

Case worker's reward is helping people

Lincolnite's home also branch office

By Jana Pedersen

Suzie Miller Schoen has a tough time explaining her work. "For me," she said, "there is no such thing as an average day."

As a Lincoln case worker for the Nebraska AIDS Project, Miller Schoen may spend an entire day on the always-ringing AIDS project telephone.

And when the phone rings, her work just begins.

Some calls request speakers for group events. A few are volunteers offering to help. Others come from social or medical agencies, sometimes returning her messages, sometimes seeking her experience.

But most calls are the kind that make Miller Schoen's job so satisfying, she said. They are clients seeking to solve everyday problems.

"I like to be able to offer those services," she said. "What I do is deal with the issues at hand, and that is whatever it is they need."

Those issues vary, she said. Some clients need help with paperwork, whether its the kind government requires to give financial aid or the kind hospitals require to give medical aid.

The AIDS Project telephone number can be the first "official" call people with HIV or AIDS make for help. That telephone line, along with the Lincoln office of the Nebraska AIDS Project, is in Miller Schoen's home.

Country wallpaper and sturdy wooden furniture adorn the AIDS Project office, which doubles as a dining room. A black cat rubs her neck against a chair. Organized piles of paper fill a work desk in the corner, while the phone rings nearby.

At first glance, the surroundings seem appropriate. The caring tone Miller Schoen takes when speaking of a client is just a bit shy of motherly.

And, she joked of her job, "Sometimes I describe it as being a den mother."

But such a patronizing term hardly fits. Miller Schoen said patronizing is the last thing she wants to be.

"I don't want to come off as . . . only happy when I can help others make their lives happy, because I'm not that way at all," the mother of two teenagers said. "I don't like to do that. I like it when (clients) can take care of themselves."

And her tone is far from motherly when she speaks of the disease itself.

"I hate this disease. "Sometimes I have a fantasy of taking something that breaks easily, like glass, and throwing it against a brick wall and just screaming that I . . . hate it."

But that hatred, she said, is not a product of her work.

Sometimes that outlook is hard for people to understand. Those who don't know Miller Schoen are puzzled that she doesn't get depressed by her work.

The answer, she said, is attitude. Instead of losing hope, she said, "I really do get strength from the clients and the way that they are living their lives."

She can give examples — many of them, in fact. And when she gives them, a natural, simple smile appears.

One of her clients wanted to straighten his teeth before he died, Miller Schoen said. And when he died, he still had braces.

"I think it's great," she said. "I think it's real hopeful."

Miller Schoen said she also found hope from events at Christmas — a time assumed to be depressing by those who don't know people with AIDS.

At Christmas this year, she said, the AIDS Project received donations of gifts for children whose parents have the disease.

While distributing the gifts days before Christmas, one family insisted she stay for a while.

"Immediately they opened the presents," she said. "These people don't wait for Christmas. They have Christmas whenever they can have Christmas. That was Christmas that day."

"It was so much fun to be there because they are living for the moment. If the moment arises, they say, 'Let's have it. Let's celebrate it. Let's feel it. Let's live it as much as we can.' And that's how they deal with their lives."



Suzie Miller Schoen is a caseworker with the Nebraska AIDS Project.

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When she first joined the project in 1990, Miller Schoen had five clients. Now she averages about 35. At the Omaha headquarters of the Nebraska AIDS Project, each of two case workers has some 60 clients.

The number is growing, Miller Schoen said, and the clients are changing. While most of her clients are gay men, she said, an increasing number are women and others who have contracted the disease through heterosexual sex.

She attributed the expansion of the disease to a number of factors, but they all stemmed from ignorance.

Miller Schoen said government officials should have acted more quickly to educate the public when the disease first was identified.

"I think public health officials were remiss in not coming on stronger," she said. "Everyone was concerned about alarming people instead of telling people about what was going on."

One reason for the lack of action, she said, was that, at the time, HIV was spreading among homosexuals.

The American stereotype that AIDS is a gay disease must end, she said. As the disease spreads among heterosexuals, she said, the response to it should be modeled after the gay community's actions.

"The gay community got their acts together," she said.

When AIDS first was identified in metropolitan areas like San Francisco, Miller Schoen said, it was difficult for gay men to accept that it was spread through sexual contact.

"Sexual freedom originally was a statement for the gay population to express their freedom," she said.

" . . . They were very reluctant to listen to anyone who said, 'You've got to modify your sexual behavior.' They didn't want to do it."

