Interview with Aggie Leitheiser

Interviewed by Jennifer Berger

Interviewed on April 6, 1995, in Leitheiser's office, Minneapolis

JB: How do other people describe you?

AL: Probably as caring, listening, thoughtful. It's a very hard question, because it's hard to separate out what people have told me from what I think about myself. Probably inclusive, process oriented, individualistic—that's probably what I'll stop with.

JB: When did you first become aware of AIDS?

AL: I guess 1984, probably through both some mailings from the health department but also I was asked to represent the Public Health Nursing Directors on the Commissioner of Health Task Force on AIDS in 1986.

JB: What did it mean to you then?

AL: My background is nursing, and so partly when I heard, "We have a new scary virus that we don't know a lot about," I thought it's real scary, I guess. Things about it—that we're not sure how to prevent it, you can't really treat viruses, you just kind of wait and let the body respond. And so it was that there are a lot of public health implications, also a lot of medical care implications, and a lot of costs and some potential for community panic.

JB: What does it mean to you now?

AL: I think it's become part of the landscape. I think when we first began to hear about it, it was like, "Well, at some point there'll be a cure for this or a vaccine," or "It'll go away," and I think that a lot of us spent some time telling ourselves those things. I think where I'm at today is that AIDS is part of the diseases that people get. People don't get measles so much anymore, but people get colds, and that's not surprising. People will get HIV probably for the rest of—certainly my lifetime if not humankind—so that we have
to adjust to it; it's not a new, special, unique thing anymore. It has to be part of our whole overall planning.

**JB:** When did you first become aware of the impact of AIDS on your life?

**AL:** Probably when I became a member of the Commissioner's Task Force, because then I began to get more in-depth information as opposed to just cursory. It was much more detailed. The [Minnesota Department of Health] has had several AIDS Task Forces over time.

The first one that I was on was a group of physicians and people from the blood banks and gay men and various groups that represented people from the Minnesota AIDS Project, which was just starting up at that time. The task force looked at the public health issues, the recommendations for prevention, for control, and for services. We were advising the Commissioner of Health about public health policies related to AIDS.

Also at that time there was a planning group that was developing training for public health agencies throughout the state. I was a community health director for a county just west of the Twin Cities here, and we talked about the need to do training for staff, for physicians, for nurses, for public health agencies and helped plan that workshop.

Personally I think I wasn't aware of AIDS and its effect on individuals other than as sort of a public health global thing until I came to work for the department and began to know people who were infected or with AIDS or people who worked with HIV or their family members. A classmate of my sister died of AIDS. And one of the people that worked in our section died of AIDS, so there's some personal context to that.

**JB:** Was there a defining moment in your consciousness?

**AL:** Like, where was I when Kennedy was shot?

**JB:** Yes, exactly. [Laugh]

**AL:** Which I remember. I don't think so. I think when I got a call from someone who worked at the health department about a position that was opening up here was probably where I
first began to see working with AIDS as a career, and that it was going to be a larger part of my life as opposed to just one of many things. It then became the only thing I did, so probably that was a defining moment, when I got the call and thought would I change what I was doing to take a job that was involved with AIDS. That meant I would be doing very different things from what I had been doing. So that would probably be a defining moment.

**JB:** How does your work in AIDS fit into your larger commitments?

**AL:** Well, I took the job with AIDS, and my first assignment, my first position here at the department, was to work with public health agencies to prepare them for incorporating AIDS into their agencies, AIDS prevention and AIDS services. And I worked with a task force that developed the guidelines for how to do that. Actually we asked for money, too—we didn't get the money but we did get everything else.

At the time I had been doing generalized public health nursing and I was the director of an agency, and when I came here, rather than being the head of something, I was just a staff person, so it was a big adjustment that way. But I saw the opportunity to use AIDS as a way to get people to think differently about changing health behaviors, about bringing their communities together, about approaching how things got done with sort of a new impetus. We'd been working in public health, and communicable diseases had gone away, and we were left with heart diseases and cancer, which are very important but not as immediate, and so I saw that this sort of return to communicable diseases was a way to rethink all the good things. And as I've changed positions in the department over time I think that's held true; that AIDS has helped us rethink how we look at health care and health prevention and behaviors. It continues to teach us ways to rethink how we look at things.

