIDS Rochester headquarters. I remember when I was offered a cup of coffee, I wondered to myself, "Do I want to drink a cup of coffee from here?"

I knew little or nothing about AIDS. Living in rural Livingston County at that time, I attached little meaning to the term AIDS. I thought the disease was just a city problem.

But Jackie Nudd, then executive director of AIDS Rochester, gave me a crash course in "AIDS 101." When she was done, I knew that it was not just a man's disease, nor did it just affect city people.

As the housing project progressed, I realized that I wanted to become more involved with people affected by AIDS and HIV, especially children.

About that time, I saw an article in the *Catholic Courier* about Farano House in Albany. The house's staff was caring for New York City "boarder babies" — infants who had been left at the hospital by their mothers. Many of these babies were born HIV-positive or addicted to cocaine — and sometimes both.

became known as the Maternal and Child AIDS Intervention Program. The initial task force included myself, Colin Garwood, then associate director of development for residential services at Catholic Charities for the Diocese of Rochester's Social Ministry, and representatives from Strong Memorial Hospital, Jordan Health Center, AIDS Rochester and Threshold.

The group wrestled with what form the program should take. While we were engaged in this process, Bishop Matthew H. Clark issued his 1988 pastoral letter on AIDS, entitled *The Lord Himself Taught Me to Have Compassion*. In the letter, Bishop Clark cited the need for services for women and children affected by AIDS, and the need for housing for people with AIDS and HIV disease.

After some internal discussion, the group decided to develop a program to meet Bishop Clark's call.

At the same time as these discussions were continuing, Rochester's Corpus Christi Parish had a house donated to it for use in ministry. Through the grapevine, Father James Callan, the parish's administrator, heard about our project and offered the house for our use. The parish then became an intricate part of the task force planning the house.

In early 1991, the project had reached a point where a staff member could be hired. Having been involved with the project since its inception, I applied and got the job.

The program has two components. The first is Mary's House, a supervised, non-medical housing program located in the building provided by Corpus Christi. Mary's House pro-

making positive decisions.

Much of our work is done in the people's homes. We have found that we develop trust and a rapport, because we come to them in their homes and not in a sterile office.

This also means that we sometimes get close to people. When they are hurting, we hurt as well. But we still have to maintain our professionalism, which is sometimes difficult.

Happy times also occur. For example, last year I took a deaf client to Darien Lake with my family and a circle of friends.

The experience was a real eye-opener. She was from New York City. I thought she was going to jump out of the car on the way to Darien Lake when she saw a cow. She had never seen a cow before.

She'd never been to an amusement park before, either. It was sad to realize that we were with somebody who was 28-years-old and had not experienced things we take for granted.

I think I enjoyed most watching her discover cotton candy and pretzels, and going on the rides. We had two 9-year-olds with us, and it was like having another 9-year-old — she was that excited.

Recently, I have been spending more time with the program's administrative responsibilities. Our staff is growing, and they are doing more of the hands-on provision of services.

I miss that. I miss not seeing our babies grow to become toddlers. I miss seeing the women and the progress they have made in their lives: kicking their drug habits and celebrating one or two years of sobriety; starting school; getting jobs; moving into their own



A poster that hangs in the office of Sister Maureen Joyce, director of the Farano Center for Children, says many children with AIDS babies entrusted to the center.

apartments; or telling their friends, "there is not room for me anymore."

These women have touched my heart with their strong dedication to their families. We have kept them together for as long as possible. It's the choice between putting food on the table and spending money to take a child to a doctor, they will opt for the former. It's not easy, but they rarely complain.

As I begin my third year as director, I am glad that I live in a community that is fortunate. Rochester has excellent services for people and families affected by HIV. The majority of us work to provide the most appropriate services for each individual's needs.

Rarely does "turf" become an issue. We have been able to develop cooperation with other agencies such as the one that began in Syracuse, the Maternal and Child AIDS Intervention Program providing case-management services to DayBreak Alcoholism Treatment Center's HIV-positive clients.

By beginning to provide services to an inpatient, we are able to have a rapport with the client. When a client is discharged from DayBreak, he or she knows the case manager. In this way, management services have begun to take place.

From the beginning, the program has been blessed with many volunteers. We have much support from the community, churches, social ministry committees, foundations, service organizations and individuals have donated money for the program's operation and the client's well-being.

Despite such support and success, I am constantly asked, "Why are you so depressed working with AIDS?"

The answer is "no," because I know the life and all that it has to offer. I am not depressed, when we lose a client, we also have to look at all that people have gone through and am glad that they are no longer suffering.

I also look at the fact that I have seen the lives of these people's lives and how their lives have been a little bit better because of that presence.

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