"But they did. There were people on the street corners of San Francisco showing how to put a condom on a cucumber or a banana, saying, 'This is the only way we have right now that you can help protect yourself.'"

Now, heterosexuals must learn the same lesson, Miller Schoen said.

Those who think preaching abstinence is the answer are not helping stop the spread of HIV, she said.

Although the only certain way to avoid the virus is to abstain from sex, she said, it is unrealistic to think most people, especially youth, will do so.

"The reality is people are sexually active, young people, young adults are sexually active," she said. "So, I would be negligent if I didn't stand up and tell you how to protect yourself, too."

Miller Schoen said that teaching youth to wear latex condoms was the realistic way to prevent the spread of HIV.

"This disease could stop today if everyone who is sexually active or an (intravenous) drug user would start using condoms and stop sharing needles."

Sending that message to youth is especially important, she said.

"The very thing that's so wonderful about youth will get them infected," she said. "They think they're invincible. That may get them in trouble."

Some young people complain that condoms are uncomfortable, she said. But her answer to that complaint is to the point:

"I don't know of any sex that's so good it's worth dying for."

The best way to prepare youths to use condoms is to teach them role-playing skills, Miller Schoen said. Then, they will know how to ask sexual partners to use condoms.

"The power to make good choices — that will keep them from contracting the virus."

But because the spread of the disease centers on sexuality, Miller Schoen said, officials are handling education about AIDS differently from other public health issues.

"They talked to us about ringworm," she said. "They talked to us about how it was spread and how we can stop the spread of it and all those kinds of things. Do they do that now? It's not the same kind of effort."

While public health officials are working to improve AIDS education, she said, "we haven't heard anything on high, like Oval Office high."

Miller Schoen has, she said, a standard analogy:

"If this disease affected only politicians, only their vocal chords and their sexual organs, we would have not only a cure but a vaccine."

"Or maybe a whole new set of politicians. Who knows?"

The lack of emphasis on education has caused problems in the long run, Miller Schoen said.

Now, much of the public money for AIDS must be spent on medical care and social services, because it wasn't spent on education years ago. For states like Nebraska, which ranks 41st nationally for incidents of HIV or AIDS, that means needed funding for education will go elsewhere.

"This is not a crisis," she said. "This is an ongoing problem. Crises have a peak and then some resolution."

For Nebraskans with AIDS and their loved ones, a way of coping came at the beginning of Miller Schoen's work with the AIDS Project.

In October 1990, the Names Quilt came to Lincoln. The quilt is made of sections with messages and names of people who

have died of AIDS-related illnesses.

Working to bring the quilt to Lincoln gave Miller Schoen a "wonderful experience in camaraderie," she said.

And the quilt itself is moving, she said. She called it "a way to pour out some love, to cry, to grieve."

"And that's how I started this job, so that's part of me."

The quilt itself contained powerful statements, Miller Schoen said.

Some statements were sad and hard to read. Other messages told of the problems associated with AIDS.

One, she said, was particularly meaningful:

"For killing two men, you gave me a medal. For loving one, you gave me dishonorable discharge."

"That kind of says it all about our society and this disease," she said.

"It's a disease that has affected so many people, but it often affects them privately because they're afraid even to talk to their neighbors."

Because of social stigma attached to the disease, she said, sometimes AIDS is not mentioned at funerals of those who have died from AIDS-related illnesses.

"Families deal with that alone, or the families have not been there, and then friends deal with that alone."

For those people — those who have HIV or AIDS and those who love them — Miller Schoen works to make life simpler.

"I wish there was some way that they didn't have to go through some of the things they have to go through. . . . It's hard enough to have to deal with the disease and not have to bother with all the paperwork that goes with being sick and hospitalized and having to take care of all that."

Perhaps "guide" would be a more appropriate term to describe Miller Schoen's work: as she leads clients through masses of paperwork, as she shares the ups and downs of each client's journey, as she educates others on how to prevent the disease.

After all, a guide requires flexibility to deal with changing elements. And Miller Schoen's work demands flexibility.

Of her average day, she said, "I may start out thinking, 'I'll put on jeans, I don't plan to go anywhere,' and I'll think, 'I'm going to get all this paperwork caught up today.' Then, I'll get a call from a hospital asking me to come out and visit a patient, and I'll go."

" . . . It's so hard to describe it."

It seems so.

But even if Miller Schoen can't detail her daily tasks, she does know what she wants in the long run for her job:

"It's one job I'd like to see go because it wasn't needed any more." ♦