**JB:** How would you describe your larger commitments in general?

**AL:** These are interesting questions. I guess I see my larger commitments to communities and their multiple ways of being defined both geographically, by interest, by communality of purpose, of gathering, so there's multiple ways of being a community. My work is to help identify problems and
strengths in those communities and help resolve them.

My role here, though, it's not as directly related to people. I work with staff who then do those things. So it's a little more removed. I help people with brainstorming, with problem solving, with some of the administrative nitpicky stuff. I have a commitment to the profession of nursing, public health nursing, and nursing itself in that our commitment to the individual, to the family, to the community be individualized, be caring, be knowledgeable, and be professional. I have involvements with the profession of nursing and some committees and things that I'm on. I see a commitment to the people that work in this division that I have some responsibility for that they get what they need to do their jobs.

Sometimes that's not as easy as you might think. Getting pencils is easy; sometimes some other things are not. But I guess I see the commitment to helping people think about the broader context. Sometimes people can get real focused on their one individual program area, and part of my job as I see it and my commitment is to helping people remember what they control. I used to do just AIDS specifically, which has not been how I've done my career and my work, and how I've approached things, so that was a little bit odd. I'm back to being more of a generalist, which fits better, and I then can help with the bigger pictures too. People over here with Lyme disease can learn from what AIDS did in a particular situation.

JB: How do you describe or define your faith?

AL: You're the second person who has asked me that in two days.


AL: Actually the person asked me whether I would define myself as a spiritual person, and I certainly would. Well, I think that there's an inherent good in people and that

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1The Division of Disease Prevention and Control, which includes supervising the AIDS/Sexually Transmitted Diseases Prevention Services Section. Leitheiser served as chief of the section and is now acting director of the division.
collectively people are stronger than any individuals. I think that there's also a tendency to take the easy way out or the lazy way out and sometimes that can be resisting change. I'll get back to the faith thing. But that's part of it. It's harder to resist change--which could be defined as lazy, although it's more work--but change is part of what we have to do to evolve in this life. So part of my faith is about being open to change, trying to identify when I'm being resistant to it, or when I'm presenting a change to others in a way that increases their resistance to it. That faith is about that change is good, for me and for others.

Part of my struggle on a day-to-day basis is [asking], What's the right thing to do? What's the moral thing to do? How would God do it if God were here right now? I've had to struggle through the difference between religion and spirituality and that "Wait a minute, that's not the same thing!" That was a freeing event, to learn that spirituality is about my relationship with God, despite all those little frills and ruffles that religion might try to put on it. And that my job is to be like God. So if I were to define my faith, I guess it would be that my job is to be like God, and to be open to thinking, to be open to people and to opportunities, and to let go of the scariness that someone's going to ask me to do something that I don't know how to do. So I'm constantly struggling with that.

JB: What role would you say that faith plays in you life?

AL: I would say it's fairly important. I sometimes maybe don't think about it as much as I would like to think about it, and sometimes rediscovering the discovered. Yes, that's a way to think about this issue. I would say it's a fairly large part, I guess. To be really honest about it and struggling with the moral and the right and the ethical, and that we in government really spend more time on that than I would have guessed, struggling with it.

JB: Does anger play a role in your response to AIDS?

AL: Well, I tend not to be an angry person, so that's kind of a hard question to answer. I think it's kind of like being angry at cancer. Probably in the abstract, no, but I think on an individual basis, yes, that to be angry at cancer or to be angry that the sun comes up or doesn't come up today is okay. I don't spend a lot of energy spending time on
that--but that an individual person suffers from such a horrible disease, there's anger and frustration. I would say probably more fatalistic response than angry response in that, well, that's not something I can do much about so I'm not going to spend my time being angry about it. Partly that's back to the philosophy of life; it's not that I don't choose not to be angry about AIDS, it's just that that's not how I approach things.

I think that if I had AIDS I would probably react somewhat differently about that. It would depend, probably, partly on how I had got it: whether I was making--I'm not going to say the innocent victim piece, that's not what I'm talking about here--but if I was infected by a blood transfusion when I had put my life in the hands of others, or if had I a partner who I was confident was not infected who then turned out to be infected, or if I had done all the things I was told to do about bleaching my needles and then it turns out that wasn't effective and I got infected anyway--that would probably increase the anger. Whereas if I had made choices saying, "Well, hmm, alright, I'm going to make some choices here and I know I might be infected, but it's a chance I'm willing to take." It's to some extent the anger that people have about environmental impact versus, "I got cancer because of smoking." I think there's less anger there because it was a choice I made, versus the stuff came down out of the sky at me. It's sort of that control issue.

JB: I think it's also an issue of being angry at the disease as opposed to being angry at yourself, like I think a lot of people...

AL: Yes, and that comes out in a variety of ways, that anger.

JB: How do you describe your community?

AL: I would say probably a big part of my community is my family. My brothers and sisters and my husband and my step-daughter and nieces and nephews. To some extent I guess I still think of the community which I grew up in2 as part of my community. I think that one of my communities is the people that I work with here. The community of my

2A rural South Dakota farming community.
neighborhood, probably not so much because of the individuals there--because I don't know lots of people in my neighborhood--but because of just the geographic location of it and the comfort I have in that community. And my friends. So I would say I have a variety of different communities, and I think I keep adding communities, and sometimes some of them fade away, but I guess I see community as a very fluid group. They come and go and they overlap.

**JB:** How do you participate in or find community?

**AL:** Well, partly by interest. I was active in the political community for a while and have been less so lately. At the time I was very interested in it, and it met some needs of mine. There's an example of finding a community as opposed to being born into one. I think probably following an interest if I have an interest. I think there will always be some pieces of my life that will always be the same; some of the communities will always be the same--my family community will always be there, my neighborhood community, whether it's the neighborhood I live in now or one I move to. I think the nursing community will probably always be a part of my life.

But I think some of my interest-focused communities, whether I belong to some kind of support group or something, that can become a community for a while and that may be come and go. Yes, interests, lifestyles, choices at this point, just in addition to the sort of foundation communities that I see always being there.

**JB:** How does your community support you?

**AL:** Oh, sometimes just by being there, knowing they're there. They don't have to do anything. I know that my mother is there and for some things I can call her [Chuckles], and that my husband is there and I can call him for things. It varies in some other parts of my communities.

I think [they help] by helping hold a mirror up to me sometimes, so that I can see myself, in a way, from their eyes. That if the community of the people that work here see that what I'm doing is not helping them and I'm just blazing away great guns thinking this is just exactly what they need, they can hold a mirror up and I can see, "Oh, that's not maybe the best way to do it." So sometimes it's "It's a great thing you're doing here"--it's not always an "Oh, this is really bad, stop it" mirror.
So I get rewards and maybe some sort of path-adjustment things from my community. I get new ideas, I get enthusiasm and new energy from different communities and different kinds of energy, which is probably why you have different communities, because sometimes you need just the soothing, everything's-going-to-be-okay stuff and sometimes you need, "It's time to get started on some new stuff." So I would say I get those kinds of things. Oh, I probably get guilt from my communities too, that I should be doing this or that or the other thing, and haven't been: Gee, I really ought to be sending out more birthday cards, or I really ought to be getting some report done that I'm supposed to be working on. So I get guilt which sometimes translates into actions, sometimes not.

**JB:** [Laughs] Yes. Why do you stay in this work? Along with that, how do you keep up your commitment?

**AL:** I think it's because I see the opportunity to help people. Things that I have done, either individually or collectively with others, have made a difference for people. Sometimes those people have faces and sometimes they're more anonymous. I think [it's also] the chance to work with people who are in this division and this department who have a great deal to teach me, and I have a great deal to learn and a few things I can teach them about what is public health, what is government's responsibility to people, what can government do to help people.

**JB:** What is this specific division?

**AL:** Disease prevention and control. Oh, I could show you the little organizational chart. Mike⁴ is the director, I'm the assistant director. And these are the sections that we have--Breast and Cervical Cancer Control, that does screening for that kind of cancer, and Chronic Disease and Environmental Epidemiology, that monitors all the cancers in the state, and also does special studies about asthma and occupational injuries and things.

Acute Disease Prevention Services does immunization things and also does refugee help. They're also working on a

⁴Michael E. Moen, the division's director, oversaw the Minnesota Department of Health's initial response to AIDS.
prevention program for Lyme Disease, which is something you get from ticks, and they're doing that in combination with Acute Disease Epidemiology, which is the group that monitors all communicable diseases in the state. This is the group where people report, like, the meningitis outbreak that we had in Mankato;\(^4\) this is the group that kind of headed that up and also are the ones who discover diseases. They also do the TB control, tuberculosis control, and count the AIDS cases. They do that work on how may cases we have and where they are. These people [Epidemiology Field Services] are located around the state to do disease prevention and control things. And this is AIDS and Sexually Transmitted Disease Prevention. Fraser\(^5\) is in charge of the services section here; they do a lot of prevention programs, and they do surveillance and screening for sexually transmitted disease and disease investigations.

**JB:** How do you keep up your commitment?

**AL:** Back when I was doing direct nursing care I would get rewards from fluffing somebody's pillows, literally. People would be more comfortable because of something I did physically to a person. When I moved into public health and did public health nursing, I got my rewards from being able to help people make choices about their lives or to make a difference. It was, "Let's see, here are some growth and development issues about your baby so that you can feed him better, that a one year old can't feed himself, you have to work with him." When I moved from seeing patients to being more of a director and moving into more and more administration and being further and further away from the individual, I had to move from that direct feedback--you go to somebody's house and they're so glad to see you; that feels good--to being really glad that I got a letter written today.

So there has to be some self-talk and self-reward: I set out some goals for the day and I met them, or I didn't meet all of them, or I didn't meet any of them. That when someone

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\(^4\)A major outbreak of meningitis in 1995 was monitored and controlled by the Minnesota Department of Health. More than twenty thousand individuals were vaccinated in four days.

\(^5\)Fraser Nelson, who oversaw this oral history project.
comes in with a problem or a thought, that I can help clarify with them where they're going, and that I help people find other places to go. I try not to be the problem-solver but the problem-helper, advisor, encourager, supporter. Sometimes I tell people, "Well, you don't have enough, you haven't thought about this enough, you need to go think about it some more and come back and we'll talk again." But part of your job is to do some of that thinking. So part of it is that you have to be aware of the little things, and you have to have some belief that you are making a difference. And sometimes it's just a teeny weeny little bit of difference. Sometimes it's that I can get my supervisor, my boss's boss, to agree that these people need to go on this trip to this conference because they will bring back some valuable information, and her first reaction was to deny it. So my job is to see that they do get some help. And so if that happens, then that's when that reinforces the commitment.

JB: How long do you think you will be able to sustain your commitment?

AL: Oh, I anticipate that I'll be--because I've reinvented my career several times, and I don't do AIDS directly so much anymore as I did when I first started at the department--I expect to be doing it for the rest of my career. I expect to be working in public health, and I expect to be working for government. I expect to be doing maybe not this job but some similar kinds of things.

JB: What are you doing to sustain it now and in the future?

AL: My commitment? Well, I just was realizing that I haven't allowed myself some training recently, and I need to do something like that. I need to go out and get some new ideas and whatever. The people in my similar positions in other divisions in the department are developing what we called a support group and gourmet dining club to try to pool our resources and to get feedback. I try to remember that I need to go out to lunch sometimes with people, I don't do that very often; I sit at my desk and eat frozen meals more days than probably is good. I try not to take work home, and I'm much better staying and working late than taking it home. I get good exercise carrying stuff home on the weekends and then carrying it back because I try to keep some separateness and some distance. I don't take it home--I think that's a real important point--unless I absolutely have to, and then
I'm not very good at it. I'm not very good at taking it home and reading it because once I'm at home, there are other things I'd rather do when I'm there.

JB: Yes. What about in the future?

AL: Oh, in the future? Oh, I toyed with the idea of going back and working on another degree, maybe in epidemiology.

JB: You have a masters in public health right now?

AL: Public health administration. That [additional degree] would give me a little bit more of a scientific base, which I probably don't have as much for some of the work that we do here. That would probably be helpful, being able to practice some of the things around here a bit more, but I haven't fully committed myself to that idea yet, because it's a bunch. At one point in my life I was going to teach nursing; I don't know that that's on my list anymore. So I think partly the commitment is to be able to allow yourself to change; that because you had a thought at one point, you can make some changes and move on and do some different things. So if I chose not to do that degree thing, I may do some other. Maybe I'll do history, or sociology, or something else, just for a change.

JB: How do you define felicity?

AL: Oh, that's hard. I don't know.

JB: And where do you find it.

AL: I'd look it up in the dictionary, probably; that is where I would start. Because that's what I would do, okay? Because I like to read the dictionary. [Looks through dictionary] Have you had people fumble with that one?

JB: Yes. Well, this is the first interview I've had, but Fraser told us that people probably won't know the word, and she said we can tell them happiness as a synonym.

AL: Okay. [She reads from the dictionary.] It means "great happiness; bliss; an instance of this. Something that causes or produces happiness; an appropriate and pleasing manner or style, or an instance of this." I don't understand that "instance of this" business, but, okay, so it's something
that causes me happiness or is happiness. So what was the question now?

**JB:** How do you define felicity, and also where do you find it? Kind of, what makes you happy?

**AL:** Well, we found it. I would define happiness, I guess, as...for myself?

**JB:** Yes.

**AL:** Okay, I'm trying to think about it for everybody, but that's not possible. I'll do it for me, that's easier. Happiness for me is having some time for myself, having people who care about me and having them close, having enough money to buy what I need. Actually, happiness would probably be buying what I want. It's different. That's a hard thing to answer because to some extent it's dependent on the day. I don't know. Today, happiness would be not having to go to the [Minnesota State] Legislature and sit there for three hours when we're done here. Where do I find it? Probably from solitude, from quiet, from close friends, from books, from physical activity.

**JB:** What is your vision of America?

**AL:** Oh, a place where everybody has access to the good life—the good life being defined as, to some extent, the middle-class kind of lifestyle that I think many of us aspire to. That there's cooperation without the loss of the competition. I think competition makes life somewhat worthwhile, that I can do "x" better than you, or at least I can believe that I do "x" better than you. Because that, I think, brings some happiness if you have that sense, but you also have the sense of cooperation that we're all in this together, working on things. That there's respect for others and others' property, that you don't have to worry about being ripped off or beaten up. That's what my vision of America would be if I were in charge.

**JB:** How is America, your community and the world affected by your activism?

**AL:** America probably not very much. My community is probably more [affected], through the various communities; my nursing community through my participation on advisory
committees and helping and shaping policy and guidelines and
background and materials and legislative ideas for nursing.
For the community here at work, oh, hopefully that there's
better planning, better thoughtfulness, better awareness and
impact on what we do on people.

I think my community is also impacted by my volunteering work
that I do. I visit people in a nursing home. That's the
individual who asked me about whether I was spiritual or not,
that's the guy I visit in the nursing home, and we had a very
good conversation about that--he affected me probably more
than I affected him. America, my community, and my world. I
don't know. The changes are probably more subtle than I
might like to think they are, and it's maybe more. I might
have an impact on an individual, who may have an impact on
another individual, who may have an impact on another
individual. That's maybe more what I would see my impact
being.

JB: And every individual is part of a community too, so...

AL: Yes. Multiple communities.

JB: What do you fear most?

AL: [Pause] Oh, I thought you were going to give me a list
and I could pick one; now I have to think of it on my own.
What do I fear most? I think making a big mistake that makes
life bad for people, whether it's people here or in my
personal life or in my community. That would make a bad
choice, which probably impacts my procrastination because I
want to be perfect, right? So sometimes I don't do things
because I might do them wrong. That's probably more in there
than I want to talk about, but that would probably be one of
my biggest fears, doing something that would have a very
large negative impact on people.

JB: What do you hope for?

AL: I'm sort of like Rodney King, with the "if we could just
all get along" thing.⁶ I think that we've lost some sight of

⁶Rodney King was the victim of a police beating that set off
riots in Los Angeles in 1992. He appeared on television in an
appeal to stop the violence and asked, "Can't we all just get
along?"
that. We all have rights to have our own dreams, and I think we don't maybe encourage that as much as we used to. I feel sorry for some of the people growing up now, who maybe don't see the world as friendly as it was when I was growing up, or as full of opportunities. And so I would hope that children growing up see the world as a safe, friendly, opportunity-filled place, and that worries me.

**JB:** How will this time in our history be remembered?

**AL:** Well, I think about that from time to time actually. A hundred years ago my grandmother lived in a sod hut on the prairie in South Dakota, and she died when she was ninety-eight. But in her lifetime she went from sod hut to people walking on the moon, and the kind of childhood that she had is as far removed from my lifetime as probably my grandchildren's lives will be removed from mine. Actually my step-daughter's life is very different from the kind of life I grew up, on a farm in a rural community.

So I think that we'll be seen as a time of great change. In some ways the Industrial Revolution, which had changed every fragment of society, or the Renaissance, which kind of changed everything, or when Charlemagne was going off and conquering everything, it changed the world—I think that AIDS will have changed the world—but I think as much [a change is] the different ways we have to communicate now. The fact that we've gone from just beginning to have telephones to everybody's got e-mail. The quickness that we can communicate doesn't mean that we've improved what we communicate, but that we can do it so quickly. I think that we'll be seen as the communication age, [similar to the way] we've had the Industrial Revolution age or the Middle Ages. I think we'll be seen as the communication age.

And to some extent AIDS is a result of that communication. AIDS is a result of the ability of people to travel quickly. I just finished reading The Hot Zone, in which they talked about the Kinsasha highway being the biggest spreader of AIDS. It used to be a dirt track, and so it was very hard to move from community to community. When they paved it, it became very easy to move from community to community, and suddenly you had truck drivers driving up and down this highway with truck stops and prostitutes along the highway, and so AIDS traveled much more quickly. So I think that communication and that need to travel more, faster, better,
contributed to the expansion of AIDS.

**JB:** How would you like to be remembered?

**AL:** Oh, as someone who cared. As someone who people could go to with their problems. As someone who helped put things together--ideas or people or concepts or philosophies or whatever. If I could be remembered in those ways, that would be amazing.

**JB:** Is there anything else you would like to say?

**AL:** I think you didn't ask the question about what I have learned from AIDS. What I've learned from AIDS is that people can change in such dramatic ways as a result of being either personally affected by AIDS or knowing people who are affected by AIDS. I have seen such great life revolutions by individuals and vicariously through stories that have been told to us. I hear of people who change their lives to be shining stars in their communities and their lives, when before they weren't that important or that well-cared for. So I think that AIDS teaches about the great human potential for reaching for the good.

And that's one of the things that every once in a while you have to remind yourself about: that AIDS does allow for people to move to that great higher plane, and that people sometimes do it in one big whoop, and it isn't just that you have to crawl up all the stairs--that you can make a giant leap. People have done that because of AIDS. So, as awful as it is, there are some positive things about it. So that's probably the question you didn't ask me that I was expecting.

**JB:** Okay, thank you.